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A systematic review of the effectiveness and cost-effectiveness of different models of community-based respite care for frail older people and their carers

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Abstract

A systematic review of the effectiveness and cost-effectiveness of different models of community-based respite care for frail older people and their carers

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Objectives: To review the evidence for different models of community-based respite care for frail older people and their carers, where the participant group included older people with frailty, disability, cancer or dementia. Where data permitted, subgroups of carers and care recipients, for whom respite care is particularly effective or cost-effective, were to be identified.

Data sources: Major databases were searched from 1980 to March 2005. Ongoing and recently completed research databases were searched in July 2005.

Review methods: Data from relevant studies were extracted and quality assessed. The possible effects of study quality on the effectiveness data and review findings were discussed. Where sufficient clinically and statistically similar data were available, data were pooled using appropriate statistical techniques.

Results: Twenty-two primary studies were included. Most of the evidence came from North America, with a minority of effectiveness and economic studies based in the UK. Types of service studied included day care, host family, in-home, institutional and video respite. Effectiveness evidence suggests that the consequences of respite upon carers and care recipients are generally small, with better controlled studies finding modest benefits only for certain subgroups. However, many studies report high levels of carer satisfaction. No reliable evidence was found that respite can delay entry to residential care or that respite adversely affects care recipients. Randomisation validity in the included randomised studies was sometimes unclear. Studies reported many different outcome measures, and all of the quasi-experimental and uncontrolled studies had methodological weaknesses. The descriptions of the studies did not provide sufficient detail of the methods of data collection or analysis, and the studies failed to describe adequately the groups of study participants. In some studies, only evidence to support respite care services was presented, rather than a balanced view of the services. Only five economic evaluations of respite care services were found, all of which compared day care with usual care and only one study was undertaken in the UK. Day care tended to be associated with higher costs and either similar or a slight increase in benefits, relative to usual care. The economic evaluations were based on two randomised and three quasi-experimental studies, all of which were included in the effectiveness analysis. The majority of studies assessed health and social service use and cost, but inadequate reporting limits the potential for exploring applicability to the UK setting. No study included generic health-related quality of life measures, making cost-effectiveness comparisons with other healthcare programmes difficult. One study used sensitivity analysis to explore the robustness of the findings.

Conclusions: The literature review provides some evidence that respite for carers of frail elderly people may have a small positive effect upon carers in terms of burden and mental or physical health. Carers were generally very satisfied with respite. No reliable evidence was found that respite either benefits or adversely affects care recipients, or that it delays entry to residential care. Economic evidence suggests that day care is at least as costly as usual care. Pilot studies are needed to inform full-scale studies of respite in the UK.

Contents

Glossary and list of abbreviations

Technical terms and abbreviations are used throughout this report. The meaning is usually clear from the context, but a glossary is provided for the non-specialist reader. In some cases, usage differs in the literature, but the term has a constant meaning throughout this review.

Glossary

Activities of daily living (ADL) Activities related to personal care, including bathing or showering, dressing, getting in or out of bed or a chair, using the toilet and eating.

Bias Systematic error(s), affecting the validity of a study. Types include selection bias, performance bias, attrition bias and detection bias.[a]

Care recipient The person receiving care from a carer.[b] Also referred to as 'patient' or 'older person'.

Carer A relative or friend who provides continuing care, usually without pay and motivated by a personal relationship with the care recipient; also known as 'informal carer'.[b]

Carer burden An outcome frequently used in trials and measured using a variety of instruments; the term encompasses the physical, psychological, social and financial impacts of caring.[b]

Carer hostility One of three symptoms of 'emotional status' measured on the Brief Symptom Inventory. Feelings or problems indicative of hostility are assessed on a five-item, four-point Likert scale.[c]

Concealment of treatment allocation A method of protecting against allocation bias, whereby the person(s) allocating participants to the study groups cannot influence the allocation process.

Cost–benefit analysis A form of economic evaluation where both costs and consequences are examined, with benefits valued in monetary units.[d]

Cost–consequence analysis A form of economic evaluation reporting one or more types of outcome, all of which are reported separately from costs.

Cost-effectiveness analysis A form of economic evaluation examining both costs and consequences, with consequences measured in natural units. Incremental change in the primary consequence is combined with incremental cost in a summary statistic.[d]

Cost-minimisation analysis A form of economic evaluation where the alternative programmes are associated with equivalent outcomes so that the only difference between them is the cost.

Cost–utility analysis A form of economic evaluation where both costs and consequences are examined, with attention focused on the quality of the (health) outcome produced or forgone by interventions.[d]

Day care Care provided outside the home, usually for morning and/or afternoon sessions up to several times a week. Provision in the UK is by local authorities, NHS and voluntary sectors. Specialist services for people with dementia may also be provided.

Direct payments A financial arrangement in the UK whereby individuals receive a cash payment to manage and organise their own care arrangements in lieu of services.

Double-blind study An experiment in which both the treatment provider and treatment recipient are unaware of which treatment or control condition is being administered.[e]

Dyad A collective noun describing the carer and care recipient.

continued

Glossary *continued*

Effect size A measure of the magnitude of a relationship between variables, e.g. the standardised mean difference statistic.[e]

Elderly See *older*.

External validity The validity of inferences about whether the causal relationship between two variables holds over variations in people, settings, treatment variables and measurement variables.[e] Also known as generalisability or transferability.

Frail Having one or more long-term health problems and/or difficulties in one or more aspects of personal care (e.g. as assessed by ADL), such that support to live independently is required.

Generalisability See *external validity*.

Heterogeneity Any kind of variability among studies in a systematic review. Heterogeneity may be clinical (variability in the participants, interventions and outcomes studied), methodological (variability in trial design and quality) or statistical (variability in the treatment effects being evaluated in the different trials, which is a consequence of clinical and/or methodological diversity among the studies).[a]

Homogeneity Similarity between studies in a systematic review. See also *heterogeneity*.

Imputation Statistical 'filling in' of missing data, making assumptions about the outcomes of participants for whom no outcome was recorded.[a]

Informal carer See *carer*.

In-home respite Respite care provided in the home of the carer and/or care recipient.

Institutional respite A temporary break where the care recipient is admitted to a nursing home or hospital.

Instrumental activities of daily living Activities related to independent living, such as preparing meals, managing money, shopping, housework or using a telephone.

Intention-to-treat analysis Units are analysed in the condition to which they were assigned, regardless of whether they actually received the intervention in that condition.[e]

Internal validity The validity of inferences about whether the relationship between two variables is causal.

Meta-analysis The statistical pooling of the results of related individual studies, to increase statistical power and synthesise findings.

Multidimensional intervention Packages of support services that may include respite. Also known as multifaceted interventions and similar to UK 'community care' packages.

Older Defined as being aged 65 years or above.

Parallel-group design Different units are studied in different conditions (also known as between-participants design).[e]

Per-protocol analysis Analysis in which participants are assessed according to the intervention they actually received, rather than according to the group to which they were originally assigned.[a]

Physical (personal) activities of daily living Activities related to independent living, such as washing, getting dressed and taking care of personal hygiene.

Power The probability of correctly rejecting a false null hypothesis, usually interpreted as the probability of finding an effect when an effect exists.[e]

Quality-adjusted life-year An index of health gain where survival duration is weighted or adjusted by the patient's quality of life during the survival period.

Quality of life A concept incorporating all the factors that may impact on an individual's life, affecting their physical, mental and social well-being.

Quasi-experimental study An experiment in which units are not randomly assigned to conditions.[e]

Regression analysis A statistical modelling technique, used to estimate or predict the relative influences of more than one variable on another. There are different types of model, including linear and logistic regression.

continued

Glossary *continued*

Relative risk The ratio of risk in the intervention group to the risk in the control group. A relative risk of 1 indicates no difference between comparison groups.

Respite care A generic term that encompasses a range of services. Respite care may be defined as care provided intermittently in the home, community or institution to provide temporary relief to the principal carer.[b]

Respite package A package of different respite options, from which the carer may receive one or more types of respite service.

Sensitivity analysis An approach for exploring how uncertainty impacts on study results.[d]

Standardised mean difference An effect size measure for continuous variables, computed as the difference between two means divided by the variability of that difference.[e] Used as a summary statistic in meta-analysis when the trials all assess the same outcome, but measure it in a variety of ways.[a]

Time trade-off Respondents decide how much length of life (expressed in future years of life) they would be prepared to trade off for improved quality of life (expressed in terms of dimensions of health or 'burden').

Transferability See *external validity*.

Type I error Incorrect rejection of a true null hypothesis, usually concluding there is an effect when there really is no effect.[e]

Type II error Failing to reject a false null hypothesis, usually concluding there is no effect when there really is an effect.[e]

Video respite A type of respite where the carer receives a break while the care recipient watches a video.

(Weighted) mean difference 'Difference in means' is a standard statistic that measures the absolute difference between the mean value in the two groups in a trial. Used as a summary statistic in meta-analysis when outcome measurements in all trials are made on the same scale. Analyses based on this effect measure are termed weighted mean difference.[a]

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[a] Higgins JPT, Green S, editors. *Cochrane Handbook for Systematic Reviews of Interventions 4.2.5* [updated May 2005]; 2005.

[b] Term reportedly disliked by some carers and the people they care for (source: expert reference group).

[c] Quayhagen MP, Quayhagen M, Corbeil RR, Hendrix RC, Jackson JE, Snyder L, *et al*. Coping with dementia: evaluation of four nonpharmacologic interventions. *Int Psychogeriatr* 2000;**12**:249–65.

[d] Drummond M, Sculpher MJ, Torrance GW, O'Brien BJ, Stoddart GL. *Methods for the economic evaluation of health care programmes*. 3rd ed. Oxford: Oxford University Press; 2005.

[e] Shadish WR, Cook TD, Campbell DT. *Experimental and quasi-experimental designs for generalized causal inference*. Boston, MA: Houghton Mifflin; 2002.

List of abbreviations

AD	Alzheimer's disease
ADHC	adult day healthcare
ADL	activities of daily living
CASP	Critical Appraisal Skills Programme
CBA	cost–benefit analysis
CCA	cost–consequences analysis
CEA	cost-effectiveness analysis
CES-D	Center for Epidemiologic Studies Depression Scale
CI	confidence interval
CMA	cost–minimisation analysis
CONSORT	Consolidated Standards on Reporting Trials
CQLI	Caregiver Quality of Life Instrument
CRBRS	Crichton Royal Behavioural Rating Scale
CSP	Caregiver Support Program
CUA	cost–utility analysis
DC	day care
ERG	expert reference group
FACS	Fair Access to Care Services
FSU	family support unit
FTE	full-time equivalent
FU	follow-up
GHQ	General Health Questionnaire
HFR	host family respite
IADL	instrumental activities of daily living
ID	duration of intervention
INR	in-home respite
IQR	interquartile range
IR	institutional respite
ITT	intention-to-treat
LTC PSQ	Long-Term Care Patient Satisfaction Questionnaire
MMSE	Mini-Mental State Examination
NA	not applicable
NICE	National Institute for Health and Clinical Excellence
NR	not reported
OARS	Older Americans Research and Service
PADL	physical activities of daily living
PCT	primary care trust
PDS	Psychological Distress Scale
PSQ	Patient Satisfaction Questionnaire
QALY	quality-adjusted life-year
RCT	randomised controlled trial
RP	respite package
RR	relative risk
SCI	Science Citation Index
SD	standard deviation
SIP	Sickness Impact Profile
SMD	standardised mean difference
SSCI	Social Sciences Citation Index
STAI	State-Trait Anxiety Inventory
TTO	time trade-off
VA	Veterans Affairs
VR	video respite
WMD	weighted mean difference

All abbreviations that have been used in this report are listed here unless the abbreviation is well known (e.g. NHS), or it has been used only once, or it is a non-standard abbreviation used only in figures/tables/appendices in which case the abbreviation is defined in the figure legend or at the end of the table.

Executive summary

Background

Three-quarters of all carers in the UK look after people who are aged 65 years and over. It is unclear what proportion of older people is 'frail', but morbidity data indicate that half of over-65s have a long-term illness that limits their activities. Caring for frail older people can adversely affect carers' health and quality of life. 'Respite care' encompasses a range of services provided intermittently in the home, community or institution to provide temporary relief to the carer. Carers have identified respite as critical to their caring efforts, but little is known about its effectiveness and added value.

Objectives

The aim of the review was three-fold:

- systematically to identify, appraise and synthesise the grey and published evidence for the effectiveness and cost-effectiveness of different models of community-based respite care for frail older people and their carers
- where data permit, to identify subgroups of carers and care recipients, for whom respite care is particularly effective or cost-effective
- to explore the practice, policy and research implications and to make recommendations for further research.

Methods

Searches were carried out for studies published in any language in or after 1980 that addressed respite interventions for carers of frail elderly people and included evidence of effectiveness or cost-effectiveness. Ongoing and recently completed research databases were searched in July 2005, with remaining databases searched in March 2005.

Data sources

Electronic/web-based searches were carried out on the following published and grey literature:

- databases of systematic reviews (CDSR, DARE)
- databases on old age and aging (AgeInfo, AgeLine)
- health/medical-related databases (AMED, BNI, CINAHL, CENTRAL, EMBASE, HMIC, HTA Database, MEDLINE, PsycINFO)
- social care databases (ASSIA, Caredata, IBSS, C2 – RIPE, SSCI, Social Services Abstracts, C2-SPECTR, Sociological Abstracts)
- economics databases (EconLit, HEED, IDEAS, NHS EED)
- databases of conference proceedings (Inside Conferences, ISI Proceedings: science and technology/sciences and humanities)
- databases of reports, dissertations and other grey literature (Dissertation Abstracts, Index to Theses, SIGLE)
- databases for ongoing and recently completed research (ClinicalTrials.gov, ESRC SocietyToday Database, MetaRegister of Controlled Trials, NRR, ReFeR).

Study selection

To be eligible for inclusion in the review, effectiveness studies had to be well controlled, with uncontrolled studies included only in the absence of higher quality evidence. Economic evaluations had to compare two or more options and consider both costs and consequences.

Data extraction and assessment of validity

For the effectiveness and economic studies, data were extracted and study quality was assessed by one reviewer and checked by another. Any disagreements were resolved through discussion, with a third reviewer acting as arbiter where necessary.

Data synthesis

The results of the data extraction and quality assessment were presented in structured tables and as a narrative summary. The possible effects of study quality on the effectiveness data and review findings were discussed. Where sufficient clinically and statistically similar data were available, data were pooled using appropriate statistical techniques.

Results

Included studies

In total, 12,927 titles and abstracts were screened for relevance and full copies of 379 references were retrieved and assessed for eligibility. Reference checking identified an additional 91 references. Forty-two studies were included in the review: 20 systematic reviews, 22 effectiveness studies (ten RCTs, seven quasi-experimental studies and five uncontrolled studies), and five economic evaluations, all of which also contributed to the effectiveness review. Most of the evidence came from North America, with a minority of effectiveness and economic studies based in the UK. Types of service studied included day care, host-family, in-home, institutional and video respite.

Assessment of effectiveness

None of the five studies undertaken in the UK was a randomised trial evaluating the adjunctive effect of respite to usual care. Evidence from countries where referral practice, service pathways and access issues may differ radically from the UK setting is difficult to generalise.

Effectiveness evidence suggests that the consequences of respite upon carers and care recipients are generally small, with better controlled studies finding modest benefits only for certain subgroups. However, many studies report high levels of carer satisfaction. No reliable evidence was found that respite can delay entry to residential care or that respite adversely affects care recipients.

The validity of the randomisation process in the included randomised studies was sometimes unclear. Studies reported many different outcome measures, and just one trial prespecified the primary consequence of respite care and used this to enrol adequate numbers of older people. All of the quasi-experimental studies had methodological weaknesses that undermine the reliability of the findings. The uncontrolled studies had methodological weaknesses. The descriptions of the studies did not provide sufficient detail of the methods of data collection or analysis. All the studies failed to describe adequately the groups of study participants. In some studies, only evidence to support respite care services was presented, rather than a balanced view of the services.

Assessment of cost-effectiveness

Only five economic evaluations of respite care services were found, all of which compared day care with usual care. One study was undertaken in the UK. The difficulty of transferring results from the remaining four day-care studies was compounded by poor specification of ‘usual care’ and limited documentation of other service-use data.

Day care tended to be associated with higher costs and either similar or a slight increase in benefits, relative to usual care.

The economic evaluations were based on two randomised and three quasi-experimental studies, all of which were included in the effectiveness analysis. The majority of studies assessed health and social service use and cost, but inadequate reporting limits the potential for exploring applicability to the UK setting. No study included generic health-related quality of life measures, making cost-effectiveness comparisons with other healthcare programmes difficult. One study used sensitivity analysis to explore the robustness of the findings.

Conclusions

The literature reviewed in this report provides some evidence that respite for carers of frail elderly people may have a small positive effect upon carers in terms of burden and mental or physical health. Carers were generally very satisfied with respite. No reliable evidence was found that respite either benefits or adversely affects care recipients, or that it delays entry to residential care. Economic evidence suggests that day care is at least as costly as usual care.

Implications for healthcare

Much of the existing literature is unable to inform UK policy and practice: there are many important gaps in the knowledge base, with a lack of UK-relevant, good-quality, controlled evaluations for all types of respite care and no economic evidence for any type of respite other than day care.

Recommendations for research

Pilot studies are necessary to inform full-scale studies of respite in the UK.

- Overarching any further research is the primary need to clarify the objectives of respite services. Further research should explicitly state the objectives chosen, recognising that these will affect both how services are provided and how outcomes are measured.

- Further studies should either focus on specific groups of older people and carers or be of sufficient size to permit subgroup analysis. The effectiveness and cost-effectiveness of respite may vary according to whether the service is provided for older people with physical frailty or cognitive impairment and whether the carer is an adult child or a partner.
- There is a need to identify the essential components of respite services, clarifying boundaries between respite and intermediate care, crisis response, day care, rehabilitation and palliative care. Study respite services need to be culturally, socially and demographically appropriate and delivered by competent staff. Comparison interventions, such as a socially acceptable basic package of care, should be determined.
- Measures should aim to target outcomes that are relevant to both carers and older people, while recognising that individuals in a care-giving relationship will simultaneously have both joint and separate interests and aspirations.

Pilot work should then inform methodologically rigorous trials that can establish the effectiveness and cost-effectiveness of UK respite services. Given the complexity and intersectoral nature of respite care, it is likely that a range of methodological approaches will be needed to address the gaps in the evidence base.

Chapter 1

Background

Description of underlying problem

The past four decades have seen a substantial change in the age composition of older people in the UK population. The proportion of people in the UK aged 85 years and over increased almost three-fold between 1961 (0.7%) and 2001 (1.9%) and is projected to rise to 3.8% by 2031.[1] Most disabled and elderly people live in the community, and are cared for mainly by family, friends or neighbours.[2] There are around 5.7 million adults in Britain who provide care for sick or disabled relatives or friends, or the elderly.[3,4] In this report, a carer is defined as "a relative or friend who provides unpaid care" (see Glossary). Around three in ten carers are 'heavily involved', devoting 20 hours per week or more to caring activities,[5] with between one-third[4] and two-thirds[3] of heavily involved carers caring for over 50 hours a week. Three-quarters of all carers in the UK look after older people, that is individuals aged 65 and over. It is unclear what proportion of older people could be classed as 'frail', but morbidity data indicate that half of all over-65s have a long-term illness that limits their activities in some way (see Glossary for the definition used in the report). People who are frail and older may require high levels of support, which can adversely affect carers' quality of life. For example, carers report high levels of stress, anxiety and depression, as well as general health problems and physical injuries such as strained backs associated with lifting. Carers 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.[6–9]

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 frail older people and their carers is essential.

Current service provision

Despite the range of mechanisms for obtaining respite care services, little is known about the types, availability and relative value of respite care services. A survey in the late 1980s of a random sample of 128 carers of confused elderly people documented an underprovision of respite services in the UK, with carers expressing a desire for more flexible, varied and frequent services.[10] In this study, 70% of older people attended some form of day care, one in three carers had regular in-home respite and around two-thirds of carers had used institutional respite. A 2004 survey of carers of people of any age in East Sussex[11] found that around 40% of carers were receiving respite care, of which one-third felt that the level of respite care received was insufficient to meet their needs. Comparing 2004 findings with similar data from 1990 and 1997, there appeared to have been little change in the provision of care in terms of quantity or quality, despite the government initiatives introduced in the 1990s. It is unclear whether the situation is similar across the UK, but anecdotal evidence from the expert reference group (ERG) suggests that national provision is highly variable, with little variety or choice for carers and an unmet need for joined-up planning and delivery of flexible, person-centred respite services (see Appendices 1 and 2).

Quality of life

Quality of life is a concept that incorporates all the factors that might impact on an individual's life, affecting their physical, mental and social well-being.[12] The essential attributes of instruments assessing quality of life are reliability, validity and sensitivity to change.[12] Previous research has demonstrated that caring can adversely affect carers' quality of life, but health-related quality of life measures may not detect some important changes in carers' quality of life, such as the impact on personal relationships or financial hardship.[13] The potential failure of these types of measure to detect an impact on quality of life may reflect inadequacies in the instrument, rather than the absence of an effect. Carer-specific quality of life instruments have been developed, such as the Caregiver Quality of Life Instrument (CQLI).[14] Researchers have distinguished the concept of quality of life from that of carer burden, arguing that quality of life can be improved even if burden remains unchanged.[15] The quality of life of the care recipient should also be taken into account when evaluating support services, to ensure at least that the intervention has no deleterious effect. If the care recipient has dementia, quality of life may be assessed using disease-specific tools such as the Progressive Deterioration Scale, the Dementia QOL, the Cognitively Impaired Life Quality Scale (for those with severe impairment) and the Pleasant Events Schedule–AD.[12] However, if proxy responses (by carers or nursing staff) are elicited, these may need to be interpreted with caution.[16] There is preliminary evidence that people with dementia emphasise the importance of choice in determining quality of life, whereas their carers place more emphasis on the maintenance or improvement of the person's intellectual capacity.[17] A literature review published in 1998 found no validated instrument that jointly assessed the quality of life of carers and people with dementia.[12]

Description of the interventions

'Respite care' is not a discrete intervention, but encompasses a range of services. In the Medical Subject Headings (MeSH), respite care is defined as "patient care provided in the home or institution intermittently in order to provide temporary relief to the family home care giver".[18] Respite services may take many forms and include day care, in-home respite, video respite, institutional respite or respite packages. Respite may also be offered in the context of other support services (multidimensional packages).

There is no consensus regarding the primary aim of respite care and short-term breaks. In the past, such services have served different and multiple purposes, including giving carers a break from caring, preparing carers and care recipients for the latter's entry to long-term care and preventing or delaying institutionalisation. While respite care is regarded as one of the key formal support interventions to alleviate the stress of caring,[19,20] it is also a service that carers have identified as critical to their caring efforts.[21,22] However, respite care needs to accommodate the practical, cultural and social requirements of carers and care recipients if it is to be useful (see Appendix 1). Respite care services are not restricted to older people who have informal carers; some recipients will be living on their own (although they may have informal carers living at a distance) and others may have no informal support. In these instances, respite care may fulfil other important functions, such as providing opportunities to stabilise symptoms through careful monitoring and adjustment of medication, to conduct detailed assessments of physical and mental health problems, to offer rehabilitation and other therapies, to avert medical crises that could otherwise lead to hospitalisation, and to maintain or reacquire self-care skills. However, as the focus of this report is upon respite for informal carers, studies that do not assess the impact of the service upon carers are excluded from this review.

Policy issues

Caring for a relative or friend can be physically and emotionally demanding, especially for individuals who combine work and care or who are also responsible for the care of young children.[23–27] UK government policies presuppose that a break from caring can benefit carers by reducing the psychological and emotional stresses they face.[27] However, there is a growing aspiration that respite services should provide a positive experience for the older person as well as their carer.[28] Furthermore, person-centred care is a central policy objective (standard 2 of the National Service Framework for Older People).[29] Respite care services, or individual placements, that are funded by local authority social services departments may require an income-tested co-payment from the user. In some instances, respite care may be funded by the NHS, in which case no co-payment is involved; or by voluntary organisations or charities, for example in the case of respite care provided in hospices for people with cancer.

Respite care is provided in different forms, including home-based respite and sit-in services, day care, and short-term residential care in private and voluntary sector residential homes. Both local authorities and the NHS may purchase respite care placements or beds in private or voluntary sector facilities. Paradoxically, evidence from the USA suggests that respite and short-term breaks for adults have low utilisation rates.[30,31] This may reflect a lack of choice about the timing or type of services,[32] or restrictions in service provision,[33–35] financial barriers or a lack of information about available services and how to access them, or resistance on the part of the person receiving care.[27,36] However, such evidence may not be applicable to the UK, where access to respite is likely to depend more on professional assessment and referral and less on private ability to pay. Furthermore, some carers see conventional respite services as poor quality or inappropriate and ill-suited to the needs of the care recipients.[37–39] Day-care programmes may limit the level of disability that can be accommodated; for example, people with behavioural problems or incontinence may not be eligible.[10,33,40]

To help to improve the range and quality of respite services in England, the government introduced the Carer's Special Grant in 1999. The grant is intended to increase the resources available to local authority social services departments to spend on respite care services and hence to extend the volume and range of provision. The grant has since been renewed and extended on a regular basis, although it is no longer ring-fenced. The introduction of direct payments and of voucher schemes under the Carers and Disabled Children Act 2000 are initiatives designed to increase the flexibility with which carers can access the respite care services of their choice. Indeed, instead of using vouchers, some councils offer annual one-off grants that carers can use to offset the cost of arranging their own break from caring. The 2006 Health and Social Care White Paper extended the government's commitment to providing respite services by promising that short-term, home-based respite support be available for carers in emergency or crisis situations[41] (paragraph 5.55). However, the volume and range of institutional-based respite care may have been affected by a number of factors that have placed considerable pressure on the residential and nursing home sector in England in recent years. These factors include more rigorous physical standards and staffing requirements required under the Care Standards Act 2000,[42] the introduction of the national minimum wage and the European Union (EU) working time directive, and the continued pressures on local authority resources that have constrained the fees payable to private sector service providers. Consequently, numbers of residential and nursing homes have dropped significantly over the past 5 years as homes (particularly smaller ones) have gone out of business. Others have to maintain continuously high occupancy levels to break even and may not be able to afford the flexibility required to offer respite care, especially on an unplanned basis. Department of Health guidance to councils on eligibility criteria for adult social care, known as FACS (Fair Access to Care Services), provides a framework for councils and care trusts about fair charging policies for home care and other non-residential care, and advice about eligibility criteria for adult social care. The framework is based on individuals' needs and associated risks to independence, and includes four eligibility bands: critical, substantial, moderate and low. The four eligibility bands are used in conjunction with local authorities' budgets: some may only be able to fund services for people who fall into the critical band, whereas others with slightly less tight financial pressures may be able to fund services for people in the substantial band. This means that access to local authority-funded respite care for broad preventive, planned or quality of life purposes will be severely restricted and that respite is likely to be used primarily for carers under great stress or where the relationship is in danger of breaking down.

At the same time, there has been a significant investment in new intermediate care services. These operate at the interface between acute hospitals and the community and are often jointly funded by local authority social services departments and NHS primary care trusts (PCTs). Intermediate care services have a variety of purposes, functions, structures and content.[43] Most are aimed at avoiding inappropriate hospital admission or expediting hospital discharge by supporting the transition between illness and recovery. Some focus on intervening before admission to hospital and provide short-term intensive domiciliary support or a short-term stay in a residential or nursing home. Others focus on assisting rehabilitation and recovery following illness or surgery. However, to the extent that respite care services may also be used in response to a crisis, such as the illness of a frail older person or the threatened breakdown of an informal care-giving relationship, the boundaries between respite and intermediate care services are far from clear.

Despite the range of mechanisms now available for obtaining respite care services, little is known about the types of respite care service that carers (and the person they are caring for) value and use, the current availability of preferred types of respite services, or the relative value of different types of respite care services (on their own or in combination with other social care services) in reducing the stress experienced by carers or preventing the breakdown of informal care-giving.

Costs

The cost of respite for older people varies according to the type of respite, provider and the client group served. For NHS provision of day care, the mean daily cost for older people is just under £120 (price year 2003/04).[44] Outside the NHS, the mean daily cost of day care ranges from £30 for voluntary sector provision to £54 for local authority day care (2004/05 prices).[45] Accommodating older people with dementia inflates these costs by around 15%, mainly owing to the higher staff/client ratios. For all types of patient, average elective NHS institutional respite costs are just under £300 per day (£1450 for a 5-day stay), whereas for emergency (non-elective) NHS institutional respite, the corresponding cost is around £225 (£2040 for a typical average stay of 9 days; price year 2003/04).[44] A private nursing home care package costs £540 per short-term resident week (price year 2004/05). Corresponding figures for provision by other sectors are £423 for voluntary residential care, £426 for private sector provision and £718 for local authority residential care (the latter figure includes capital costs).[45] However, this short-term care does not necessarily focus on respite provision and may include rehabilitative care. In-home respite costs are less clear, but appear considerably higher than those of local authority or independent sector day care. Assuming parity with costs of home-care workers, the mean hourly weekday cost would range from £10 for independent sector provision to £15 for local authority provision (price year 2004/05).[45] These costs are inflated by 30% for evenings, by 50% for Saturday services and by 100% for Sunday services. The total annual respite expenditure by the Personal Social Services on day care for older people is £320 million (2004/05).[46] Corresponding figures for provision by other sectors have not been identified.

Chapter 2

Objectives

The principal objective of the review was systematically to identify, appraise and synthesise the grey and published evidence for the effectiveness and cost-effectiveness of different models of community-based respite care for frail older people and their carers. The participant group was explicitly required to include older people with frailty, disability, cancer or dementia. Where data permitted, subgroups of carers and care recipients, for whom respite care is particularly effective or cost-effective, were to be identified. The final aim was to explore the practical, policy and research implications and to make recommendations for further research.

Chapter 3

Methods

This report is based on a systematic review of the literature on carers and respite care. A comprehensive range of databases was searched for studies published in any language in or after 1980 that addressed respite interventions for carers of frail elderly people and included effectiveness or cost-effectiveness evidence.

To be eligible for inclusion in the review, effectiveness studies had to be well controlled, with uncontrolled studies included only in the absence of higher quality evidence. The inclusion criteria for economic evaluations were that they compared two or more options and considered both costs and consequences.

Studies of day care, in-home respite (day or overnight), host family respite, institutional respite (overnight), respite programmes and video respite were all eligible for inclusion. Data extraction and quality assessment of studies were undertaken in line with standard practice guidelines.

An ERG was set up to help to interpret preliminary findings, comment on a draft report, and suggest recommendations for policy, practice and further research.

Search strategy

Thirty-seven databases were searched for references for relevant studies relating to respite care for carers of frail elderly people. These databases covered a wide range of topics (including health and medical care, social care and the elderly) and a wide range of types of data (including economic, grey literature, conference abstracts and ongoing studies). The searches were unable to discriminate between services for the carers and the care recipients, although in most circumstances terms such as 'respite' and 'break' did refer to the carer. Search terms for 'older' and for 'frail' were excluded from the search strategy, because many relevant papers did not specify the age of the care recipient in the bibliographic record or in the database indexing terms, while 'frail' terms identified all physical and mental conditions across all ages. A variety of free-text and indexing terms was used to form the search strategies and each strategy was individually tailored to run in each database (see Appendix 3).

The literature searches were restricted by date to 1980 onwards. This covers a period characterised by major changes in service delivery and organisation, as well as changes in the age structure of the population. Language restrictions were not applied. In addition, the bibliographies of all included articles were searched for additional references and citation searches of key articles were carried out on the Social Sciences Citation Index (SSCI) and Sciences Citation Index (SCI).

In addition to searching for conference abstracts in four databases (Inside Conferences, ISI proceedings, science and technology and ISI proceedings, social sciences and humanities), a web search of relevant conferences was conducted.

Literature review

Effectiveness studies

Inclusion and exclusion criteria

Two reviewers independently screened all titles and abstracts. Full paper manuscripts of any records that were potentially relevant were obtained, where possible, and the relevance of each study assessed according to the criteria listed below. Studies that did not meet all of the criteria were excluded and their bibliographic details listed with reasons for exclusion. Any discrepancies were resolved by consensus and where necessary, a third reviewer was consulted.

Study design

The review of respite care included randomised controlled trials (RCTs) of effectiveness. Where insufficient effectiveness data were found from RCTs, non-randomised, well-designed, controlled studies were included to inform the review and the economic evaluation. Studies were graded in accordance with guidelines from the Centre for Reviews and Dissemination (CRD),[47] and quality assessment findings were summarised in tables. Since uncontrolled studies are subject to a number of potential methodological biases that make findings hard to interpret, these are normally excluded from a systematic review. However, the protocol was amended to allow for the inclusion of uncontrolled studies under certain conditions (see the section 'Changes to the protocol', p. 11). For any included controlled study, where qualitative findings were reported, these were extracted and documented separately for control and intervention groups so far as the data permitted and in accordance with current guidelines.[47,48]

Interventions

For the purposes of the review, 'respite care' is defined as care provided intermittently in the home, community or institution in order to provide temporary relief to the principal carer. Respite care includes, but is not limited to:[36]

- day care
- in-home respite (day or overnight)
- host family respite
- institutional respite (overnight)
- programmes
- video respite.

Trials reporting at least one of these respite models were eligible for inclusion in the review. Respite care models where care recipients received no informal carer support were excluded. No inclusion restriction was applied to the search strategy by type of comparator intervention.

Studies reporting multidimensional support packages that include respite care were included in the review only if the comparator intervention was the same package, but without an option for respite care, or the trial report allowed the impact of respite care to be explored (e.g. where uptake of each component of the package was clearly reported). However, the protocol was subsequently amended so that if no controlled study of a multidimensional support package were eligible for inclusion, a short narrative to describe the studies and their findings could be provided (see the section 'Changes to the protocol', p. 11).

Participants

Participants included older people receiving respite care, including those with frailty, disability, dementia or cancer, and their carers. For the purposes of the review, the following definitions were adopted (see also Glossary):

- care recipient: person being cared for (patient, older person)
- dyad: carer and care recipient
- frail: having one or more long-term health problems and/or difficulties in one or more aspects of personal care (e.g. as assessed against the Activities of Daily Living Index), such that support to live independently is required.[49]
- older: aged 65 years or above.[5]

Although frailty is often experienced in late old age,[32] this definition of 'older' was adopted to reduce the risk of excluding potentially useful studies. Where trials included patients below this age, they were eligible for inclusion only if both of the following conditions applied: first, at least half of the participants were aged 65 or above; secondly, findings were reported in sufficient detail to allow appropriate subgroup analysis. For pragmatic reasons, however, the protocol was later amended to relax this condition (see the section 'Changes to the protocol', p. 11).

Setting

Studies of respite care services in all settings apart from acute medical and/or surgical inpatient wards were eligible for inclusion in the review. Settings such as nursing and residential homes, hospices, community and GP-run hospital units, day centres and domiciliary settings were all eligible for inclusion. No inclusion restriction was applied to the search strategy by funding source.

Outcomes

Data on the following categories of outcome measures (as reported for carers and care recipients separately, and by the care recipient, carer or clinician) were included:

- quality of life (carer/care recipient)
- physical health (carer/care recipient)
- mental/psychological health (carer/care recipient)
- satisfaction (carer/care recipient)
- carer burden
- utilisation of any health and social services (carer/care recipient)
- utilisation of informal or voluntary support services (carer/care recipient)
- (time to) institutionalisation
- time spent on caring tasks
- activities of daily living (ADL).

Other reported outcome measures were also documented. If a study reported no carer outcomes, such as one assessing only care recipient health, the study was excluded from the review.

Quality of life issues

For studies included in the effectiveness and cost-effectiveness reviews, all data on health- or non-health-related quality of life measures were abstracted, whether pertaining to the carer or to the care recipient, or to both. The types of instrument used and details of their construction (e.g. the dimensions addressed, the number of points on the scale) were reported (see Appendix 4, *Table 35*). Data on quality of life were summarised in a narrative (see the section ‘Effectiveness studies: findings by outcome’, p. 44 and the potential for meta-analysis was explored (see the section ‘Meta-analysis’, p. 47).

Data extraction strategy

Data relating to both study design and quality were extracted by one reviewer (KS or AM) and independently checked for accuracy by a second reviewer (KS, AM or HW). Disagreements were resolved through consensus, and if necessary, a third reviewer was consulted (JA). Where necessary, the reviewers attempted to contact authors for missing data. Data from studies with multiple publications were extracted and reported as a single study. The major attributes of trials were summarised, including model of respite care, inclusion and exclusion criteria, level of blinding, method of generation of the randomisation sequence, concealment of allocation,[50] numbers of recipients randomised, baseline comparability of carers and recipients, loss to follow-up and withdrawals. The category ‘model of respite care’ includes details on the frequency and intensity of care, staffing ratios and setting. Data were abstracted on carer and care recipient outcomes, quality of life measures and economic outcomes, including delay or prevention of institutionalisation. Where non-randomised trials were included in the review, potential confounding factors were documented. These include the appropriate management of any underlying morbidity in the older person or their carer, demographic or clinical differences between study groups, and access to and uptake of other formal or informal carer support.

Quality assessment strategy

The quality of the individual controlled studies was assessed by one reviewer (KS or AM) and independently checked by a second reviewer (KS, AM or HW) using modified criteria from CRD Report No. 4.[47] Disagreements were resolved through consensus, and where necessary, another reviewer was consulted (JA). For each included study, the components were evaluated for which there was evidence of an association with biased estimates of effect.[51] This information was tabulated and summarised within the text of the report. The quality of uncontrolled studies was also assessed by one reviewer (KS) and checked by a second reviewer (JA) using a quality appraisal checklist.[48] Three broad issues guided the appraisal of the descriptive studies: rigour, credibility and relevance. The appraisals are presented in Appendix 5.

Strategy for analysis and synthesis

The results of the data extraction and quality assessment were presented in structured tables and as a narrative summary. The possible effects of study quality on the effectiveness data and review findings were discussed. If sufficient clinically and statistically homogeneous data were available, data were pooled using appropriate meta-analytic techniques.[52] Effect sizes were estimated and forest plots constructed using Review Manager 4.2.

Economic evaluations

Types of economic evaluation

Economic evaluation is a method to identify, measure, value and compare the costs and consequences of two or more alternative programmes in order to assess their relative benefits and value for money.[53]

There are three main types of economic evaluations, namely (1) cost-effectiveness evaluations including cost-minimisation and cost–consequences analyses, (2) cost–utility analyses and (3) cost–benefit analyses, each of which use the same cost methodology but different outcome methodologies. Cost-effectiveness analysis (CEA) measures outcomes of the alternatives as measured in natural units, such as additional days in the community, and this is combined with costs to give, for example, a cost per additional day in the community. Cost-minimisation analysis (CMA) is a form of economic evaluation where the alternative programmes are associated with equivalent outcomes so that the only difference between them is the cost. Cost–consequences analysis (CCA) is the measurement of one or more types of outcome, all of which are reported separately from costs. In contrast, cost–utility analysis (CUA) is a form of economic evaluation where costs and outcomes are examined. Outcomes are valued as utilities, and combined with costs to generate cost–utilities. The outcomes for each alternative, for example life-years gained, are measured and valued using a weighted score which is a preference for the health state. In this way, an attempt is made to value the quality of life associated with the outcome so that life-years gained become quality-adjusted life-years (QALYs) gained. Lastly, cost–benefit analysis (CBA) includes the costs and outcomes of the alternative interventions, both of which are valued in monetary terms. However, one advantage is that outcomes can be more easily compared with the costs of the intervention.

Data extraction and quality assessment

As described in the section 'Search strategy' (p. 7), the information officer searched the published literature to obtain economics data for the review. Beyond the effectiveness data, this encompassed searching for evidence on quality of life, the cost of respite care and economic evaluations. A data extraction form (see, for example, Appendix 4, *Table 30*) and quality assessment checklist (see Appendix 5, *Table 37*), both previously used in National Institute for Health and Clinical Excellence (NICE) Technology Assessment Reviews, were applied to all the studies that were included in the review of economic evaluations. One reviewer extracted and quality assessed data from each of the studies (HW, AM) and another reviewer checked the data extraction and quality assessment (HW, AM).

The data extraction form was used to extract key elements of the economic evaluations to aid their systematic review. Data extracted included the type of economic evaluation, the perspective of the analysis, the types of programme compared, the source of the effectiveness, resource-use and unit-cost data and the links between them, the clinical outcomes measured and valued, the costs measured, the type of model used, the economic outcomes measured and valued, the result of the economic evaluation, details on how uncertainty was handled, and the authors' conclusions or stated implications of the study for practice. The studies were quality assessed to aid transparency about the extent to which the studies used methods to minimise bias, the aim being to assess whether the study results are likely to approximate the 'truth' and the extent to which they are likely to be applicable to routine practice.[47]

Research synthesis

Various techniques are available to synthesise the data to provide a summary of the diverse respite care evidence base. Within the cost-effectiveness section a narrative review is provided, as well as structured tables for reference. Beyond summarising the data narratively, other options for summarising the data include the use of statistical models such as meta-analytic techniques for pooling effectiveness data (see the section 'Strategy for analysis and synthesis', p. 9) and the use of economic models to synthesise cost and effectiveness data. The latter provide an explicit methodology for aggregating costs and effectiveness findings from different sources within a quantitative framework. It was an aim of the project to conduct an economic model, subject to the availability of sufficient data.

Expert reference group

The advantages of involving the public in the design, conduct, analysis and reporting of research are well known.[54] There is evidence to show that systematic reviews can be enhanced, and the results made more useful, if practitioners and consumers contribute to the design and interpretation.[55] The Cochrane Collaboration Consumer Network, which includes individuals and community organisations worldwide, has been established specifically to support and develop consumer participation in the work of the Collaboration, and to help to ensure that information is both accessible and intelligible to consumers.

An ERG was set up to enable stakeholder involvement in this project. From the 17 organisations approached, 13 members were recruited from statutory, voluntary and independent sector organisations (see Acknowledgements). The members were made up of professionals, providers and representatives of service user groups, who together brought a wide range of expertise and interests to bear on the research. Some people were themselves either current or former carers.

The local ethics committee reviewed the protocol and confirmed that ethical approval was not required. Advice from the ERG was sought at key points in the review process. The group:

- identified relevant local studies or policy documents that may have been missed by the formal search strategy
- reviewed a draft report of preliminary findings
- participated in a one-day workshop
- provided expert views on current service provision and resource use for respite.

Communication between the review team and the ERG was generally through e-mail, telephone and by post. In addition, a one-day workshop was held at the King's Fund in London. The workshop took place 13 weeks before the project completion date, to allow time for the views and expertise of the

ERG to inform the final report for the HTA. Three weeks before the workshop, a draft report presenting preliminary findings from the review was sent to the ERG members, who were invited to submit written comments in return for a fee. Travel expenses incurred by the group as a result of attending the workshop were reimbursed.

The workshop opened by giving the ERG the opportunity to say what, in their experience, were the 'big issues' about respite, such as service provision, funding and access to care. Next, evidence on effectiveness and cost-effectiveness of respite was presented and the ERG was invited to ask questions or to make comments. ERG members were then requested to complete a questionnaire on resource-use issues, to help to inform the economic component. The questionnaire asked for views on current patterns, take-up and service provision. ERG members who did not attend the workshop were subsequently sent a questionnaire by post or e-mail. Lastly, policy, practice and research implications were debated and recorded on a flipchart. At the end of the workshop, ERG members were informed that they would receive copies of both the final draft report and the final report.

Proceedings from the workshop were recorded as written notes by the review team members and on flipcharts, which were subsequently synthesised by one team member (AM) and then agreed by the whole team. A summary of the themes and concepts arising from the workshop was drafted, then edited and revised in light of the ERG's written reviews of the draft report. The ERG was then given the opportunity to comment on this draft. A summary of key findings from the ERG is presented in Appendix 1. These themes represent the subjective views of the ERG and should be interpreted accordingly.

Changes to the protocol

The following changes to the protocol were made and formally agreed with the sponsors.

Special consumer summary abandoned

It had been planned to provide a consumer summary for any lay members recruited to the ERG. However, it was decided that a consumer summary was unnecessary. This was partly because it was clear that all of the participants were capable of reviewing the full report. It was also realised that the workshop in December would be more productive if all ERG members had had access to the same information. The money budgeted for providing the summary was diverted towards the higher peer-review payments.

Additional database searches carried out

SCI was not searched individually, but as part of SSCI. Two additional databases were searched: the Applied Social Sciences Index and Abstracts (ASSIA) and Social Services Abstracts.

Inclusion criteria for studies widened

Uncontrolled studies

Since uncontrolled studies are subject to a number of potential methodological biases, which make findings hard to interpret, the protocol excluded these from the systematic review of effectiveness. However, there might then be no evidence from controlled studies available for some types of respite or some patient groups. Therefore, the protocol was amended to exclude uncontrolled studies unless no higher level of evidence were available (e.g. for a particular type of respite care and/or patient group). In this case, the authors would quality appraise the study and interpret any findings in the light of the quality assessment.

Multifaceted interventions

Some studies of multifaceted (or multidimensional) interventions that included respite were retrieved. The protocol stated that these studies would be excluded unless the distinct impact of respite could be determined. However, none of the studies retrieved met the inclusion criteria. Instead of excluding these studies completely, it was decided to include a short review to describe the packages and outline the findings. One reason for this decision was that multifaceted interventions more closely reflect usual practice in the UK (community care packages) and information on these studies may therefore be useful in informing policy. In addition, the impact of respite care as part of a package, rather than as an individual service, may differ; if these studies were excluded, then this could not be explored.

Participant age

The protocol stated that the review would include studies only with participants aged 65 and over or, if the study included participants aged under the age of 65, inclusion would be dependent on whether age-related subgroup analyses were reported. However, just one study had an inclusion criterion of participant age over 65; many studies did not provide an age range for participants (so it was unclear whether under-65s were included or not); and some studies included small proportions of participants aged under 65, but reported no subgroup analysis. Excluding the latter would almost certainly discriminate against studies with better reporting methods in favour of those that reported less information. Therefore, where trials did not explicitly exclude patients below this age, the studies were included, but the limitations were highlighted in the interpretation of the findings.

Chapter 4

Results: overview

When the searching was complete and duplicates had been removed, the EndNote library contained 12,927 records. The size of the library resulted from the broad search, which was designed to minimise the risk of missing relevant studies (see the section 'Search strategy', p. 7). At least two of the reviewers (out of AM, KS, HW and JA) screened all 12,927 records, using the criteria outlined in the section 'Search strategy' (p. 7) (Inclusion and exclusion criteria), to identify effectiveness studies, relevant literature reviews, background papers and economic evaluations. Since non-randomised studies were eligible for inclusion in the effectiveness analysis, the screening process was longer and more complex than that normally undertaken for a systematic review.

The initial screening process identified around 3% (379) of the records in the EndNote library as being potentially relevant and these references were retrieved (*Table 1*). Studies may have been retrieved for more than one reason (e.g. potential economic evaluation and potential study).

Key reasons why records in the EndNote library failed to meet the inclusion criteria are given in *Figure 1* (records may have been rejected for more

TABLE 1 *Overview of the initial screening process*

	No. of hits	% of EndNote library (*n* = 12,927)	% of papers retrieved (*n* = 379)
Papers retrieved	379	2.9%	100.0%
Potential studies	171	1.3%	45.1%
Potential economic evaluations	45	0.3%	11.9%
Reviews	85	0.7%	22.4%
Background	106	0.8%	28.0%

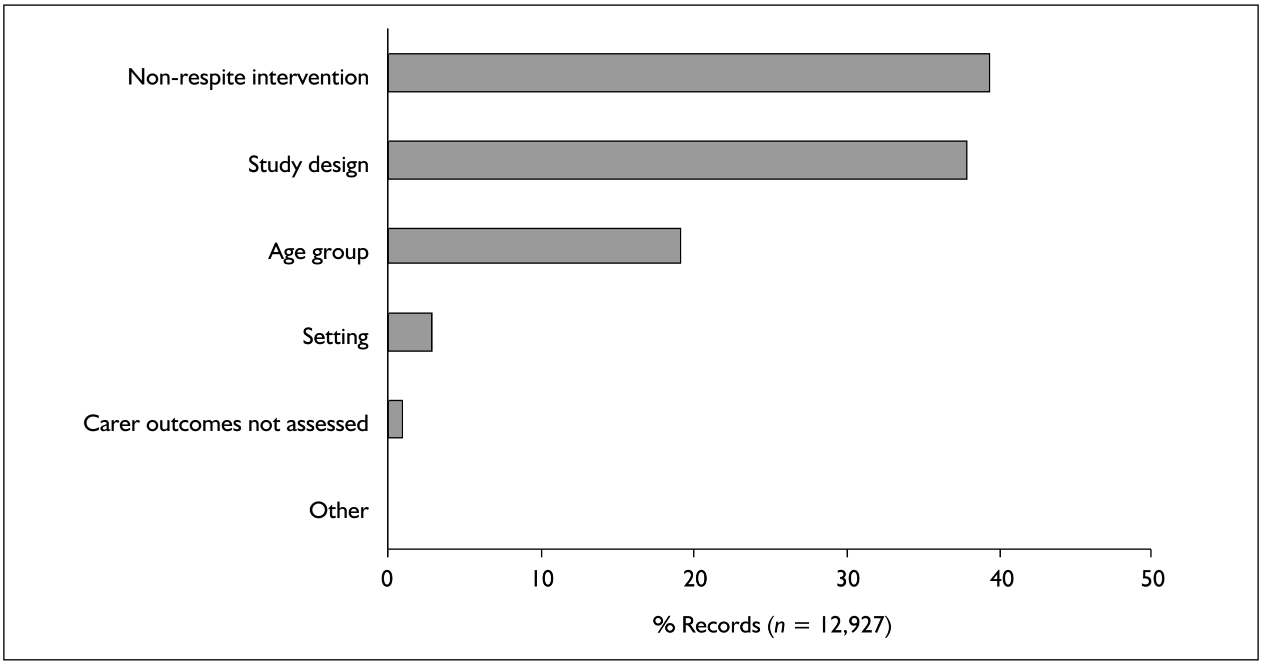


FIGURE 1 *EndNote records: key reasons for exclusion from the review*

than one reason). Around 171 (45%) of the 379 papers retrieved were scrutinised further for eligibility for the effectiveness analysis. Some of these were multiple references to the same study. A further 85 papers (22%) were literature reviews; the bibliographies of these were checked to identify any relevant studies missed by the formal search process and the systematic reviews summarised (see the next section). The remaining papers addressed cost-effectiveness, quality of life or costing issues, or provided background for the review, such as those relating to uptake issues or assessments of the relationship between respite use and institutionalisation.

Bibliography checking, citation searches and retrieval of background material yielded a further 91 references, bringing the total number of records in the EndNote library to 13,018.

The screening process identified seven potentially relevant non-English papers, published in Japanese and Spanish (two papers each), and Dutch, German and Korean (one paper each) When ordering the Japanese and Korean papers, translations were requested but none was available. The remaining papers were read by the reviewers and one Spanish study was included in the review.

Where key outcome data were missing from studies, attempts to contact authors were made. However, contact details supplied in the publications were out of date (reflecting the studies' publication date) and efforts to request additional data were therefore unsuccessful.

Findings from existing systematic reviews

The search process identified twenty systematic reviews addressing respite care.[56–75] *Table 2* (p. 16) provides an overview of findings from these reviews. Of these 20 reviews, just two examined outcomes for carers of cancer patients.[66,67] Therefore, three non-systematic reviews of respite services for cancer patients (of any age) were also retrieved, to check the bibliographies for relevant studies.[80–82] In total, five additional studies were identified from the bibliographies of the 20 systematic reviews. Although these were all identified from one review,[58] this is likely to reflect the order in which reviews were checked (alphabetically, by first author).

Four of the reviews undertook a meta-analysis, pooling findings from different studies to determine the effect size of interventions.[56,68,72, 75] Two other reviews found that a meta-analysis was not possible, because of heterogeneity of outcomes or interventions.[66,69] Two meta-analyses found positive effects for respite upon carer outcomes only when non-randomised studies were included;[72,75] in the review by Yin and colleagues,[75] the overall effect size for quasi-experimental studies was around three times larger than that of randomised trials. The meta-analysis by Acton and colleagues[56] found that respite had no significant effect on carer burden while the review by Knight and colleagues[68] found that respite had a 'moderate' effect on carer distress. However, the present review classified two of the interventions contributing data to this analysis as multidimensional packages,[78,83] rather than as respite interventions (see *Table 15*, p. 58).

Five reviews of cancer support services were identified,[66,67,80–82] of which two were systematic reviews.[66,67] Harding and Higginson[66] identified three studies on respite care, all of which had been identified by the electronic searches.[84–86] Ingleton and colleagues found no empirical study on the effects of respite on carers of cancer patients.[67] Neale and Clark[80] identified just one study on respite care,[85] and cited others that offered comments or carer opinions, but that were not evaluations.[87,88] Pasacreta and McCorkle found no evaluation of respite care for carers of cancer patients and commented on the "dearth of data-based literature describing interventions aimed at caregivers".[81] The review by Salisbury and colleagues was primarily focused on patient outcomes and did not examine the impact of interventions on carers.[82]

Overview of the review evidence

Ninety-one additional references were found by checking the bibliographies of papers, further citation searches and retrieval of background material, bringing the total number of references in the EndNote library to 13,018. Eligible papers for the effectiveness and economic literature were scrutinised further by two reviewers (AM, KS, HW). Where studies clearly met the inclusion criteria, data were extracted and the studies were quality assessed. In total, the review included 22 effectiveness studies (reported in 43 papers) and five economic evaluations (reported in 17 papers) (*Table 3*, p. 23). Most of the effectiveness studies (13/22) and economic evaluations (3/5) were set in North America, with a minority of effectiveness studies (5/22) and economic evaluations (1/5) based in the UK. Ten of the 22 effectiveness studies were randomised trials and two of the five economic evaluations were based on RCT evidence of effectiveness. Although a wide range of disease areas was covered in the broad search, most of the effectiveness studies included people with cognitive impairment, either exclusively (13/22) or in part (7/22). Disease areas included by the broad search covered AIDS, heart failure, multiple sclerosis and renal disease. However, no controlled respite study of frail elderly people, focused specifically on any of these diseases, was identified. However, in some studies the proportion with cognitive impairment was low; for example, this comprised just over one in five in the study by Burch and Borland.[89] Physical impairment was also apparently common, although this was inconsistently reported. No study of respite services for carers of cancer sufferers met the review protocol inclusion criteria. Therefore, a narrative review of two uncontrolled respite studies for carers of people with cancer is reported (see the section 'Changes to the protocol', p. 11), one assessing a multidimensional package and the other in-home respite.[84,85] 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. Controlled effectiveness studies of day care, institutional care, in-home respite and respite packages were found. No controlled study of host family respite or video respite was identified, so uncontrolled studies of these services were reviewed.[90–92] Day care was the only form of respite for which evidence on cost-effectiveness was identified.

TABLE 2 *Overview of systematic reviews of respite care* (n = 20)

Review	Interventions (no. of respite studies reviewed)[a]	Inclusion criteria	Carer outcomes reported	Care recipient outcomes reported	Key findings reported	Comments
Acton, 2001[56]	Support groups; education (including psycho-education); counselling; **respite care** (4); multicomponent interventions	Studies published between 1966 and 1999; caregivers of adults with dementia; relevant intervention and outcomes assessed; controlled studies or uncontrolled before-and-after studies	Caregiver burden, e.g. Zarit burden interview		Only multicomponent interventions significantly reduced carer burden. Pooled results from four studies of respite care found no significant impact on carer burden (effect size –0.02). When analysed individually, just one respite study found to have a significant effect on burden (Kosloski[76]) (see the section 'Effectiveness studies: findings by outcome', p. 44)	Meta-analysis undertaken
Acton, 2002[57]	Education; support and education; counselling; case management; **respite** (16); **day care** (8); **in-home respite** (1); **institutional respite**; (5) **respite programmes** (3); multicomponent interventions	Nursing research studies published in any year; non-nursing research published between 1991 and 2001; unpublished studies; caregivers of elderly adults with dementia; controlled studies or uncontrolled before-and-after studies	Dysphoric measures (burden, stress, anxiety) psychosocial measures (coping)	Physical health; rate of institutionalisation	Family carers may need more flexible respite options than those that have been empirically tested	
Arksey, 2004[58]	**Day care** (21); **in-home respite** (8); **host family respite** (1); **institutional/overnight respite** (12); **respite programmes** (3); **multidimensional carer support packages** (4); **video respite** (2)	English-language studies published or reported in the grey literature between 1985 and 2003; interventions directed at informal carers of people with dementia; experimental or observational studies, including qualitative studies	Any reported	Any reported	Effects reported by qualitative studies are higher than those reported in experimental studies. For overnight respite, there was evidence that carers had more sleep. For the other types of respite, there was no experimental evidence showing significant short-term benefits to carers or care recipients and long-term effects were unclear	Five new studies identified from the bibliography of this review

continued

TABLE 2 *Overview of systematic reviews of respite care (n = 20) (cont'd)*

Review	Interventions (no. of respite studies reviewed)[a]	Inclusion criteria	Carer outcomes reported	Care recipient outcomes reported	Key findings reported	Comments
Bedini, 1999[59]	Programmes in recreation, leisure or social support that facilitated carers' pursuit of leisure (including **respite**) (5)	Studies published between 1990 and 1998; interventions for carers of older adults; studies assessing impact on leisure as primary or secondary end-point; studies of any design examining proposed or actual interventions	Any reported		Four of the five respite studies were evaluations. Respite can provide time for carers to pursue leisure activities, but it is less clear that these potential benefits are realised, as carers tend to use the time to do chores	
Bhogal, 2003[60]	Social support (instrumental/emotional); family education; social and leisure activities; leisure therapy; interventions affecting caregiver burden and depression (including **respite care**) (0); impact of family interactions on stroke outcomes	Studies published between 1970 and 2002; RCTs (family education/leisure therapy); all study designs (other interventions); studies examining outcomes for care recipients and/or carers	Caregiver burden depression; any others reported (e.g. problem-solving skills, quality of life)	Any reported	No studies of respite care for carers of stroke patients were identified	
Catty, 2001[61]	**Non-medical day centres** (0)	Studies published between 1963 and 1999; RCTs of interventions for people with severe mental illness; day centre care, excluding specialist work units or crisis centres	Quality of life; satisfaction	Death (suicide or natural cause); clinical response; withdrawal from study; behavioural measures; service utilisation; economic outcomes; quality of life satisfaction	No relevant trial was identified	Unclear whether any of the excluded trials were of elderly people, as authors do not report study details

continued

TABLE 2 *Overview of systematic reviews of respite care* (n = 20) *(cont'd)*

Review	Interventions (no. of respite studies reviewed)[a]	Inclusion criteria	Carer outcomes reported	Care recipient outcomes reported	Key findings reported	Comments
Chesson 2004[62]	**Respite** (9), including day care, inpatient respite, day hospital respite, institutional respite, sit-in services	English-language studies in the peer-reviewed and grey literature published between 1989 and 2003; effectiveness studies of respite for carers of children or adults	Any reported, including physical health, emotional health satisfaction; open-ended responses		Nine UK studies of respite were identified, of which six included carers of older people. None was a controlled trial. Reviewers concluded that a coherent, comprehensive body of UK research on respite care is lacking	Reviewers highlight the difficulty in identifying effectiveness studies in this area, reflecting international differences in terminology, the diversity of databases to be searched and the retrieval problems relating to grey literature
Droes, 2004[63]	Any support services, including support groups, **respite care** (8), education, befriending, support programmes, behavioural interventions	Studies published between 1980 and 2000; intervention studies of caregivers of people with dementia living at home; studies reporting specified outcomes	Caregiver burden	Institutionalisation; quality of life	Based on eight studies, respite care can have a significant impact on the carer's feeling of burden, although not all studies found an effect	Reviewers report findings for chronological periods and discuss implications of evolving support services
Flint, 1995[64]	**Respite care** (4)	English-language studies published between 1975 and 1994; primary research; controlled trials of respite intervention for people with dementia; studies reporting relevant outcome measures	Burden/stress; mental health; physical health; attitude to care recipient	Cognition; behaviour; physical health; rate of institutionalisation/days in the community	The four studies included in the review provided little evidence that formal respite had a significant effect on outcomes	
Hanson, 1999[65]	**Respite care** (36); **institutional respite** (9); **day care/day hospitals** (3); **in-home respite** (17); **holiday respite** (5)	English-language studies published between 1990 and 1998; respite for carers of frail, older people: effects, definitions, locations, barriers to uptake	Not specified		The effects of institutional respite are equivocal. Evidence from the USA has found little effect for day hospital care. In-home respite is the type most popular with carers. Psychological and practical barriers to uptake were identified	The reviewers comment on the inflexibility and lack of choice regarding current respite provision in the UK and Europe

continued

TABLE 2 *Overview of systematic reviews of respite care* (n = 20) *(cont'd)*

Review	Interventions (no. of respite studies reviewed)[a]	Inclusion criteria	Carer outcomes reported	Care recipient outcomes reported	Key findings reported	Comments
Harding, 2003[66]	Home nursing care; **respite care** (0); social networks/activity enhancement; problem solving/education; group work	Studies published between 1966 and 2001; interventions for carers of non-institutionalised cancer and palliative care patients	Not specified		No controlled study of respite for carers of people with cancer identified (three uncontrolled studies found). "The current evidence contributes more to understanding feasibility and acceptability than to effectiveness"	One of two systematic reviews examining outcomes for carers of cancer patients. Meta-analysis was not possible, owing to the heterogeneity in outcomes and study design
Ingleton, 2003[67]	**Respite** (28)	English-language studies published in peer-reviewed journals between 1966 and 2002; studies addressing palliative care, respite for adults and carer outcomes	Carer well-being		As no empirical study of the impact of respite care upon carers of palliative care patients was identified, no conclusion about efficacy can be drawn	One of two systematic reviews examining outcomes for carers of cancer patients
Knight, 1993[68]	Psychosocial interventions; **respite** (4)/care planning interventions	Controlled studies published between 1980 and 1990; studies reporting carer distress as an outcome measure; limits on study design unclear	Caregiver distress, including subjective burden, depression, anxiety, hostility or other dysphoric emotional outcomes		Individual respite programmes are moderately effective, but there are important gaps in the evidence base (effect size 0.63)	Meta-analysis undertaken; it is unclear how any heterogeneity (variation) between the studies was handled. Reanalysis of three studies (excluding one study with depression as the outcome measure) found much smaller effect sizes.[77] One of the four studies included in the review was of a multicomponent package[78]

continued

TABLE 2 *Overview of systematic reviews of respite care* (n = 20) *(cont'd)*

Review	Interventions (no. of respite studies reviewed)[a]	Inclusion criteria	Carer outcomes reported	Care recipient outcomes reported	Key findings reported	Comments
Lee, 2004[69]	**Respite care** (3)	Studies published between 1966 and 2005; RCTs comparing respite care for people with dementia and their caregivers with a control intervention	Abuse burden; economic outcomes; physical health; psychological health/stress; quality of life	Behaviour and ADL; cognition/mental functioning; drug use; institutionalisation; mortality; physical health; quality of life	Current evidence does not demonstrate that respite care offers either benefits or harms for care recipients or their carers. Only two of the three respite studies contributed data for the meta-analysis. Pooling was not possible, owing to heterogeneity (variation) in the interventions, outcomes and duration of care	Meta-analysis planned, but not undertaken. Positive findings reported in one study[79] could not be replicated; the reviewers suggest misreporting of data or errors in the original analysis as possible causes
McNally, 1999[70]	**Respite care** (29)	English-language studies published between 1966 and 1997; studies assessing carer outcomes	Caregiver well-being	Institutionalisation	There is little evidence that respite care has a consistent or an enduring effect on carer well-being. Respite has the potential to influence institutionalisation, but the direction of this influence is unclear	Not limited to care recipients of a specific age group. Research reviewed was "methodologically poor"
Roberts, 2000[71]	**Respite care** (5); **day programmes** (4); counselling; congregate living; special care units	Studies published between 1986 and 1996; controlled studies assessing relevant outcomes for persons with dementia and their caregivers	Burden/distress/mood; quality of life; satisfaction	ADL; drug use; mental confusion; economic outcomes; social participation	Evidence suggests that respite offers little reduction in burden	Day programmes may offer respite to carers, but their principal goal is to offer benefits to care recipients

continued

TABLE 2 *Overview of systematic reviews of respite care* (n = 20) *(cont'd)*

Review	Interventions (no. of respite studies reviewed)[a]	Inclusion criteria	Carer outcomes reported	Care recipient outcomes reported	Key findings reported	Comments
Sörensen, 2002[72]	Psycho-educational interventions; supportive interventions; **respite/adult day care** (13); psychotherapy; educational interventions; multicomponent interventions; miscellaneous	Studies in English, German, French or Russian (year limits not reported); care recipients aged ⩾60 years, with or without dementia; comparator is no treatment; at least one prespecified outcome reported; effect sizes calculable; study published in peer-reviewed journal	Ability and knowledge; self-rated depression; subjective well-being; uplifts (sources of satisfaction)	Any reported	When non-randomised studies were included in the meta-analysis, respite interventions were found to be effective for carer burden, carer depression and carer well-being. There was no significant effect on care recipient symptoms. When non-randomised studies were excluded from the meta-analysis, respite care was found to have only one significant effect: a negative impact on carer ability/knowledge. However, this finding was based on one small study	Meta-analysis undertaken. Regression analysis used to assess impact of moderators (e.g. presence of dementia), but results not reported separately by intervention
Stoltz, 2004[73]	Any supportive interventions (including **respite**) (1)	Studies in English or Scandinavian languages, publication date not restricted; studies on support (interventions/need/experience) for cohabiting carers of elderly people	Any reported		Based on 26 studies, the authors concluded that family carers fear social isolation and want to be involved in networks and to use respite care. However, the five studies of supportive interventions provided no evidence that carers benefit from support services	

continued

TABLE 2 *Overview of systematic reviews of respite care (*n *= 20) (cont'd)*

Review	Interventions (no. of respite studies reviewed)[a]	Inclusion criteria	Carer outcomes reported	Care recipient outcomes reported	Key findings reported	Comments
Visser-Meily, 2005[74]	Any supportive interventions (including **respite**) (0)	Studies in English, German or Dutch published from 1966 to 2003; controlled studies and uncontrolled before-and-after studies; studies of interventions for carers of stroke patients	Burden; emotional state; knowledge; psychosocial outcomes; quality of life; satisfaction		No respite study identified	
Yin, 2002[75]	Group interventions (including **respite**) (2); individual interventions (including **respite**) (1)	Controlled studies published between 1980 and 2000; studies focusing on caregivers of elderly people; studies reporting caregiver burden as an outcome measure	Caregiver burden/strain		Positive effect sizes found for both group and individual interventions, although effect size was lower when non-randomised studies were excluded from the meta-analysis. Effect sizes for respite care interventions ranged from 0.067 to 1.152	Meta-analysis undertaken

[a] Respite studies in bold.

TABLE 3 *Overview of the evidence on respite care for carers of frail older people*

Type of respite	No. of studies included in the effectiveness review				No. of studies included in the cost-effectiveness review[b]				Country[c]						Publication year (range)
	Randomised trials	Quasi-experimental studies	Uncontrolled studies[a]	All	CEA	CCA	Other	All	Australia	Canada	Germany	Spain	UK	USA	
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 UK ($n = 1$) and the USA ($n = 2$).

Chapter 5

Results: the effectiveness of respite care

Twenty-two effectiveness studies were included in this review, of which five were uncontrolled and reviewed only because of the absence of higher quality evidence for particular types of respite or disease areas (see *Table 3*, p. 22). Ten of the 17 controlled studies were randomised trials, but the validity of the randomisation process in some studies was unclear. The quasi-experimental studies had methodological weaknesses and findings that may be more to do with the design of the study than the benefit of respite.

Only five studies were undertaken in the UK, none of which was a controlled trial comparing respite with usual care. Evidence from outside the UK, where referral practice, service pathways and access issues may differ radically, is therefore difficult to apply to the UK. Studies typically measured a large number of potentially interrelated outcomes, which increases the risk of spuriously identifying a 'significant' finding by chance. Only one trial followed good research practice by clearly prespecifying the primary consequence of respite care and enrolling adequate numbers of participants (care recipients).[93] However, no study was powered on the basis of carer outcomes.

Establishing that trials included only older people (i.e. aged 65 years or over) was problematic because reporting standards were variable. Only one trial reported the age range of participants[92] and three studies specified the minimum age of eligible participants as 60[35,94] or 65.[95] Three additional studies stated explicitly that the study population included a proportion of under-60s (4%)[76] or under-65s (6%[40] and 16%[96]). Three studies did not report the age of participants at all,[34,91,97] and it was unclear in the remaining 12 trials whether the study sample included people aged under 65. Rather than discriminating against studies with better reporting standards, the protocol was amended to allow the inclusion of all studies of 'older' people (see the section 'Changes to the protocol', p. 11) and these limitations were highlighted in the interpretation of the findings.

The consequences of respite upon frail older people and their carers are generally small, with better controlled studies finding modest benefits only for certain people with particular characteristics: not everyone benefited. However, many studies report high levels of carer satisfaction. No reliable evidence was identified that respite delays entry to residential care or that respite adversely affects care recipients.

Day care may reduce 'carer hostility' (see Glossary) when used early in the caring process. Subgroup analyses suggest that day care may be more beneficial for care recipients who are not married, who are satisfied with existing informal support and who have not recently been hospitalised. Respite packages, which incorporate a range of respite services, may afford carers slightly more relief than usual care and in-home respite appears to be the most popular choice for carers. There is tentative evidence that 'vulnerable' carers – those with a mismatch between need and support – may be the most likely to benefit from in-home respite. Evidence from one small RCT suggests that institutional respite benefits carers less than full-time institutional care, but the validity of this finding is unclear. Carers appear satisfied with host family respite and video respite, although neither service has been subject to a controlled evaluation. The only evidence on multidimensional packages that reported outcomes for the respite component separately came from an uncontrolled study of carers of cancer patients,[84] so the added value of respite is unclear.

Studies included in the review

This section presents a narrative description of findings from the included studies (a meta-analysis of study findings is presented in the section 'Meta-analysis', p. 47. First, an overview of the findings by respite type is presented. Secondly, some studies are described in more depth, exploring how the findings should be interpreted and their potential policy relevance. Thirdly, an overview of the outcomes assessed is presented, and the findings are considered by type of outcome. Lastly, an overview of study quality is presented. Further details of quality assessment can be found in Appendix 5.

Included studies: findings by type of respite

Various types of respite were identified by the review (see the section 'Overview of the review evidence', p. 14). While the review criteria limited the analysis of effectiveness to randomised or well-controlled studies, the protocol was amended to allow for the inclusion of uncontrolled studies if higher levels of evidence were unavailable (see the section 'Changes to the protocol', p. 11). Therefore, although they did not meet the protocol criteria for inclusion, the study on video respite by Lund and colleagues[92] and two studies on host family respite[90,91] were included. As no controlled study of respite for carers of cancer sufferers was identified, two further uncontrolled studies on respite for carers of people with cancer were included, one reporting in-home respite[85] and the other reporting a multidimensional package of care.[84] Data from uncontrolled studies were extracted using the controlled-studies template. However, the quality assessment of uncontrolled studies was based on a separate methodology,[48] with findings reported in Appendix 5. *Table 29* in Appendix 4 provides a descriptive summary of all the included studies, including study design, number of participants and details of the intervention and comparator.

Adult day care

Most of the evidence on respite is for day care, and most of this evidence has emerged from the USA. *Box 1* provides a brief background to US day care.

The effectiveness of day care (or 'adult' day care) was evaluated in eight studies (*Table 4*),[35,89,93,95,101–104] and a further three studies included day care as part of the respite package on offer to carers (see the section 'Respite packages', p. 31).[76,116,117] Further information on study characteristics is presented in Appendix 4 (*Table 29*), with quality assessments in *Table 36* (Appendix 5). Five economic evaluations of day care were identified (see the section 'Day care', p. 63).

Studies were heterogeneous in several ways. Regarding the intervention itself, the type of day care provided was variable: studies offered a range of services to care recipients, and even within a study, provision between study sites was not uniform.[93] Some day-care centres also provided carer support services such as counselling.[35,101] Only two studies[95,101] did not provide transportation, although transport provision varied between sites in the Hedrick study.[106] In addition, the study comparator varied, with usual care being the most popular (6/8 studies). In the Adult Day Health Care Study,[93] the Department of Veterans Affairs (VA) prohibited the simultaneous use of day-care and home-care services for participants in the intervention arm.[118]

Studies varied also in their duration (from 2 to 12 months), size (from around 100 to over 800) and design (four RCTs and four quasi-experimental studies). The average age of care recipients ranged from 72 to 80 years, with carers' mean age ranging from 54 to 72 years, reflecting differing proportions of adult child carers in the study populations. Although not consistently reported, it appears that most carers were women (range 58–77%, $n = 6$); care recipients were

BOX 1 *US adult day-care programmes*

The huge growth in adult day-care programmes in the USA, from fewer than 20 in the mid-1970s to around 4000 by 2001, in part reflects the changing role of women in the workforce and the need for respite and support for carers.[98,99] Around nine in ten programmes operate on a non-profit basis; approximately half of clients are cognitively impaired and most dependent in at least one ADL. Daily participant charges range from several dollars to \$185 (approximately £100[a]), depending on the intensity of service provision and availability of public or private sources of reimbursement. Awareness of this variation among adult day-care services is important when assessing effectiveness.[99] There are at least three distinct models of care:[100]

- those that emphasise rehabilitation, and are often affiliated to nursing homes or rehabilitation hospitals
- those that offer case management, nutrition, education, counselling, transportation and health assessment services
- special-purpose centres that serve a single type of client, such as those with mental illness or those with particular functional status.

Patterns of referral and the level of charges may differ not only between models of day care, but also between countries and over time. These factors also need to be considered when assessing effectiveness.

[a] Converted at 1 USD = 0.569 GBP (rate at 3 March 2006).

TABLE 4 *Findings from studies of respite for carers of frail older people: day care (n = 8)*

Study	**Purpose**	**Design** **Country** ***n***	**Intervention** **Comparator**	**Authors' findings**	**Authors' comments**	**Reviewers' comments**
Artaso Irigoyen, 2002[95]	To assess the impact and cost implications of psychogeriatric day care upon patients and carers relative to usual care	Quasi-experimental with matched controls Spain Carers: unclear; care recipients: 96	Psychogeriatric day care: services include prosthetics, physical and mental rehabilitation, reality orientation therapy, behavioural skills training, pharmaceutical therapy and family support Usual care	Psychiatric day care was associated with higher costs than usual care, with no significant between-group differences in care recipient health, carer quality of life or carer burden. However, satisfaction with caring remained higher in the intervention group, relative to the control group, throughout the year-long study	The study sample may not be representative of other populations and the short follow-up period over which costs were estimated may further limit the transferability of findings	This was the only study in the review explicitly to exclude participants aged <65 years. Findings for the original sample (*n* = 96) are not reported, and it is unclear how this may have affected findings. The quasi-experimental design of the study means that unknown differences between the groups cannot be ruled out. The study includes an economic analysis
Baumgarten, 2002[35]	To determine effects of multipurpose day centres (moderate intensity clinical/social or general-purpose day centres) on symptoms of depression and anxiety in care recipients, care recipient functional status and carer burden	Parallel-group RCT with waiting-list control Canada Carers: unclear; care recipients: 251	Day-centre care, multipurpose: broad range of group-based activities aimed at functional, psychological and social rehabilitation, with care tailored to need and ability. Education, support groups, exercise groups and carer counselling may be provided Usual care (waiting-list control); no day care used	There was no evidence that day-centre care improved care recipient anxiety, depression or functional status, or that there was any impact upon carer burden. Costs were higher in the intervention group than in the control group, but the difference was not statistically significant	The study failed to demonstrate a positive impact of day care on symptoms of anxiety and depression in older care recipients over 3-month period, or to provide evidence of improvement in functional status or carer burden. Reported interviews suggest that day care reduces symptoms of loneliness and half felt less anxious and less depressed. Perceived burden also decreased among carers where care recipients attended the day centre. Heterogeneity of centres (structure, activities, care recipient mix, etc.) makes it difficult to assess impact	The study provides little detail of care recipients' conditions. The study includes an economic analysis

continued

TABLE 4 *Findings from studies of respite for carers of frail older people: day care (n = 8) (cont'd)*

Study	Purpose	Design Country *n*	Intervention Comparator	Authors' findings	Authors' comments	Reviewers' comments
Burch, 2001[89,105]	To compare the outcomes of rehabilitation of older patients in two settings and to assess the impact upon carers	Parallel-group RCT UK Carers: unclear; care recipients: 105	Day hospital: offer of occupational therapy (with leisure activities) Day-centre care: physiotherapy, education, informal personalised plans, use of limited equipment, transportation provided, 2 days per week; median number of treatments over 3 months: 10 (IQR 5–14)	When analysed on an ITT basis, improvements in functional ability and carer strain were similar in both groups. No improvement in care recipient morale was observed in either group	Day-care rehabilitation was less popular, with higher attrition in the day-care group (ten subjects transferred to day hospital care) and some potential participants refusing to enrol because they did not want day care. Practical difficulties, such as the lack of rehabilitation space and resentment arising between study and non-study day-care attendees	As a high proportion of care recipients were admitted to the study as inpatients, reductions in carer strain may reflect the potentially stressful baseline status of study participants, rather than an effect of rehabilitation care or respite. The analysis was on an ITT basis. Although this reflects real life practice, it is unclear whether both settings delivered comparable functional improvements
Donaldson 1989[40,104]	To assess the impact of the FSU upon time to admission to long-term care or time to death	Quasi-experimental with matched controls UK 105 dyads	FSU: tailor-made service including day care, evening care, special occasional residential care to suit carer interests, plus "mix of community services" (see comparator). Transportation by minibus Usual care: "mix of community services" without FSU. Community services included day care (provided by local authority, NHS or voluntary sector), day hospital, home help, meals on wheels, institutional respite (local authority, NHS or private) and 'other' social services	The FSU results in prolonged life at home, thus saving costly long-term care beds. If life at home is preferable to long-term care, FSU can be judged to be cost-effective	The FSU may be cost-effective relative to long-term care, depending on what type of long-term care is used and how much it costs. A CEA would require further research. Results suggest little or no difference in overall costs of daily care between the two groups	The study included a small proportion (6%) of people aged <65 years. The quasi-experimental design of the study means that important differences between the two groups cannot be ruled out (e.g. disease severity is not reported). Both intervention and control groups used respite and rates of formal service utilisation were higher in the intervention group. These factors mean that the interpretation of findings is unclear. The study includes an economic analysis

continued

TABLE 4 *Findings from studies of respite for carers of frail older people: day care (n = 8) (cont'd)*

Study	**Purpose**	**Design** **Country** ***n***	**Intervention** **Comparator**	**Authors' findings**	**Authors' comments**	**Reviewers' comments**
Hedrick, 1993[93,106–112]	To maintain or improve patient function (establish patient health status; to enable patient to remain at home through rehabilitation; to encourage self-care); to achieve satisfaction with care; to provide support and respite for carer. Study enrolment from July 1987 to January 1990	Parallel-group RCT USA Carers: 586; care recipients: 826	ADHC (Department of VA): intensive health and social services, professionally staffed. Concurrent use of homecare services for those using VDC prohibited. Transportation not provided Usual care: care recipients had some non-VA day care, but not significantly more than those in the intervention arms	Patients or carers offered VA day care services had no apparent incremental health benefit compared with participants receiving usual care	Findings were compared with observational data on another form ('contract') of day care. The findings on VA day care and usual care are more reliable than those for contract day care, since the latter was based on non-randomised evidence from a smaller sample	This large and carefully designed study appears to show that day care is not cost-effective relative to usual care for frail older people. However, it is unclear what services were provided under 'usual care' and participants were mainly male (96%) and veterans. Findings may therefore not be transferable to other settings. The study includes an economic analysis
Quayhagen, 2000[101]	To evaluate the efficacy of four non-pharmacological interventions on outcomes for spouses coping with dementia	Parallel-group RCT USA 103 dyads	Early-stage day care: 8 weeks, 4 hours per week. Patients participated in structured activities, including social time, physical exercise, outings and community involvement. Transportation not provided. Active cognitive stimulation: 1 hour per day, 5 days per week, for 8 weeks Dyadic counselling Dual seminar: group and individual meetings, to discuss, support and problem solve Waiting-list control group: 8 weeks	Early day care did not improve care recipient outcomes. There was a significant decrease in carer hostility in the day-care group, but no significant change in any other outcome for this group	Similarities in programme content reduced the potential for quantitative differentiation among the groups	The authors do not appear to have prespecified primary and secondary end-points, but report a large number of outcomes. This increases the risk of identifying a statistically significant effect by chance

continued

TABLE 4 *Findings from studies of respite for carers of frail older people: day care (n = 8) (cont'd)*

Study	Purpose	Design Country *n*	Intervention Comparator	Authors' findings	Authors' comments	Reviewers' comments
Zank, 2002[103,113]	To evaluate the effects of day care on carers and care recipients	Quasi-experimental with matched controls Germany Carers: unclear (not all care recipients had carers); care recipients: 148	Geriatric day care plus usual home-based community care (morning and evening assistance with personal care). Day care tailored for individual care recipient may include rehabilitative and educational activities Usual home-based community care: morning and evening assistance with personal care 7 days per week, up to five times daily	Day care had a significant positive effect on care recipient well-being and dementia symptoms, relative to controls. There were no significant differences between the groups in terms of general health or functional capacity. No effect upon carer outcomes was observed, but high levels of satisfaction were reported	Findings on cognitive improvements for day-care patients should be treated with caution. As baseline assessments were conducted within 10 days of day-care use commencing, estimates of effect size may be conservative. The absence of any observed effect on carer outcomes may be due to the small sample size, or inadequacies of standardised outcome measures	This per-protocol analysis cannot demonstrate the impact of offering day care to older people and their carers. It is unclear whether the observed benefits for care recipients were equally distributed within the group, or whether benefits were confined to particular individuals (e.g. younger or the less cognitively impaired people)
Zarit, 1998[102,114,115]	To evaluate the psychological benefits of adult day care for family carers of people with dementia	Quasi-experimental study with controls taken from a state with similar demographics USA 566 dyads	Day-care services, mostly providing care 5 days per week, 7 hours per day. Offered transportation and "a variety of therapeutic activities sensitive to the needs of dementia patients" No day-care services and ⩾8 hours per week paid help	Substantial adult day-care use (at least twice a week for at least 3 months) by carers of people with dementia results in lower levels of carer-related stress (overload) and better psychological well-being (depression) compared with controls	The study is unusual in that it compared groups using substantial respite with those using none, both groups had positive attitudes to day care and neither group at baseline had used day care during the previous 3 months. The findings may not be generalisable to other types of carers and other patient groups	The authors do not report an ITT analysis. The per-protocol analysis could indicate the maximum carer benefit of respite, although flawed methodologies undermine this potential. Patient outcomes are not reported, so one cannot be confident there were no adverse effects upon care recipients or that baseline differences do not confound findings. An economic analysis of this intervention was reported by Gaugler[114]

FSU, family support unit; IQR, interquartile range; ITT, intention-to-treat; VA, Veterans Affairs; VDC, Veterans' Day Care.

generally more likely to be women, with the obvious exception of the Hedrick study on day care for veterans (96% male).[93] Where reported, most care recipients (82–93%, $n = 2$) and carers (89%, $n = 1$) in these studies were white. Regarding disease areas, four studies focused on carers of persons with cognitive impairment,[95,101,102,104] one study explicitly included people who had suffered a stroke,[89] and other studies included people with digestive, circulatory, renal or respiratory disorders, osteoarthritis, incontinence or fracture. One study reported that care recipients typically suffered between three and four health complaints,[103] and 66% of the care recipients in Hedrick's Adult Day Health Care (ADHC) study met at least two of the four impairment criteria.[106]

Evidence from randomised trials
Of the four randomised trials, two studies found no difference in carer outcomes when day care was compared with usual care.[35,93] Both studies were from North America, and so it is unclear how closely the comparator (usual care) reflects service provision in the UK setting. This means that findings should be applied to the UK setting with caution. UK day care was the subject of a study by Burch and Borland.[89] When compared with a rehabilitation hospital, outcomes at the day-care centre were similar, with carer strain diminishing over time in both groups. However, this observed effect may have been a reflection of the high baseline stress levels for carers of people recently admitted to hospital following fracture or acute illness.[89] As study patients were able to 'cross over' to day hospital care (and many did), it is unclear whether the less well-equipped day-care centre delivered equally good functional outcomes. Only one randomised trial found a statistically significant between-group difference. Quayhagen[101] compared early-stage day care with three other 'active' interventions and one control. A significant decrease in 'carer hostility' was found for the day-care group carers relative to the control group, but no difference in any of the other outcome measures, including depression, anxiety or stress, was identified. 'Hostility' was one of three symptoms of 'emotional status' measured on the Brief Symptom Inventory (Derogatis and Spencer, 1982). Feelings or problems indicative of hostility were assessed on a five-item, four-point Likert scale.

Randomised evidence suggests that day care did not in general either benefit or harm the older people studied. One study found that certain subgroups of care recipients benefited: those who were not married, those who were not hospitalised at enrolment and those very satisfied with social support had better health outcomes than those receiving usual care.[93]

Evidence from quasi-experimental studies
The Spanish study by Artaso Irigoyen and colleagues of psychogeriatric day care found no between-group difference in carer outcomes, although satisfaction levels were consistently higher in the intervention group throughout the duration of the study.[95] The UK study by Donaldson and Gregson found that the FSU prolonged life at home and increased carers' sense of freedom and relaxation.[104] In the German study by Zank and Schacke, day care was reported to have a significant positive effect on care recipient well-being and dementia symptoms, relative to controls.[103] No effect on carer outcomes was observed, but high levels of satisfaction were reported. The study by Zarit and colleagues[102] found that carers 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 carer depression and carer burden ('overload').

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 (see *Table 29* in Appendix 4). In addition, both the Zank study[103] and the Zarit trial[102] provided only per-protocol analyses, with findings based on treatment completers (see the section 'Assessment of study quality', p. 53, for a critique of this issue). Transferability of findings is impaired by a lack of clarity over the age range of study participants: only the Spanish study[95] focused exclusively on people aged 65 and over, while the UK study[40] included a small proportion (6%) of under-65s. In the remaining studies, the age range of participants was not explicitly reported.

Respite packages

Four studies of respite packages were identified, all relating to the USA and all published from the late 1980s to early 1990s. Two of the studies were randomised and two quasi-experimental. Three offered a package that included day care, in-home respite or institutional respite;[76,116,117] in the fourth study, carers in the intervention arm chose between in-home respite and institutional respite.[94] 'Usual care' was a comparator in all four studies, although the 12-month Lawton study supplemented this with counselling and information at enrolment[116] and the Montgomery[117] study randomised patients to one of six arms. Further details are provided of findings from the studies of respite packages (*Table 5*), study characteristics, including details of the interventions and comparators (Appendix 4, *Table 29*), and quality assessments (Appendix 5, *Table 36*). No economic evaluation of respite packages was identified.

Trial duration for respite package studies varied from around 2 months to 1 year. One pilot study reported data for just 15 carer–care recipient dyads,[94] but two studies included over 500 dyads.[116,117] The age of participants was reported in three studies: care recipients' mean age ranged from 76 to 82 years, with carers having a mean age of 60 years (range 38–89). The Kosloski study included a number of care recipients aged under 60.[76] Although this study therefore did not strictly meet the inclusion criteria, the protocol was amended to allow its inclusion because the proportion of the sample affected was small (4%) (see the section 'Changes to the protocol', p. 11). However, findings are interpreted in the light of this limitation. Most carers (between 74 and 83%, $n = 3$) and care recipients (between 52 and 67%, $n = 3$) were women. Just one study reported the proportion of white participants (carers: 75%).[116]

Only one of the respite package studies included some participants without dementia. In this randomised trial of family carers of 'impaired' people including a disparate range of disorders, 25% of care recipients had Alzheimer's disease, 28% had serious mental impairment and 57% reported their general health to be 'fair' or 'not good at all' (representing the lower two rankings of five-point categorical scale).[117]

Evidence from randomised studies

Of the two randomised studies, the Montgomery trial[117] compared various packages of support with respite or no intervention (see Appendix 4, *Table 29*). The published papers[117,119–121] reported few data (e.g. the numbers randomised to each arm are not reported) and attempts to retrieve the full report for the sponsoring body were unsuccessful. Overall, the trial identified few significant benefits for carers: carers in the respite group were slightly more relieved and more satisfied with support (from any sources) relative to the control group. In the other randomised study, a flawed statistical analysis makes findings from the outcomes assessment difficult to interpret (see the section 'Assessment of study quality', p. 53).[116]

Evidence from quasi-experimental studies

Both quasi-experimental studies reported positive findings for carer outcomes. Conlin's comparison of in-home or institutional respite with usual care found that respite was associated with significant reductions in carer stress.[94] However, the small sample size (15 dyads) and differences between groups in demographic characteristics undermine the reliability of this finding (see Appendix 4, *Table 29*). The other non-randomised study reported benefits for carer morale and subjective burden.[76] However, the study groups differed in racial composition and income, which casts doubt on the internal validity of findings. The external validity of findings is also unclear, as study carers had not used respite before and a small percentage (4%) of care recipients were under the age of 65.

In-home respite

Four studies of in-home respite met the inclusion criteria, of which three were randomised trials[79,97,124] and one was a quasi-experimental study[96] (all four studies of respite packages also included in-home respite as an option; see section 'Respite packages', p. 31). Study findings (*Table 6*), further details of the study characteristics (Appendix 4, *Table 29*) and quality assessments (Appendix 5, *Table 36*) are presented in tables. No economic evaluation of in-home respite was identified.

In addition to the four studies of in-home respite, two studies of respite for carers of cancer patients were retrieved.[84,85] One of the cancer studies was of in-home respite and is summarised in this section; the other reported a multidimensional intervention and is presented in the section 'Multidimensional packages' (p. 42). Although they did not meet the review inclusion criteria, the protocol enabled the inclusion of uncontrolled studies in the event of an absence of controlled evidence for a particular disease area or particular type of respite.

The interventions ranged in duration from 10 days[97] to 1 year.[124] In one study, respite was provided by qualified home health aides, trained in the management of Alzheimer's disease;[97] the other four studies were staffed exclusively,[79,96] or in part,[85,124] by (mostly trained) volunteers. Carers were typically in their late fifties or early sixties, although in a study recruiting spouse carers, the mean age was 73 years.[97] On average, over three-quarters of carers were women ($n = 5$). The proportion of spouse carers varied from 37%[124] to 100%.[97] Just two studies reported carer

TABLE 5 *Findings from studies of respite for carers of frail older people: respite packages (*n *= 4)*

Study	**Purpose**	**Design** **Country** ***n*** **Type of respite**	**Intervention** **Comparator**	**Authors' conclusions**	**Authors' comments**	**Reviewers' comments**
Conlin, 1992[94]	To determine whether respite care could reduce carer stress and mood disturbances	Quasi-experimental study (waiting-list control) with controls matched by dementia severity score USA 15 dyads IR, INR	Respite care provided in adult assisted-living facility or at home, according to carer preference. Respite care for 6–8 hours per day, 2 days per week for 10 weeks. Mean hours respite use over study period: 15.3. 5/7 used in-home respite, 2/7 chose institutional respite Usual care (no meal delivery, home help or home health services)	Respite care for demented people living at home significantly reduces stress experienced by carers and particularly diminishes feelings of bewilderment	Small sample size limits the power of the study to detect significant differences. The sample size reflected difficulties recruiting participants	Respite intervention could be either in-home or in an assisted-living facility; more carers chose in-home respite (5/7). Disparity between groups regarding carer demographic characteristics. Given the small sample size and non-randomised design, findings should be interpreted with caution
Kosloski, 1993[76]	To evaluate the impact of the Michigan Model Projects Specialized Respite Care programme on caregiver subjective and objective burden and morale	Quasi-experimental 'non-equivalent' control-group design USA 116 dyads DC, INR	Respite programme: adult day care (2/7 sites; 5 days per week, 9 hours per day); in-home respite (2/7 sites: day/evenings on weekdays, provision flexible); adult day care and in-home respite (3/7 sites). Over the 6-month study period: mean hours use of respite in the intervention group: 220 (range 4–1137, median 130) No respite (waiting-list control)	The respite programmes had beneficial effects upon carer morale and carer subjective burden, but the relationship did not appear to be linear, suggesting that more use is not necessarily better	Study participants were first-time users of respite, so findings should be generalised (applied to other settings) with caution	Although this study did not strictly meet the inclusion criteria (some care recipients were aged <65 years and subgroup analysis for those aged ⩾65 years was not reported), it was included because the proportion of under-60s was small (4%). Although findings may still be relevant for the review, they should be interpreted in light of this limitation

continued

TABLE 5 *Findings from studies of respite for carers of frail older people: respite packages (n = 4) (cont'd)*

Study	Purpose	Design Country *n* Type of respite	Intervention Comparator	Authors' conclusions	Authors' comments	Reviewers' comments
Montgomery, 1989[117,119–121]	To evaluate the effects of respite services on family carers of older people with dementia	Parallel-group RCT USA 632 dyads DC, IR, INR	Three types of subsidised respite care offered in context of 12-month package (case management, counselling, informational and educational services): (1) in-home involving a sitter, a person to perform homemaker services or provide personal care, available regularly or occasionally, during the day or evening or weekend; (2) adult day care, 1–5 days per week (transportation/medical services provided according to need); or (3) institutional respite, emergency or planned (limited to a stay of ≤21 days). Participants offered respite services at baseline and, where respite was not taken up, at 2 months, with a 'flexible' subsidy capped at $1000 per family per year At baseline interview, control group carers were assessed, counselled and provided with a list of local agencies and resources that offered services to impaired elders and their families	The authors found that families caring for elders in the community are resistant to using support services. Carers generally prefer frequent short-term, in-home respite over day care or institutional respite options. Spouse carers spend more time caring than do adult child carers, and use of support services by spouse carers is associated with an increased likelihood of care recipient nursing home placement; for adult child carers, support services are associated with a decreased likelihood of care recipient nursing home placement	Families caring for older community-dwelling people are difficult to reach and serve. Many families only present to services once in a desperate situation and so it is not possible to assess preventive measures. Difficulties in getting families to use project services. Caregivers in study not representative of range of families caring for family members. Need for studies to target non-users of services to explore characteristics of this group and target respite interventions	Known as the 'Family Support Program'. Published papers provide very limited data; the report to the funding body could not be obtained within the time-frame of the review. The finding that spouse carers respond differently from adult child carers to support services is based on subgroup analyses of a rare event and its interpretation is therefore unclear

continued

TABLE 5 *Findings from studies of respite for carers of frail older people: respite packages (*n = 4*) (cont'd)*

Study	**Purpose**	**Design** **Country** ***n*** **Type of respite**	**Intervention** **Comparator**	**Authors' conclusions**	**Authors' comments**	**Reviewers' comments**
Lawton, 1989[33,116,122,123]	To assess the benefits, costs and feasibility of different support programmes for family carers of older people, including the potential for delaying nursing home placement	Parallel-group RCT USA Carers: 541 (some caring for two people); care recipients: 576 DC, IR, INR	Respite services: provided on a fee-for-service basis through Medicare waivers. Families could buy any combination of respite: in-home: 2–3 hours or overnight; day care: up to 5 hours per day; overnight extended stay in nursing home. Actual use: all respite: uptake: 64.6%, *n* = 189; in-home respite: uptake: 82%, *n* = 122 (29/100 used overnight in-home respite; for short stay visits: mean hours per visit: 3.32); day care: uptake: 13%, *n* = 122 (median number of visits: 21; mean hours per visit: 5.0); overnight nursing home respite: uptake: 15%, *n* = 122 (mean days per visit: 8.4) For comparison groups, see *Table 29* (Appendix 4)	Although respite was ineffective for carer burden and mental health, satisfaction was very high and so respite has the potential to improve carers' quality of life	More information is needed on the differences between caregivers who seek out respite and those who do not. Although respite provides time off for caregivers, reasons for needing time off are diverse and so respite does not focus on one problem. Respite is used late on in the caring process, usually at times of crisis	Known as the 'Multiservice Respite Program for Family Caregivers'. The unit of randomisation was a mixture of (support) group and individual; the analysis did not reflect this distinction and a number of significant between-group baseline differences was observed. The authors adjusted for these differences in the statistical analysis, but the unit of analysis was the carer or care recipient (which assumes that each allocation is independent and takes no account of the group-level allocations). Findings are therefore difficult to interpret

DC, day care; INR, in-home respite; IR, institutional respite.

TABLE 6 *Findings from studies of respite for carers of frail older people: in-home respite* (n = 5)

Study	**Purpose**	**Design** **Country** ***n***	**Intervention** **Comparator**	**Authors' conclusions**	**Authors' comments**	**Reviewers' comments**
Grant, 2003[97]	To assess whether in-home respite was associated with a reduction in psychological and physiological indicators of stress in spousal carers of persons with AD and to explore the impact of carer 'vulnerability', defined as "a severe mismatch between caregiving demand and help received in the preceding 6 months"	Parallel-group RCT USA 55 dyads	In-home respite care: 10 days of in-home help (up to 6 hours per day) over a 2-week period. Carers could leave, do chores, hobbies or anything else they chose. Actual mean utilisation: 43.0 hours (20.8 SD); five carers (none 'vulnerable') did not use the intervention Usual care	In-home respite may reduce sympatho-adreno-medullary activation, independently of psychological symptoms in vulnerable older carers	The study offers preliminary evidence, with limited sample size. Covariates other than vulnerability could have explained findings. Larger studies are needed to address these issues	Further research may help to explore whether and how the observed changes in stress chemical levels can be translated into improved psychological health
Johnson, 1988[85]	To support relatives of dying patients and to avert unnecessary hospital admissions	Uncontrolled, retrospective descriptive study of referral data UK Carers: 190; care recipients: 244	Relative support scheme: in-home respite. Mean use (hours): 3.1 (range 0.5–6). Median number of visits: 2.5 (range 0–50). Mean total hours' respite: 14.4. 30% of appropriate referrals received one or no visits	Although a high proportion of referrals died at home (61%), the late stage of referral and lack of correlation between place of death and level of service received mean that other factors may have caused this effect	Despite the presence of a nurse coordinator to offer support and advice, volunteer sitters had higher levels of perceived stress than paid sitters and 50% of volunteers resigned over the 2-year study period	Findings from this study support those of Montgomery[124] in identifying the need to support adequately voluntary respite providers

continued

TABLE 6 *Findings from studies of respite for carers of frail older people: in-home respite (n = 5) (cont'd)*

Study	Purpose	Design Country *n*	Intervention Comparator	Authors' conclusions	Authors' comments	Reviewers' comments
Montgomery, 1985[124]	To implement and assess family support services that were aimed at enhancing the ability and willingness of families to retain the primary responsibility for caring for the aged family members	Parallel-group RCT USA Carers (primary): 298 (eight caring for two people); carers (secondary): 40; care recipients: 306	Volunteer in-home respite services: provision of temporary relief from caring tasks for carers for up to 4 hours per week, twice a week. Uptake: mean use of volunteer respite: 12 visits (range 1–37); mean use of paid respite: 11 visits (range 1–32); % of eligible: 35% Family education services Respite plus family education services Usual care	Families seeking help at late stages of the caring career did not use services for preventive purposes, and the study services (as offered and used) had little impact. The low levels of available paid respite had to be focused on high-dependency individuals, meaning that some participants' need for respite could not be accommodated	To provide a satisfactory service for these high-dependency older people, volunteer programmes are useful only to augment paid respite services. The study findings provide some insight into questions about the feasibility and costs of various support services, but do not provide definitive answers to many of the critical policy questions	The study was adversely affected by recruitment difficulties, but as power calculations are not reported and there is inadequate reporting of other important data (such as numbers enrolled in each arm of the trial, withdrawals and numbers of participants contributing data), the impact of this problem upon the reliability of findings is unclear. An important qualitative finding from the study is that volunteer respite providers were often unable to cope with the care needs of the frail older people. This emphasises the need to ensure that interventions are properly piloted before a randomised trial is conducted

continued

TABLE 6 *Findings from studies of respite for carers of frail older people: in-home respite* (n = 5) *(cont'd)*

Study	**Purpose**	**Design** **Country** ***n***	**Intervention** **Comparator**	**Authors' conclusions**	**Authors' comments**	**Reviewers' comments**
Niebuhr, 1989[96]	To assess the need for and effectiveness of home-based respite programmes in reducing psychological strain among family carers and to identify characteristics of individuals most distressed and responsive to such services	Quasi-experimental study with non-equivalent controls (from neighbouring county with no volunteer respite provision) USA 57 dyads	In-home respite two to four times per week for 3 months No volunteer respite services	The study fails to show indicate evidence of any statistically significant effects on psychological distress symptoms as a result of receipt of home volunteer respite services for 3 months. Subgroup analyses revealed no significant differences for spouse carers vs non-spouse carers; for carers of cognitively vs non-cognitively impaired people; for those with higher vs lower levels of perceived social support; or for those receiving all respite sessions vs those receiving limited respite	The study may have been underpowered to detect between-group differences	The study included a small proportion of participants aged <65 years (16%), which means that findings should be generalised with caution. The reliability of findings is limited by the small sample size and by the demographic and clinical differences between the study groups at baseline
Wishart, 2000[79]	To assess the effectiveness and costs of a visiting/walking programme provided by volunteers	Parallel-group RCT, with waiting-list control group Canada 24 dyads	'Special Steps' visiting/walking programme to provide assistance and companionship for care recipient; target of 2 hours per week. Actual use: 11/13 used the service (hours per week not reported). Dropouts were due to death or illness Usual care (waiting list)	The visiting/walking intervention significantly reduced carer burden, relative to no intervention	The study was limited by small sample size, short follow-up and lack of assessment of care recipient clinical outcomes	One-third of the study sample included people with mild dementia; it is unclear whether these could be described as 'frail' as no other functional outcomes were reported. A systematic review of respite care for people with dementia failed to replicate the positive findings from this study,[69] which the reviewers attribute either to misreporting of data or to flaws in the original analysis

AD, Alzheimer's disease.

ethnicity (% white: 95–97%, $n = 2$). Four studies explicitly included people with cognitive impairment.[79,96,97,124] The average age of care recipients was 74 years (range 66–82, $n = 4$) and around two-thirds were women ($n = 3$). One study included a proportion of care recipients aged under 65 (16%),[96] but it is unclear whether under-65s were included in the other studies, as the age range of participants was not reported.

Evidence from randomised studies
In addition to the comparison between those receiving and not receiving respite, Grant and colleagues explored the impact of carer 'vulnerability', defined as "a severe mismatch between caregiving demand and help received in the preceding 6 months".[97] 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 only in the subgroup of 'vulnerable' carers. However, the authors advise that further research is needed to validate this preliminary evidence (see Appendix 4, *Table 29*). Although the Canadian study by Wishart and colleagues[79] found a significant reduction in carer burden, a Cochrane review was unable to replicate the finding (*Table 6*).[69] The meta-analysis undertaken as part of this review is presented in the section 'Meta-analysis' (p. 47), and confirms the Cochrane reviewers' findings (*Figure 7*, p. 55).

The US study by Montgomery and colleagues experienced severe staff recruitment and retention difficulties (*Table 6*).[124] The authors found no significant between-group differences in carer 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 carers in the control group. Inadequate reporting of 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.[96] The study population was frail (people whose level of impairment required care comparable to intermediate or skilled nursing), although 16% were aged under 65. No significant between-group differences were found in terms of impact on carers' psychological distress. However, the non-comparability of the groups at baseline may help to explain this finding (*Table 6*). The age distribution of the care recipients may also mean that findings may not be generalisable to the frail older population.

Evidence from uncontrolled studies
The study by Johnson and colleagues examined a relative support scheme funded by Marie Curie and a Sheffield hospice, St Luke's.[85] Malignant disease was the principal reason for referral to the scheme in 85% of cases. The number of visits received by patients over the 2-year study ranged from 0 to 50 (median 2.5). On average, visits were just over 3 hours in duration (range 0–6).

Carers were invited to record their views on the service by a postal questionnaire. In general, carers were very satisfied with the service, with 90% describing the scheme as vital or of great help. However, one-third of those responding believed that they had been offered the service 'too late'.[85] No objective assessment of carer outcomes was reported.

Host family respite

The searches identified one study of host family respite.[90] In addition, the review by Arksey and colleagues[58] identified another qualitative study in the form of an unpublished MSc thesis,[91] and contact with the author identified a poster presentation.[17] No controlled study or economic evaluation of host family respite was identified. *Table 7* provides an overview of the two studies. A summary of the study characteristics (*Table 29*) and corresponding quality assessments are reported in Appendices 4 and 5, respectively.

Evidence from uncontrolled studies
The study on host family respite by Robertson evaluated a service provided in Scotland for people with dementia and their carers.[91] Entitled 'Time to Share', the scheme provided joint family breaks for both carer and care recipient. The short break was set in the service provider's home. The service provider offered hospitality to the couple, looking after them by providing meals, a bed and companionship. Some service providers also took the couple for outings and played board games with them, with respite care being flexible to accommodate the couple's needs and preferences. 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.[17,91]

The breaks generally lasted for between 5 and 7 days, and took place every 2 months. Carers and

TABLE 7 *Findings from studies of respite for carers of frail older people: host family respite* (n = 2)

Study	Purpose	Design Country *n*	Intervention Comparator	Authors' conclusions	Authors' comments	Reviewers' comments
Robertson, 2002[17,91]	To assess the impact of a short-break service on people with dementia and their partners	Uncontrolled qualitative study UK Carers: 6; care recipients: 4	Short-break service: service provider's home used for carer and care recipient to have a joint break for 5–7 days, approximately every 2 months None	The short-break service provided a very positive experience for carers and care recipients, with participants reporting feeling relaxed, happy and refreshed	The longer term effects of host family respite are not known	As with other studies of respite services, reported satisfaction levels were high. The absence of a comparison group means that the impact of the intervention is unclear
Holm, 2003[90]	To assess the extent to which the programme met the needs of participants and overcame limitations associated with other types of respite	Uncontrolled qualitative study Australia Carers: unclear; care recipients: 25	Short-break service: service provider's home used for up to six care recipients for 6 hours per day, once a week. Services included games, tea and lunch, exercise, crafts, conversation and occasional outings. Transport to and from respite provided. Fee of AUS$8 per session. Average annual attendance: 17 weeks (range 1–45) None	Feedback from participants suggested that the short-break service provided a positive experience for carers and care recipients	The model may be suitable for some ethnic groups, as it offers the potential for culturally sensitive provision. Government guidance is needed to avoid potential cost-shifting and to encourage high-quality care	Reported satisfaction levels were high. However, the impact on the health and well-being of participants is unclear

TABLE 8 *Findings from studies of respite for carers of frail older people: institutional respite* (n = *1*)

Study	Purpose	Design Country *n*	Intervention Comparator	Authors' conclusions	Authors' comments	Reviewers' comments
Wells, 1987[34,125]	To assess the effectiveness of a specialist dementia nursing home unit, relative to community care with periodic respite	Parallel-group RCT, with waiting-list control group Australia 26 dyads	Community care with option of respite Special nursing home unit (institutional care)	Admission to the special nursing home greatly benefited carers' psychological health (anxiety) and quality of life, with no adverse impact on care recipients	Further research is needed to determine the effectiveness of other forms of nursing home care	In this study, the respite is the comparator rather than the intervention. The validity of the randomisation method is unclear and groups differed in demographic and clinical characteristics at baseline. It is therefore possible that factors other than the intervention could explain observed differences in outcomes

care recipients were interviewed individually or together, according to preference, and invited to comment on intervention, given in response to "simply phrased, open-ended questions about experiences and feelings", phrased in "concrete day-to-day terms".[91]

All participants described the experience as "a happy one". For carers and care recipients, the homely 'normal' environment, companionship (with service provider and their family), emotional and practical support were important features. One carer (who was frailer and older than the others) expressed a preference for respite separately from his wife, but the other couples particularly enjoyed the joint nature of the respite offered. In sum, the short-break service provided a very positive experience for carers and care recipients, with participants reporting feeling relaxed, happy and refreshed.

The Australian study by Holm and Ziguras[90] examined a 'host-home' respite programme for older people with dementia who had problems accessing centre-based respite owing to communication and language difficulties. The study aimed to investigate which specific needs were met and how limitations identified in other models were overcome. The programme provided care for up to six care recipients in the home of a care-worker. Groups met for 6 hours (09.00–15.00 hours) and transportation to the programme was provided. At the time of the study, two groups were operating, one with four members and the other with six people. The programme was informal, but structured to provide a range of activities (such as bingo, gentle exercise, discussion of current affairs and reminiscing). Outings were occasionally organised, such as a concert or fishing trip. The groups were run by two care-workers with extensive professional caring experience, with volunteers also supporting some of the larger groups. An attendance fee was charged.

To elicit the views of care recipients and carers, qualitative interview methods were used. In a 12-month period, 25 care recipients with dementia had used the programme, with data available for 18. Fifteen users were women, 11 were born in Australia (six in UK, one in India) and the average age was 81.5 years. Seven were using the programme at the time of the study, five lived with a relative and the other two lived in a retirement village. Details are provided of the seven carers interviewed. Six were women, three were born in Australia (three overseas where English was the main language and one from a non-English-speaking country). Two had partners attending the programme, and five their mothers.

Telephone interviews were carried out with the carers. Four had no prior experience of respite and so were not able to compare the host home with other forms of respite. Three who could make comparisons thought that the small group setting was beneficial and appreciated the home-like location. Comments were overwhelmingly positive, in particular, the attitudes of the care-workers and activities, "Wonderful, doing a great service ...". The carers also recognised benefits for themselves in terms of having a break and being confident their relative was being well cared for and was safe. They also commented on benefits for their relative, "Loves it. Just loves the people. So happy to be involved" (p. 143).[90]

Care recipients' views were gathered by researchers while attending one of the respite programme groups, through observations and talking to care recipients. The respite programme was described as an important part of their week and there were benefits to the smaller host-home programme, "... here you see the same people each week and get to be friends" (p. 143). Care recipients enjoyed the activities, being able to socialise and form friendships.

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 was included in the review: an Australian RCT by Wells and colleagues comparing full-time nursing home care with community care that included the option of periodic institutional respite.[34] Study findings (*Table 8*), further details of the study characteristics (Appendix 4, *Table 29*) and a quality assessment (Appendix 5, *Table 36*) are presented. No economic evaluation of in-home respite was identified.

Evidence from randomised studies

The 12-week trial examined 26 carers of persons with a formal diagnosis of dementia, but who were in 'reasonable' physical health. Care recipients in both groups were highly dependent, with a mean Mini-Mental State Examination (MMSE) baseline score of around 9 (MMSE scored 0–32, with lower scores indicating higher cognitive impairment). No demographic baseline care recipient characteristics were reported. Carers in the control group had significantly better psychological health than those in the intervention group (see Appendix 4, *Table 29*).

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

Although the authors adjusted their statistical analyses to take account of baseline difference in carer health, the existence of these differences raises the possibility that the randomisation method was unsound. *Table 36* (Appendix 5) includes a quality assessment of this study and shows that, from the information given in the paper, it is unclear whether the method of allocating participants to the groups was really random. If the randomisation method were flawed, then 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 should be treated with caution.

Multidimensional packages

Several studies were identified evaluating respite as part of a multidimensional package of care, none of which met the inclusion criteria because the distinct impact of respite was unclear (see the section 'Assessment of study quality', p. 53, and *Table 15*). The randomised study by Montgomery and colleagues[117] compared respite with and without other interventions (see Appendix 4, *Table 29*), but as a control group was also evaluated, the study is classified as reporting a respite package (see the section 'Respite packages', p. 31, and *Table 5*). Very few data were reported by the Montgomery study – for example, the number of participants randomised to each arm is not stated and very few findings are reported by allocation group – and so further details are not presented in this section. However, an uncontrolled study of carers of cancer patients was eligible for inclusion, because no controlled study evaluating this patient group was identified (see the section 'Changes to the protocol', p. 11). Findings are summarised in *Table 9*, with quality assessments of the uncontrolled studies presented in Appendix 5, p. 149.

Evidence from uncontrolled studies

Clark and colleagues evaluated a pilot initiative known as the Macmillan Carers Schemes.[84] Developed in the 1990s as an extension of the Macmillan nursing service, the service was provided at seven sites in England.[84] The ERG indicated that these schemes are still operational, generally providing in-home care during the day, or occasionally at night. Strategic partnerships with other charitable organisations are being developed, with services aiming to complement public sector provision.

Around three-quarters of the patients included in the evaluation by Clark and colleagues were aged over 60 and around one in five was aged over 80 years. As subgroup findings by age were not reported, this means that the broad study findings may not be directly generalisable to the population of carers of frail older people.

The pilot scheme offered respite as part of a multidimensional package. A team of healthcare assistants, Macmillan carers, provided practical support, intimate care (for patients) and emotional support to patients with cancer and their carers. In addition to in-home respite and companionship, support might include help with washing, dressing, cooking and other ADL. The evaluation of 624 services users found that respite for carers was the principal reason for referral (42% of all referrals), but emotional support (15%), enabling the patient to die at home (11%) and support following discharge from hospital (11%) were also cited. On average, each patient received seven visits, although the range was from one to 56. Around 3% of the study participants received sit-in services from alternative providers. When asked about their satisfaction with the respite services, 86% of the 121 carers responding to the survey indicated that they felt able to go out and leave the Macmillan carer in charge. Annual costs of operating the scheme ranged from £5000 to over £50,000, reflecting the size of each scheme; cost per referral ranged from £76 to £550 (1996/97 prices).

Video respite

Five references reporting on video respite were identified,[92,126–129] but only one study met the inclusion criteria.[92] Findings from this uncontrolled study are presented in *Table 10* and Appendix 4 (*Table 29*), with a quality assessment reported in Appendix 5. No economic evaluation of video respite was identified.

Evidence from uncontrolled studies

The paper by Lund and colleagues[92] describes two studies: a completed study undertaken in special care units (reported in full elsewhere[127]) and an ongoing study of video respite used by informal carers at home (the reviewers were unable to identify a paper reporting the full findings). The

TABLE 9 *Findings from studies of respite for carers of frail older people: multidimensional packages* (n = *1*)

Study	**Purpose**	**Design** **Country** ***n***	**Intervention** **Comparator**	**Authors' conclusions**	**Authors' comments**	**Reviewers' comments**
Clark, 2000[84]	To describe the management, operation and content of schemes; to describe carers', users' and staff views	Uncontrolled descriptive study using qualitative and quantitative, retrospective and prospective methods UK Carers: 542; care recipients: 624	Multidimensional package, including in-home respite option. The schemes offered intimate care, social and emotional support, and practical help. Respite the key reason for referral (42% of carers; *n* = 542) and the service most commonly used (uptake: 24%; *n* = 542). Mean visit duration (hours): 3.5 (range 4–20+); mean number of visits: 7 (range 1–56) None	Macmillan Carers Schemes were perceived by carers to be timely, appropriate, friendly and safe	Since the service overlaps health and social care, there is a danger of 'cost shunting'. The study presents findings from early-stage schemes and further developments are planned	The scheme provided a range of patient services that afforded the carer an opportunity for respite. Reported satisfaction levels were high, but the impact upon health and welfare is unclear

TABLE 10 *Findings from studies of respite for carers of frail older people: video respite* (n = *1*)

Study	**Purpose**	**Design** **Country** ***n***	**Intervention** **Comparator**	**Authors' conclusions**	**Authors' comments**	**Reviewers' comments**
Lund, 1995[92]	To assess the benefits and limitations of video respite for carers and care recipients	Uncontrolled within-patient study USA 31 dyads	Video respite tape, to be used by carer as required: "Favourite Things" (33 minutes), designed for people with AD to encourage participation and attention. Two-thirds (67%) of carers used the tapes over the study period: mean use 14 times per month (range 0–60) None	Early research findings indicate that most people with AD watch the tapes and participate; carers use the time for respite	These findings relate to a 9-month assessment for a 2-year study	This was the only study explicitly to report the age range of participants. No report for the full 2-year study was identified by the literature search

study of video respite at home involved 31 dyads. All care recipients had Alzheimer's disease, their mean age was 78 years (range 58–98) and 45% were men. Two-thirds of the carers were women, with a mean age of 66 years (range 38–89). Most carers were spouses ($n = 21$) or adult children ($n = 9$).

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

Two-thirds (67%) of carers used video respite at least once over the 1-month study period, with four carers 'forgetting' to use the video at all. Some carers watched the video with the care recipient. On average, carers used the video 14 times, but one carer reported using the video twice daily. Summary measures of carer satisfaction are not reported, but views of two of the 31 carers are cited. One carer 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". Carer views on the Lawrence Welk tape were not reported.

Effectiveness studies: findings by outcome

This section presents a narrative description of the findings by category of outcome measure. *Table 35* (Appendix 4) shows the outcome measures used by the 22 effectiveness studies. Outcomes related either to the carer or to the care recipient, but none assessing both members of the carer–patient dyad simultaneously was identified. A quantitative synthesis of outcomes is reported in the section 'Meta-analysis' (p. 47).

Quality of life

Four studies assessed quality of life data for the carer[34,95,103,116] and one study assessed care recipient quality of life.[103] Only one study found a statistically significant effect upon carer quality of life. In this Australian randomised trial, quality of life was assessed using a 'new' 20-item questionnaire that covered social relationships, work, sleep, leisure, finance and personal space. Carers receiving periodic respite had significantly poorer quality of life than carers of people who were admitted to institutional care (see the section 'Institutional respite', p. 41).[34] The US randomised study by Lawton and colleagues[116] examined the impact of respite packages on carer subjective well-being, reported as a profile of various measures covering physical health, psychological health, burden and caregiving attitudes. No impact for respite upon any of these dimensions of quality of life was found, although the reliability of the analysis is unclear (see the section 'Assessment of study quality', p. 53, for a critique of study quality). The German quasi-experimental study of day care found no significant impact upon carer quality of life, but found that the quality of life of care recipients in the intervention group stabilised, while quality of life fell for their counterparts in the control group.[103] However, the Zank[103] analysis focused only on participants who were compliant with the protocol. Therefore, care recipients in the intervention group who discontinued day care, perhaps because it adversely affected them in some way, did not contribute data to the findings on quality of life. This means that the validity of the finding is unclear. The Spanish quasi-experimental study by Artaso Irigoyen and colleagues found that day care did not improve carer quality of life significantly more than usual care, as assessed on the 'Cuestionario de Calidad de Vida'.[95] Details of the content of this outcome tool were not reported. Insufficient data on quality of life were found for the purposes of meta-analysis (see the section 'Meta-analysis', p. 47).

Physical health

Physical health was assessed in 14 studies, of which seven assessed only care recipient health.[34,76,84,85,89,95,104] Three studies reported no informative post-test findings.[86,94,124] No study identified an adverse impact upon care recipient health (see the section 'Meta-analysis', p. 47, for a meta-analysis of findings on care recipient mortality rates). Only one study found that respite offered any significant benefit, which was for carers. Grant and colleagues undertook a randomised trial to examine the impact of in-home respite upon chemical stress levels in carers.[97] No significant between-group difference was found, but respite appeared to improve chemical stress levels for a subgroup of vulnerable carers (those with a severe mismatch between caring demand and help received). Given the small numbers of participants contributing data to this finding ($n = 27$), the authors advise caution in interpreting this result.

Mental health

Mental health was a popular focus for assessment, with 14 out of 22 studies using at least one measure for either carers or care recipients, or both. Seven studies detected no statistically significant differences between intervention and control groups on any of the measures assessed.[35,89,93,95–97,116] Of the remaining seven studies, one reported assessments at baseline only,[40] one reported no findings by allocation group[124] and five reported mixed findings. Positive findings for the effects of respite were reported for stress (a quasi-experimental study comparing day care with a waiting-list control),[94] carer morale (a quasi-experimental study comparing a respite package with no intervention),[76] care recipient depression (a quasi-experimental study comparing day care with community care),[103] carer hostility (a randomised trial comparing early day care with a control group)[101] and carer depression and carer anger (a quasi-experimental study comparing day care with no day care).[102] In addition, an RCT comparing institutional care with periodic respite found improved carer anxiety and improved general psychological health for carers of the institutionalised group,[34] but factors other than the intervention may have given rise to this finding (see *Table 8*). Meta-analyses of findings for care recipient cognitive status (MMSE) and carer depression are reported in the section 'Meta-analysis' (p. 47).

Satisfaction levels

Satisfaction levels were assessed in 15 studies, although there was no methodological uniformity between studies in the assessment tools used. While most studies assessed satisfaction with the interventions, satisfaction with marital life[103] or with the caring process more generally[116] was also reported. Some studies assessed only the intervention group and just three studies assessed the significance of any between-group differences: all reported significantly higher levels of satisfaction for respite, compared with usual care[93,95] or the provision of information and a single counselling session.[116] Just one study assessed care recipients' satisfaction with the intervention.[93] There was no significant difference between the groups, although those using day care were more satisfied than the subgroup of 'usual care' participants who had been admitted to a nursing home.

Carer burden

Carer burden encompasses the physical, psychological, social and financial impacts of caring.[130] Carer burden was assessed in 13 studies, of which eight found no statistically significant between-group difference,[35,89,93,95,96,103,116,117] one study did not report findings by allocation group[124] and another used 'duration of caring' as a proxy for burden.[40] Of the remaining three studies, positive findings were reported for subjective burden (a quasi-experimental study comparing a respite package with no intervention),[76] the Zarit Caregiver Burden Index (a randomised trial comparing an in-home respite visiting/walking service with usual care),[79] and overload and strain (a quasi-experimental study comparing day care with no day care).[102] However, none of these positive findings can be taken at face value because of the studies' methodological weakness. The Kosloski[76] comparison groups differed in racial composition and income. This means that factors other than the respite intervention may have caused the observed between-group difference. The study by Wishart and colleagues[79] was included in a Cochrane review,[69] but the reviewers were unable to replicate the positive findings reported by the authors, casting doubt on the reliability of the original analysis or the accuracy of reported data (see *Table 6* and *Figure 7*). There are several quality concerns about the study by Zarit and colleagues[102] that call for a cautious interpretation of findings (see the section 'Assessment of study quality', p. 53, for a fuller discussion and *Table 36,* Appendix 5, for the quality assessment summary for this study). A meta-analysis of findings from eight studies that provided sufficient data is presented in the section 'Meta-analysis' (p. 47).

Use of healthcare or social care resources

Fourteen studies included in the effectiveness review examined the use of healthcare or social care resources and seven of these studies appraised a range of resources for both intervention and control groups,[35,40,79,93,95,116,124] of which five were randomised trials. The US study of day care by Hedrick and colleagues found that day-care services were substituted for ambulatory services (e.g. clinic visits, home care visits), but these cost savings did not offset the additional costs of day care, which were marginally higher than those of usual care.[93] The intervention had no impact upon the number of hospital admissions or hospital length of stay. The reduction in the use of home visits in this study almost certainly resulted from provider regulations that prohibited the concurrent use of day-care and home-care services in the intervention arm of the trial.[118] The 3-month Canadian study of day care by Baumgarten[35] assessed utilisation of hospital care, day care, physician care, home care services (e.g. home carer, visiting nurse, meals on wheels), outpatient professional services (e.g. physiotherapy, social work), day hospital, long-term care (e.g. respite care, rehabilitation, nursing home) and transportation. Although a trend towards higher costs in the intervention group was found, the trend was non-significant. The 12-month US study by Lawton[116] offered subsidised respite care in the context of ongoing case management, counselling, informational and educational services. Use of formal health and social services was significantly higher in the intervention group than in the control group (who received some information and counselling at the outset of the study). Although this finding appears plausible, the study is methodologically problematic (see the section 'Assessment of study quality', p. 53, for a discussion of this issue). Another 12-month US study[124] found no significant difference in use of community services between those using in-home respite and those receiving usual care. The 6-week Canadian study of home respite by Wishart[79] found no significant between-group difference in resource use. Both quasi-experimental studies reported higher use by the intervention group, relative to controls.[40,95] Of the remaining seven studies, three assessed only respite use,[84,92,117] two further studies, both quasi-experimental in design, looked only at the use of home care services (no significant difference was found, either in the German day-care study[103] or in the US respite package study[94]), one reported only baseline assessments[96] and the Australian study comparing periodic respite with institutional care examined the use of formal services by the control group only.[34] Further details of resource use are given in the results from the economic evaluations (the section 'Included studies', p. 63).

Use of informal support and time spent on caring tasks

The use of informal support (eight studies) and time spent on caring tasks (nine studies) were also assessed, with seven studies assessing both outcomes. These measures may help to interpret health outcomes. Lawton and colleagues[116,123] found that over the 12-month study period, carers in the respite group received a significantly greater increase in informal support from secondary carers than did carers in the control group, but that time spent by primary carers was similar in both groups. However, this finding may be attributable to the fact that carers in the control group were less depressed and care recipients less cognitively impaired than intervention participants. Although the study was randomised, flaws in the analytical approach may explain this apparent imbalance between the study groups at baseline (see the section 'Assessment of study quality', p. 53). Three studies found no difference between the respite and control groups' use of informal support.[40,101,103] Reporting was unsatisfactory in the remaining studies, with two studies failing to present findings for each group,[117,124] and two reporting disaggregated findings with no summary measure.[79,93] The study by Zank and colleagues reported that control group carers spent around 67 hours a week on caring tasks,[103] while for the carers in the study by Hedrick and colleagues, the corresponding figure was around 19 hours.[93] This raises the possibility that 'time spent caring' was defined differently in different studies, which would make comparisons between studies inappropriate.

Time to institutionalisation

Time to institutionalisation was not reported by any study included in the review. Therefore, any outcomes related to institutionalisation were included in this category. Overall, the proportion of participants institutionalised ranged between 4 and 48%. These figures reflect heterogeneity (variation) between studies, in terms of the patient group, the sample size, the duration of follow-up and the ease of access to institutional care. The statistical significance of differences between control and intervention groups was not always reported, but in any case, studies were not explicitly powered to detect a difference. Lawton and colleagues assessed 'days alive in the community' (community tenure), but only for the subgroup remaining in the community throughout the whole study period.[116] Community tenure was found to be statistically significantly higher in the intervention group. Montgomery and colleagues found no statistically significant difference between groups in the rate of institutionalisation at 12 months or at 20 months.[117] However, subgroup analyses showed that adult child carers in treatment groups were less likely to institutionalise care recipients than carers in the control group, while spouse carers in the treatment groups were more likely to institutionalise care recipients, relative to the control group. Further research would be needed to validate this finding. The trial by Zarit and colleagues reported that the proportion of intervention group institutionalised was twice that of the control group.[102] However, since groups were drawn from separate geographical areas, selected for differences in access to respite care, it is possible that differential access to institutional care may help to explain this finding. The section 'Meta-analysis', p. 47, presents a quantitative synthesis of findings on institutionalisation.

ADL

ADL was assessed in ten studies, but only four studies reported findings at follow-up. Three studies, all assessing day care, found no significant between-group difference[35,89,103] and the fourth study reported only that ADL was correlated with nursing home placement.[117]

Other findings

Ten trials assessed outcomes that did not fit into any of the above categories. Donaldson[104] asked carers in the FSU (day care) group or control group about the adverse effects of caring, the perceived service benefits and the opportunity cost of caring. Carers felt that day care significantly improved their sense of freedom and relaxation, and also helped to improve care recipient behaviour. Lawton[116] assessed carer 'attitudes', including caregiving 'competence' (mastery) and caregiving ideology. No significant difference between the groups was identified. Montgomery[117] asked participants who had not been offered respite as part of the study which type of respite they would prefer. In-home respite (short stay 56%, overnight 48%) was more popular than either day care (28%) or overnight institutional respite (24%). Montgomery[124] used the 'affection/obligation scale' to assess the caregiving relationship. However, findings were not reported by allocation group. Zank[103] explored this issue in more depth, using a range of instruments [Family conflict and Job-Caregiving Conflict scales (both instruments developed by Pearlin, 1990); 'subjective deficits' (carer response to memory/behaviour problems); non-cognitive symptoms (Alzheimer's Disease Assessment Scale); and the Memory problems and Behaviour problems checklists (German versions, adapted from Zarit, 1983, 1990)]. The only significant effect for day care was an improvement in non-cognitive symptoms. Quayhagen[101] also used the Memory and Behaviour problems checklist and similarly found no significant between-group effect. The Hedrick[93] study found that day care had no effect upon care recipients' overall health, as assessed by the Sickness Impact Profile (SIP, incorporating both physical and psychological health assessments). Three uncontrolled studies also reported additional outcomes: the video respite study by Lund[92] assessed the viewers' attention, whereas the studies by Clark[84] and Holm[90] reported service costs.

Meta-analysis

As data on both intervention and control groups are required for statistical synthesis, only controlled trials were eligible for inclusion in the meta-analysis. Of the 17 controlled trials included in the review, all but one[34] compared the impact of a respite intervention with usual care (*Table 11*). For the remaining 16 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 by type of respite intervention (*Table 12*). The review included trials reporting both continuous and dichotomous data. For continuous data, some studies that reported the same outcome measure did not consistently report the scale used, or simply reported that a 'modified' version had been used (*Table 13*). For these studies, findings were pooled using SMDs. However, some studies reported end-point scores and others reported change scores; these different types of scores should not be combined as SMDs, because the difference in standard deviation does not reflect differences in measurement scale, but differences in the reliability of the measurements.[131] In this case, findings can be pooled using weighted mean differences (WMDs), provided that trials used identical scales.[132] However, as measures of carer burden differed, findings for this outcome were not pooled. For dichotomous data, such as mortality rates or institutionalisation rates for the care recipient (*Table 14*), the period covered by the data varied by study. Therefore, the relative risk (RR) was calculated for these data, as this measure is generally held to be less time sensitive in chronic disease models than the risk difference, and is therefore the metric recommended by the Cochrane collaboration.[131] Findings were represented using forest plots as a graphical summary of intervention effect, separating findings for randomised trials from those reported by quasi-experimental studies. Study quality is proxied by whether treatment allocation was concealed (see Appendix 5, *Table 36*). With randomised and quasi-experimental studies treated separately, there were insufficient data to allow pooling by type of respite care, and so figures present findings for any type of respite care compared with usual care. When conducting meta-analysis, a random effects model was routinely fitted, reflecting the heterogeneous nature of the interventions studied. However, if the random effects model demonstrated an absence of heterogeneity, a fixed effects model was fitted. *Figure 2* illustrates the process by which eligibility for randomised trials in the meta-analysis was determined; the corresponding data for quasi-experimental studies are shown in *Figure 3*.

Findings by outcome: mortality rate

Three randomised trials and one quasi-experimental study contributed mortality data from 1582 participants (care recipients) for the

TABLE 11 *Controlled studies: summary of data contribution for meta-analysis (*n = *17)*

Study	RCT	Intervention	Comparator	Contributes data for meta-analysis
Artaso Irigoyen, 2002[95]	×	DC	Usual care	Yes (MMSE; carer burden)
Baumgarten, 2002[35]	✓	DC	Usual care	Yes (carer burden)
Burch, 2001[89]	✓	DC	Usual care (day hospital)	Yes (mortality rate; proportion institutionalised; carer burden)
Conlin, 1992[94]	×	RP (INR, IR)	Usual care	Yes (proportion institutionalised)
Donaldson, 1989[104]	×	DC	Usual care	Yes (mortality rate)
Grant, 2003[97]	✓	INR	Usual care	Yes (carer depression)
Hedrick, 1993[93]	✓	DC	Usual care	Yes (mortality rate; proportion institutionalised; MMSE; carer burden)
Kosloski, 1993[76]	×	RP (DC, INR)	Usual care	Yes (carer burden)
Lawton, 1989[116]	✓	RP (DC, INR, IR)	Usual care	Yes (mortality rate; proportion institutionalised)
Montgomery, 1985[124]	✓	INR	Usual care	No: no useful data reported
Montgomery, 1989[117]	✓	RP (DC, INR, IR)	Usual care	No: no other study reports similar data Care recipient: months spent in nursing home (reported for subgroup only)
Niebuhr, 1989[96]	×	INR	Usual care	Yes (carer burden; carer depression)
Quayhagen, 2000[101]	✓	DC	Usual care	No: no other study reports similar data Carer: Health Assessment Scale; Stress (Memory and Behaviour Problems Checklist); Geriatric Center Morale Scale; views on benefits/problems of interventions Care recipient: verbal fluency; immediate memory; delayed memory; problem solving; behaviour problems
Wells, 1987[34]	✓	IR	Institutional care	No: comparator is not usual care
Wishart, 2000[79]	✓	INR	Usual care	Yes (carer burden)
Zank, 2002[103][a]	×	DC	Usual care	No: no useful data reported
Zarit, 1998[102][b]	×	DC	Usual care	Yes (proportion institutionalised; carer burden; carer depression)

[a] Study reports coefficients from regression analysis, rather than means and standard deviations.

[b] Study does not report standard deviations for continuous outcomes; imputed from *p*-values, which were in turn derived from reported *F* statistics.

Type of respite: DC, day care; RP, respite package; INR, in-home respite; IR, institutional respite.

meta-analysis (*Figure 4*). Data used in the analysis are shown in *Table 14*. The RCT by Lawton[116] assessed the impact of a respite package, and the other three studies all assessed day care. No study found a statistically significant effect for respite, although there was a trend in favour of respite in the small quasi-experimental study by Donaldson.[40]

Findings by outcome: proportion institutionalised

Three randomised trials and two quasi-experimental studies contributed data on institutionalisation rates from 1826 participants (care recipients) for the meta-analysis (*Figure 5*). The study by Donaldson[104] reported 'mean number days alive in the community', and these data were too dissimilar and could not therefore be synthesised within the analysis. Data used in the analysis are shown in *Table 14*. Two studies were of respite packages[94,116] and the remaining three assessed day care. Only one study found a statistically significant effect, which was in favour of the control group.[102] However, since comparator groups in this study were selected from a geographical region with low levels of service provision and subsidies, findings may be more indicative of access differences than an adverse effect of respite. Pooled findings from randomised and quasi-experimental studies demonstrated that the overall effect size was not statistically significant [effect size 1.17, 95% confidence interval (CI) 0.79 to 1.73]. However, this finding was associated with substantial

TABLE 12 *Meta-analysis: number of studies with data by outcome category*

Outcome category	No. of studies with useful data		Comments
	Randomised ($n = 9^a$)	Quasi-experimental ($n = 7$)	
Quality of life (carer/care recipient)	0	1	Pooling not possible
Physical health (carer/care recipient)	3	1	Mortality rate (care recipient) was the only outcome measure in this category reported by more than one study. Pooled fixed effects model, with effect size estimated using relative risk
Mental/psychological health (carer/care recipient)	1	2	Depression (carer) was the only carer outcome measure in this category reported by more than one study. Effect sizes estimated using SMD, pooled with random effects model
	1	1	MMSE (care recipient) was the only care recipient outcome measure in this category reported by more than one study. Effect sizes estimated using SMD, pooled with fixed effects model
Satisfaction (carer/care recipient)	0	0	Pooling not possible
Carer burden	4	3	Studies report different measures, but these are assumed to assess the same underlying construct, so effect sizes estimated using SMD. Studies report a mix of change scores and endpoint scores, so pooling not undertaken
Time to institutionalisation	3	2	All studies reported the proportion of study participants (care recipients) institutionalised during the study period. Effect sizes estimated using relative risk. High levels of heterogeneity indicated that pooling of RCTs with non-randomised studies was inappropriate
Time spent on caring tasks	0	0	Pooling not possible
ADL	1	0	Pooling not possible
Other results (including qualitative results)	0	0	Pooling not possible

[a] The randomised trial by Wells (1987)[34] was excluded from the meta-analysis because it compares institutional care with periodic respite, rather than respite vs usual care.

[b] SMD, standardised (weighted) mean difference.

TABLE 13 *Studies contributing data to the meta-analysis: continuous outcomes*

Outcome measure Total no. of participants contributing data	**Studies contributing data**	**Intervention**			**Comparator**			**Measure**
		Mean	**(SD)**	***n***	**Mean**	**(SD)**	***n***	
MMSE (care recipient)	Artaso Irigoyen, 2002[95]	13.4	8.3	34	15.1	9.1	35	Minexamen Cognoscitivo (Lobo *et al.*, 1979); scoring unclear
$n = 453$	Hedrick, 1993[93]	23.7	5.2	198	24.2	5	186	MMSE; 11 items: 0–30; higher scores indicate better health
Carer burden	Artaso Irigoyen, 2002[95]	53.6	15.4	34	50.5	11.4	35	Zarit Burden (scale unclear); higher scores indicate greater burden
$n = 989$	Baumgarten, 2002[35]	21	18.4	88	19.8	19.3	90	Carer Burden Inventory (Novak and Guest, 1989; scored 0–96); higher scores indicate greater burden
	Burch, 2001[89][a]	–1.45	2.4	23	–1.59	2.44	27	Caregiver Strain Index (Robinson, 1983; 13 items, scored 0–13); higher scores indicate greater burden
	Hedrick, 1993[93]	33.6	9.5	185	34.1	9.8	174	Caregiver Impact Questionnaire (Montgomery and Borgatta, 1985; 12-item, five-point scale; scored 12–60); higher scores indicate greater burden
	Kosloski, 1993[76]	13.15	3.7[b]	47	15.04	3.7[b]	25	Zarit Burden Index (modified; four items; range unclear); higher scores indicate greater burden
	Niebuhr, 1989[96]	39.8	12.1	21	41.2	4.5	26	Zarit Caregiver Burden Index (Zarit and Zarit, 1983) (22 items); higher scores indicate greater burden
	Wishart, 2000[79][a]	–4	6.8	11	1.51	9	10	Zarit Caregiver Burden Index (22 items); higher scores indicate greater burden
	Zarit, 1998[102]	19.8	2.6[c]	73	21.2	2.6[c]	120	Role Overload (seven items, four-point scale, scored 7–28); higher scores indicate greater burden
Carer depression	Grant, 2003[97]	4.9	4.4	32	6.1	5.7	23	Hamilton Depression Scale; higher scores indicate worse health
$n = 295$	Niebuhr, 1989[96]	10.6	7.4	21	10.4	6.8	26	Geriatric Depression Scale (30 items); higher scores indicate worse health
	Zarit, 1998[102]	12.8	9.0[c]	73	16.1	9.0[c]	120	Depression: CES-D (20 items: 0–60); higher scores indicate worse health

[a] Change score.
[b] Standard deviation imputed from *t*-test statistic.
[c] Standard deviation imputed from *F* statistic (via derived *p*-values).
CES-D, Center for Epidemiologic Studies Depression Scale.

TABLE 14 *Studies contributing data to the meta-analysis: dichotomous outcomes*

Outcome measure Total no. of participants contributing data	Studies contributing data	Intervention			Comparator			Measure
		With condition	Without condition	*n*	With condition	Without condition	*n*	
Mortality rate (care recipient) $n = 1582$	Burch, 2001[89]	8	47	55	6	44	50	Mortality rate
	Donaldson, 1989[104]	3	21	24	20	50	70	Mortality while at living at home
	Hedrick, 1993[93]	87	293	380	70	301	371	Survival rate: DC 77%; C 81%
	Lawton, 1989[116]	60	257	317	66	249	315	Survival rate: R 81%; C 79%
Proportion institutionalised (care recipient) $n = 1826$	Burch, 2001[89]	2	53	55	3	47	50	Number admitted to nursing home
	Conlin, 1992[94]	2	5	7	1	7	8	Number institutionalised over study period
	Hedrick, 1993[93]	182	198	380	182	189	371	% Admitted to nursing home (VA institutions): DC 40%; C 42%; (non-VA institutions): DC 8%; C 7%.
	Lawton, 1989[116]	73	130	203	76	110	186	% Institutionalised: R 36%; C 41%
	Zarit, 1998[102]	83	178	261	48	257	305	% Institutionalised: DC 44%, $n = 188$; C 26%, $n = 185$

C, control group; DC, day care group; R, respite group; VA, Veterans Affairs.

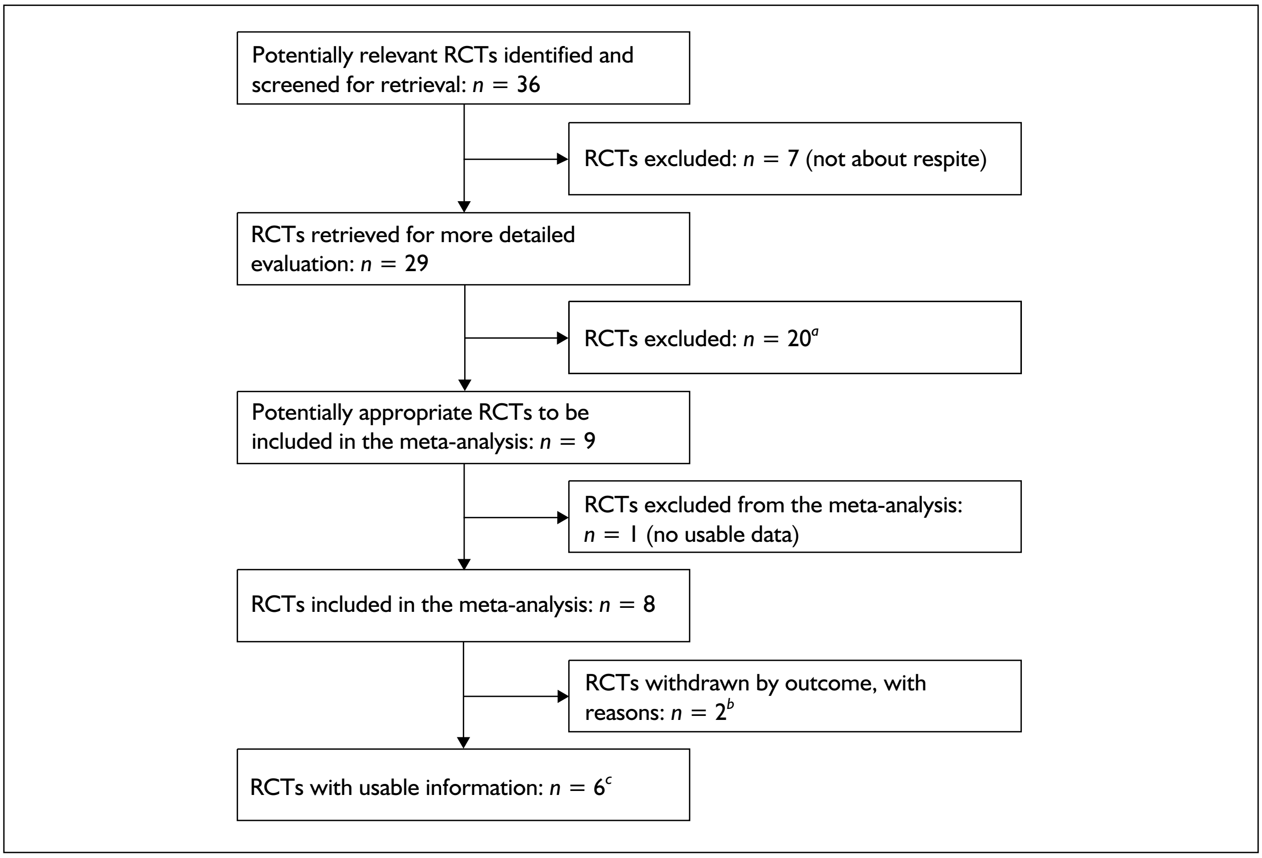


FIGURE 2 *Flow diagram for meta-analysis of RCTs.* [a] *Non-respite intervention (*n *= 1); comparison not usual care (*n *= 1); study design (*n *= 3); no carer outcomes (*n *= 3); multidimensional intervention where impact of respite unclear (*n *= 3); additional reference for excluded (*n *= 7) or included (*n *= 4) studies.* [b] *Single trial reports each outcome, so pooling not possible.* [c] *Mortality rate (*n *= 3); MMSE (*n *= 1); proportion institutionalised (*n *= 3); carer burden (*n *= 4), carer depression (*n *= 1).*

heterogeneity (*I*-squared statistic 80.7%) and so the overall pooled effect was removed from *Figure 5*.

Findings by outcome: MMSE

One randomised trial and one quasi-experimental study contributed data on care recipients' cognitive state (MMSE) from 453 participants (care recipients) (*Figure 6*). Data used in the analysis are shown in *Table 13*. Findings were pooled using the SMD, as it was unclear whether the scale reported by Artaso Irigoyen and colleagues[95] was a Spanish version of that used by Hedrick.[93] Both studies assessed day care. Unsurprisingly, neither study found a statistically significant effect in favour of the intervention or of the comparator. The trial by Wells[34] also included data for the MMSE. As this study compared institutional care with periodic respite, it was excluded from the meta-analysis (see *Table 12*), although findings were similar (effect size 0.38, 95% CI –0.47 to 1.23).

Findings by outcome: carer burden

Four randomised trials and four quasi-experimental studies contributed data on carer burden from 989 carers (*Figure 7*). Data used in the analysis are shown in *Table 13*. As a variety of scales was used by the studies, effect size was calculated using the SMD (see *Table 12*). However, as two studies[79,89] reported change scores, findings should only be pooled if the WMD metric is used.[131] Five studies assessed day care,[35,89,93,95,102] two studies were of in-home respite,[79,96] and the study by Kosloski[76] assessed a respite package. Two studies, both quasi-experimental, found a statistically significant effect on carer burden in favour of respite. The pooled effect size for the randomised studies showed no significant difference between respite and usual care (effect size –0.03, 95% CI –0.19 to 0.13; I^2 0%). There was substantial heterogeneity for pooled findings of the quasi-experimental studies, alone (I^2 59.8%) or combined with the randomised studies (I^2 52.2%), and pooling was removed from *Figure 7*.

Findings by outcome: carer depression

One randomised study and two quasi-experimental studies contributed data on depression scores for 295 carers. Data used in the analysis are shown in

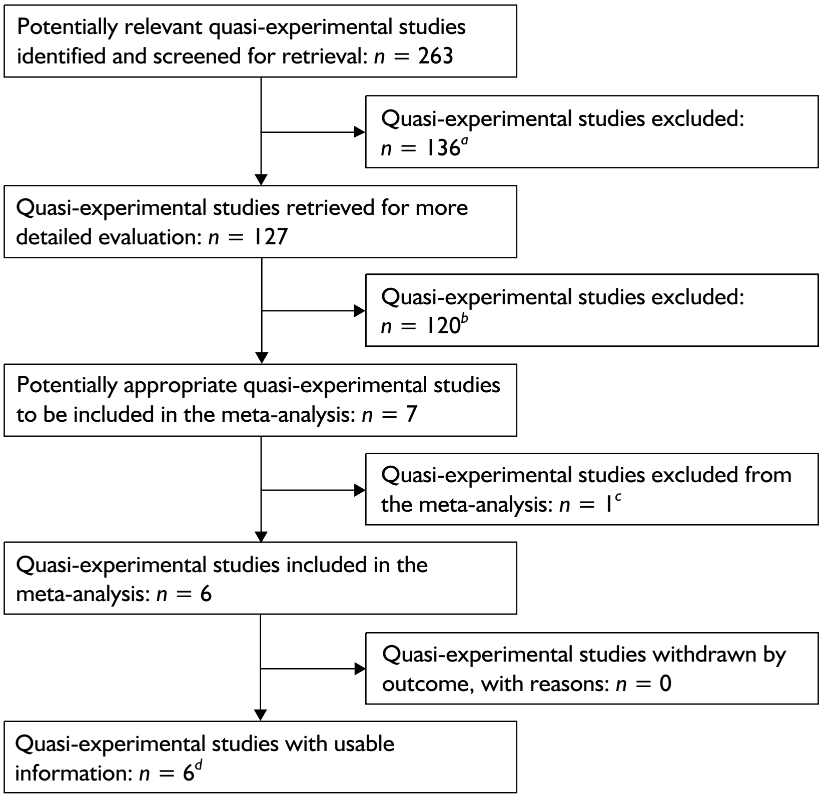


FIGURE 3 *Flow diagram for meta-analysis of quasi-experimental studies.* [a] *Not about respite* (n = *26); age group* (n = *2); study design* (n = *90); no carer outcomes* (n = *5); irretrievable* (n = *13).* [b] *Not about respite* (n = *16); age group* (n = *1); study design* (n = *72); review* (n = *17); no carer outcomes* (n = *2); multidimensional intervention where impact of respite unclear* (n = *2); additional reference for included study* (n = *10).* [c] *No usable data reported* (n = *1).* [d] *Mortality rate* (n = *1); MMSE* (n = *1); proportion institutionalised* (n = *2) ; carer burden* (n = *3); carer depression* (n = *2).*

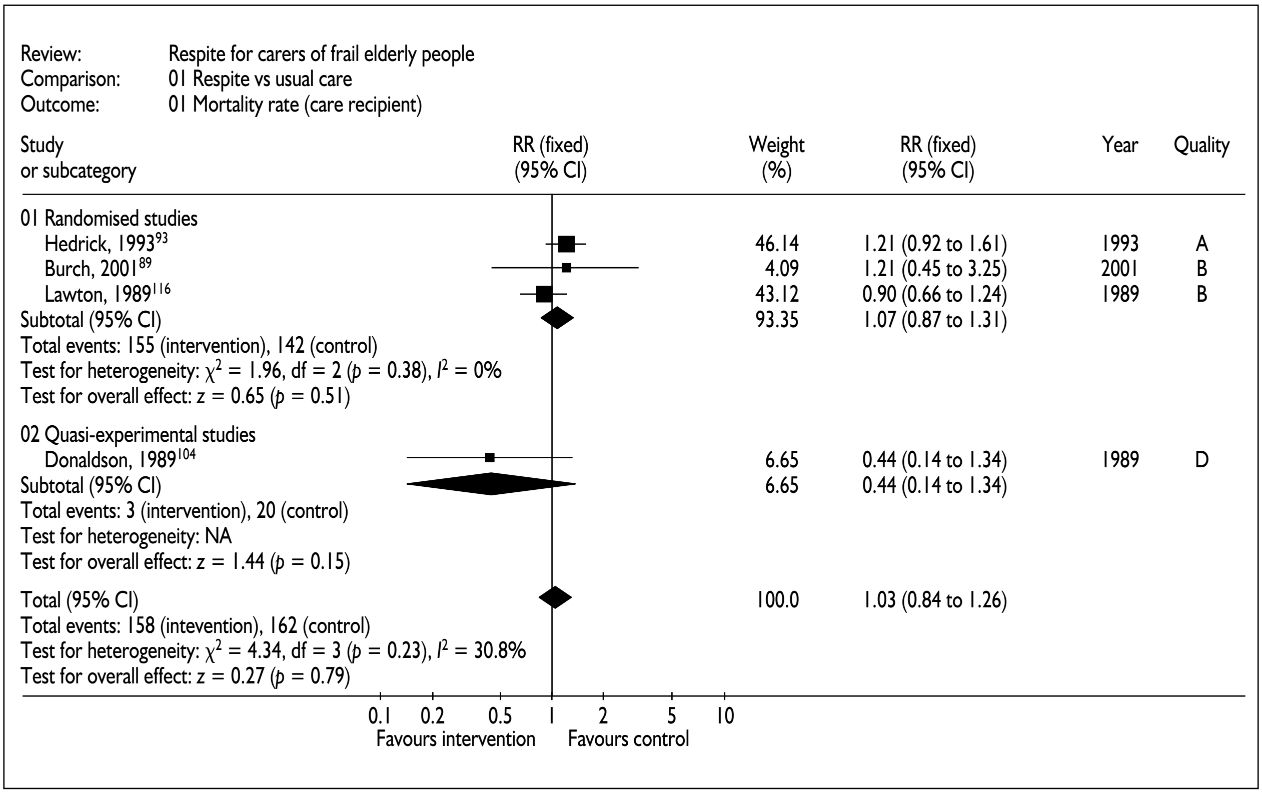
Table 13. Two studies assessed in-home respite[96,97] and one evaluated day care.[102] Pooled findings found a statistically significant effect upon carer depression (effect size –0.32, 95% CI –0.62 to –0.02), but it is clear from *Figure 8* that the positive overall effect was due to one study, Zarit and colleagues' trial of day care.[102] 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 (see the next section).

Assessment of study quality

Much of the existing literature is unable to inform policy and practice, on account of its poor quality. A ten-item assessment tool was used to assess the quality of controlled studies (see Appendix 5, *Table 36*) and a separate tool was used for uncontrolled studies[48] (see Appendix 5).

Quality assessment of controlled studies

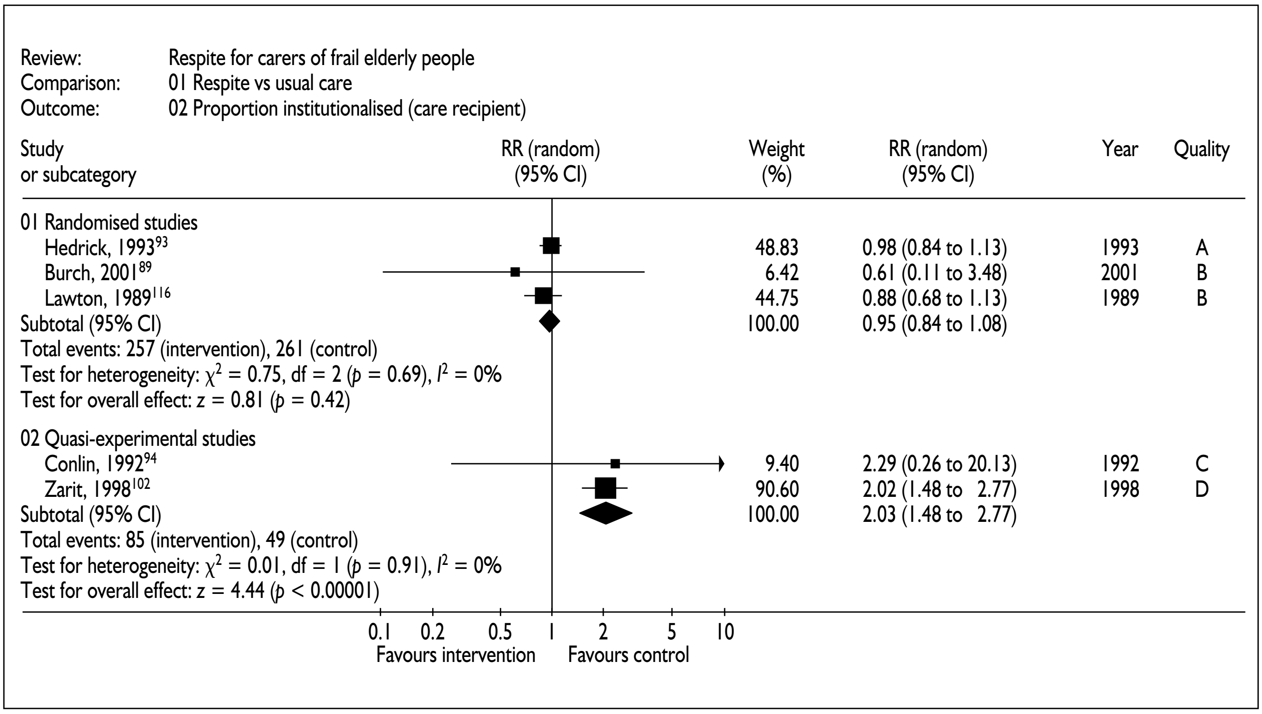
Perhaps the most important feature of a randomised study is the 'concealment of treatment allocation'. This means that the person, or people, allocating study participants to the groups cannot 'cheat' and influence the allocation process so that participants they think are more likely to benefit, or who are more deserving, enter the intervention arm of the trial. Only two of the ten RCTs reviewed clearly demonstrated that the allocation process was concealed. In some RCTs, the study groups were non-comparable at baseline, suggesting that the randomisation process may have been flawed. Therefore, factors other than the respite intervention, such as clinical or demographic characteristics of the carers or care recipients, may explain findings: the observed changes cannot reliably be attributed to the intervention. Another important quality marker of any controlled study is whether the outcomes assessor was 'blind' or masked to treatment allocation. Just two of the 17 controlled studies reported that this had been done. In addition, trial data should be analysed on an ITT basis, so that data from every participant enrolled in the trial are included in the analysis.[47] This ensures



Review: Respite for carers of frail elderly people
Comparison: 01 Respite vs usual care
Outcome: 01 Mortality rate (care recipient)

Study or subcategory	Weight (%)	RR (fixed) (95% CI)	Year	Quality
01 Randomised studies				
Hedrick, 1993[93]	46.14	1.21 (0.92 to 1.61)	1993	A
Burch, 2001[89]	4.09	1.21 (0.45 to 3.25)	2001	B
Lawton, 1989[116]	43.12	0.90 (0.66 to 1.24)	1989	B
Subtotal (95% CI)	93.35	1.07 (0.87 to 1.31)		
Total events: 155 (intervention), 142 (control)				
Test for heterogeneity: $\chi^2 = 1.96$, df = 2 ($p = 0.38$), $I^2 = 0\%$				
Test for overall effect: $z = 0.65$ ($p = 0.51$)				
02 Quasi-experimental studies				
Donaldson, 1989[104]	6.65	0.44 (0.14 to 1.34)	1989	D
Subtotal (95% CI)	6.65	0.44 (0.14 to 1.34)		
Total events: 3 (intervention), 20 (control)				
Test for heterogeneity: NA				
Test for overall effect: $z = 1.44$ ($p = 0.15$)				
Total (95% CI)	100.0	1.03 (0.84 to 1.26)		
Total events: 158 (intevention), 162 (control)				
Test for heterogeneity: $\chi^2 = 4.34$, df = 3 ($p = 0.23$), $I^2 = 30.8\%$				
Test for overall effect: $z = 0.27$ ($p = 0.79$)				

FIGURE 4 *Forest plot for respite studies reporting mortality rate (*n *= 4). NA, not applicable.*



Review: Respite for carers of frail elderly people
Comparison: 01 Respite vs usual care
Outcome: 02 Proportion institutionalised (care recipient)

Study or subcategory	Weight (%)	RR (random) (95% CI)	Year	Quality
01 Randomised studies				
Hedrick, 1993[93]	48.83	0.98 (0.84 to 1.13)	1993	A
Burch, 2001[89]	6.42	0.61 (0.11 to 3.48)	2001	B
Lawton, 1989[116]	44.75	0.88 (0.68 to 1.13)	1989	B
Subtotal (95% CI)	100.00	0.95 (0.84 to 1.08)		
Total events: 257 (intervention), 261 (control)				
Test for heterogeneity: $\chi^2 = 0.75$, df = 2 ($p = 0.69$), $I^2 = 0\%$				
Test for overall effect: $z = 0.81$ ($p = 0.42$)				
02 Quasi-experimental studies				
Conlin, 1992[94]	9.40	2.29 (0.26 to 20.13)	1992	C
Zarit, 1998[102]	90.60	2.02 (1.48 to 2.77)	1998	D
Subtotal (95% CI)	100.00	2.03 (1.48 to 2.77)		
Total events: 85 (intervention), 49 (control)				
Test for heterogeneity: $\chi^2 = 0.01$, df = 1 ($p = 0.91$), $I^2 = 0\%$				
Test for overall effect: $z = 4.44$ ($p < 0.00001$)				

FIGURE 5 *Forest plot for respite studies reporting proportion institutionalised (*n *= 5)*

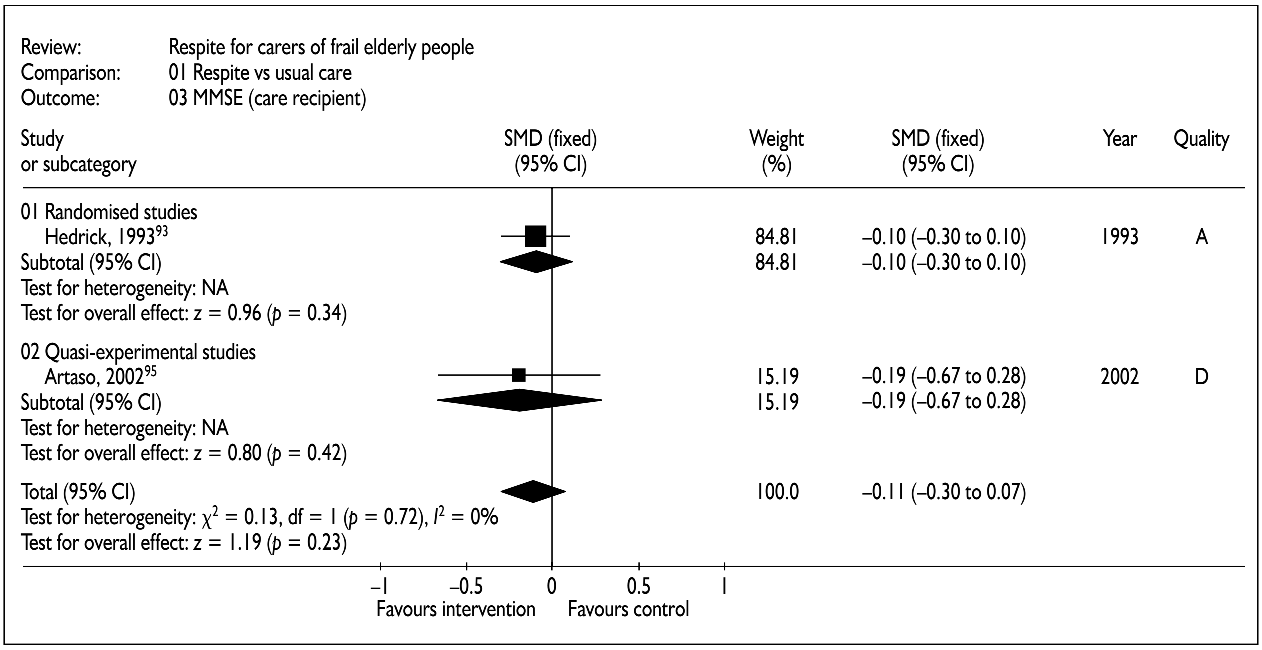


***FIGURE 6** Forest plot for respite studies reporting MMSE (*n *= 2)*

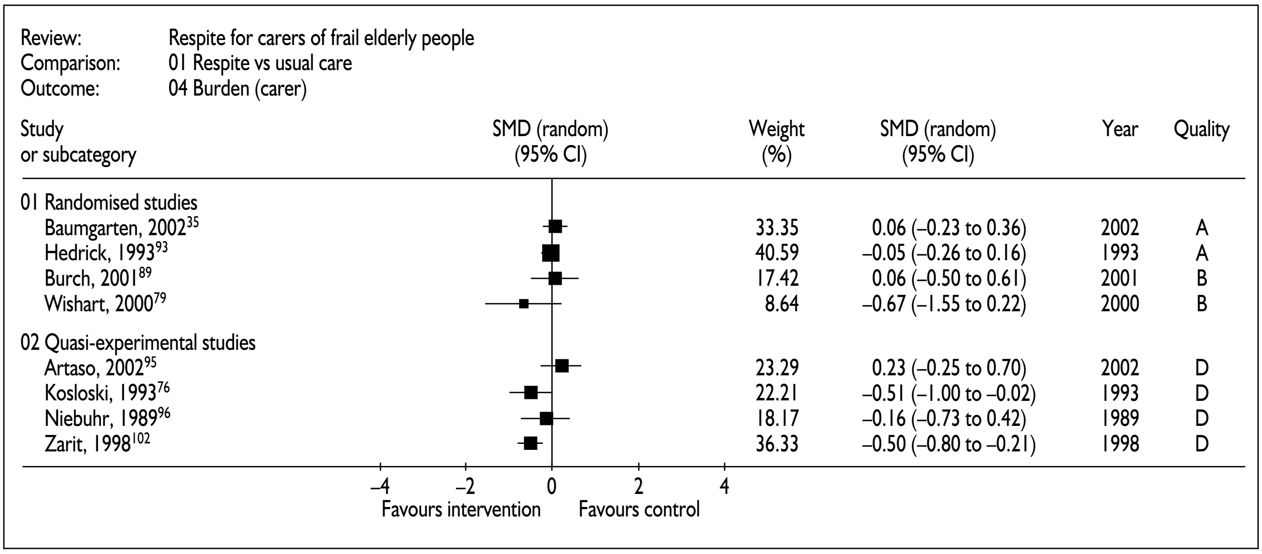


***FIGURE 7** Forest plot for respite studies reporting carer burden (*n *= 8)*

that the effect size is not artificially inflated by ignoring those who dropped out of the trial, either because respite did not work for them or because of adverse effects (e.g. exacerbated care recipient behaviour). Only three studies used an ITT approach and just one trial provided enough information on people who withdrew from the trial to allow a full assessment of effects to be made. Two trials adopted a strict per-protocol methodology, including in their analysis only those carers who adhered to strict conditions throughout the course of the study.[102,103] For example, in the study by Zarit and colleagues,[102] intervention participants who used less than twice-weekly day care or who used over 8 hours a week of formal care, and control participants who started using day care or whose care recipients became too ill to be able to use day care, were excluded from the study and therefore contributed no data. These would include carers whose care recipients were institutionalised; those who found day care to be unsuitable, or detrimental, either to their own or to the older person's health and well-being; and people who may have benefited, but who found that the financial or personal costs outweighed any advantages. The per-protocol

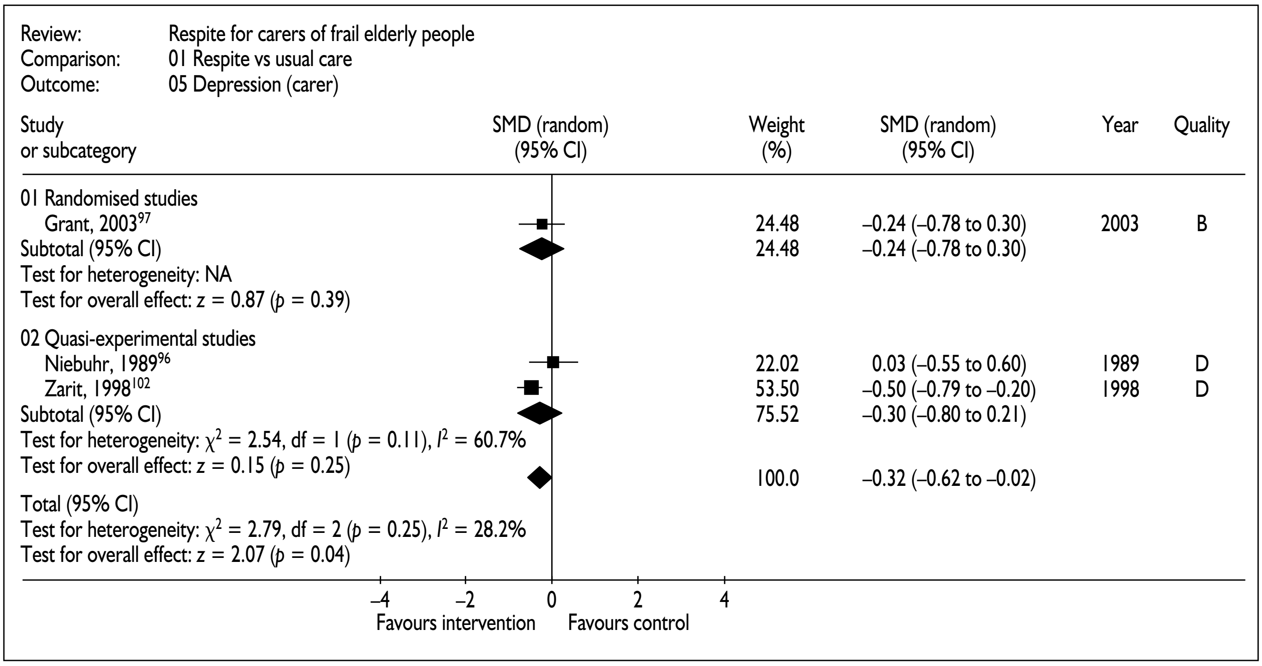


***FIGURE 8** Forest plot for respite studies reporting carer depression (n = 3)*

methodology means that this study provides no information about the potential adverse effects of day-care provision, and the information on outcomes is, at best, selective. The study therefore is unable to clarify the effects of offering day care on carers of older persons with dementia.

Only four studies clearly used appropriate statistical analyses.[35,89,94,97] In one randomised trial by Lawton and colleagues,[116] the unit of randomisation was a mixture of (support) group and individual. The analysis did not reflect this distinction and a number of significant between-group baseline differences was observed. The authors adjusted for these differences in the statistical analysis, but the unit of analysis was the carer or care recipient. This approach assumes that each allocation is independent and takes no account of the group-level allocation. Findings from the formal assessment of outcomes are therefore difficult to interpret.

In both randomised and quasi-experimental studies, authors used statistical techniques to attempt to adjust for known between-group differences at baseline. Ideally, the methodology for a regression analysis should be clearly specified at the protocol stage of the study, to make it clear that the data have not been used retrospectively for exploratory purposes. However, the methodology used in the trial by Zarit and colleagues[102] could increase the risk of a type I error (i.e. mistakenly finding a significant difference where none exists). First, the authors undertook a type of stepwise regression, which can yield confidence intervals for effects and predicted values that are falsely narrow (statistically overprecise).[133] Secondly, the analysis of covariance included only variables that were correlated with outcomes. This approach artificially narrows the error variance, compounding the problems associated with stepwise regression and heightening still further the risk of 'finding' a non-existent difference. Further analysis of the same data by Gaugler and colleagues,[115] which adopted a more conservative statistical approach by incorporating all baseline variables as covariates, found smaller benefits only for a subgroup of participants; in the authors' words, "the findings of this study must be interpreted with caution".[7] Even with an appropriate statistical analysis, unknown differences between the groups may still exist and undermine the validity of findings, although this risk is greatly reduced if the randomisation process is sound. Lastly, most studies assessed multiple outcomes and all but one[93] failed to specify a primary or secondary end-point. This approach increases the risk of spuriously identifying a 'significant' finding by chance, which undermines the reliability of the reported findings.

Quality assessment of uncontrolled studies

There is a lack of agreement on suitable methods for assessing the quality of qualitative research and synthesising qualitative data.[48] Campbell and colleagues[134] outline key components of the debate about quality assessment: a plausible philosophical rationale for undertaking quality assessments and, if such a rationale exists, what criteria should be used to inform judgements about quality. The increasing use of qualitative methods in health and social care research has led to demands (from funding bodies and health service practitioners) on researchers to develop criteria and checklists to assist in the evaluation of qualitative studies. Many checklists have been developed.[134]

The quality of uncontrolled studies included in this review was assessed using criteria based on the Critical Appraisal Skills Programme (CASP).[48] This tool was selected because it uses three broad issues to guide appraisal: rigour, credibility and relevance. These issues are part of most checklists. However, the CASP tool has been used in another nationally funded systematic review which considers the methodological challenges of appraisal and synthesis.[135]

All of the uncontrolled studies have methodological weaknesses. Methods used in the uncontrolled studies include interviews, observation and postal questionnaires (one study allowing free text responses to a questionnaire, while the other did not). All of the studies fail to provide detailed information about methods of data collection. There is a lack of information on sampling strategies (apart from the study by Clark and colleagues,[84] where all user referrals to the Macmillan carer service were sent the questionnaire). In addition, no details are provided of participant characteristics, such as age, gender or cognitive impairment of care recipient. Data collection techniques are not explicit for four out of five of the uncontrolled studies; there is limited information about questions in the postal surveys. The only study providing details is Robertson,[91] which outlines the topic guide used for interviews. There is also a lack of description of data analysis for studies using interview data (3/5) and the selection of quotes from participants. All of the studies present positive findings: contradictory data do not appear to have been taken into account, even though one of the studies indicated that negative comments were made about the service.[84] No attempt was made in any of the studies to address potential bias and influence of the researcher on data collection, analysis or selection of data for presentation. This is problematic given that the relationship of the researcher to service provision is not made explicit, but in two of the studies the researchers clearly have some involvement in the development or provision of the respite service being studied. Three of the studies fail to address ethical issues. The lack of detail of the participants, content of the respite service and the setting makes it difficult to transfer the findings of these studies to other people, conditions and settings. The only study that may have transferability is the study by Clark and colleagues;[84] the geographical dispersion of the pilot sites implies that this scheme is of wider interest to providers of respite care for cancer patients and their informal carers.

Studies excluded from the review

Studies that did not meet the inclusion criteria on intervention, age, frailty or study design were excluded. Where it was not possible to identify eligibility from the bibliographic details, the full paper was retrieved and further details were checked. The 29 excluded 'respite' studies, together with the reasons for their exclusion from the review, are presented in Appendix 6 (*Table 38*). Nine studies of multidimensional packages were excluded, as it was not possible to ascertain the distinct impact of the respite component. However, as findings from the multidimensional package studies may still be of interest to and relevant for policy makers, a summary table has been provided (*Table 15*; see also the section 'Multidimensional support programmes', p. 70, for details of cost-effectiveness). The findings are those reported by the authors, and no critique of the internal validity or generalisability (applicability to other settings) of these studies has been undertaken. *Table 15* does not include the study by Lawton and colleagues[33,116,122,123] Although this study offered an intervention that could appropriately be interpreted as a multidimensional support package,[36] the reviewers have instead classified it as a respite service because the purpose of the other interventions was to facilitate respite use (see the section 'Respite packages', p. 31). In addition, four studies of 'respite' care were excluded because there was no assessment of carer outcomes (*Table 16*). Three were relatively small quasi-experimental studies that together tentatively suggest that respite may offer a small benefit for care recipients. The randomised trial by Weissert and colleagues[153] found an association between day-care use and improved outcomes, but suggested that factors other than day care better explained this phenomenon. Further details of the cost-effectiveness issues relating to some of these studies are given in the section 'Economic evaluations with no assessment of carer outcomes' (p. 70).

TABLE 15 *Multidimensional intervention studies excluded from the review* (n = 9)

Study	Study design *n* Setting	Patient group	Intervention package(s)	Control	Findings
Brodaty, 1989[136]	Quasi-experimental 96 dyads Australia Community	Older people with dementia and their carers	Intensive education (carers), plus 10-day residential memory retraining programme (care recipients), providing respite for carers 10-day residential memory retraining programme (care recipients), providing respite for carers	Waiting-list control	The intensive intervention programme can reduce the psychological morbidity of the carer and delay the placement of the patient in an institution without increasing the use of health services by either patient or carer
Eloniemi-Sulkava, 2001[137]	RCT 100 dyads Netherlands Community	Older people with dementia and their carers	Two-year programme of systematic, comprehensive support by a dementia family care coordinator, who arranged respite ('rest periods') for carers in the intervention group as part of a multifaceted approach	Usual care	Placement of demented patients in long-term institutional care was deferred in the short term, but by the end of the study there was no between-group difference
Hinchliffe, 1995[138]	RCT 40 dyads UK Community	Older people with dementia and their carers Carers had poor well-being (GHQ) scores at baseline	Package individualised by treating physician (16 weeks), followed by no treatment (16 weeks) Respite (day centre; sit-in services; residential respite); medication; psychological techniques; environmental adaptations; support group	No intervention (waiting list) (16 weeks) followed by intervention (16 weeks)	Significant improvement in carer well-being (GHQ) in intervention group relative to control. Improvement in behaviour scores of care recipient, maintained over follow-up period. No significant changes in outcomes for control group at any assessment point
Mohide, 1990[78,139]	RCT 60 dyads Canada Community	Older people with moderate to severe dementia and their carers	CSP: carer-focused health care; education about dementia and caring; assistance with problem solving; regular in-home respite; self-help family caregiver support group	Conventional community nursing care	The experimental group showed a clinically important improvement in quality of life, experienced a slightly longer mean time to long-term institutionalisation, found caring less problematic, and had greater satisfaction with nursing care than the control group. The economic evaluation found an incremental cost per QALY gained of Can$20,000 for the CSP, which compares favourably with other healthcare interventions[140]

continued

TABLE 15 *Multidimensional intervention studies excluded from the review* (n = 9) *(cont'd)*

Study	**Study design** ***n*** **Setting**	**Patient group**	**Intervention package(s)**	**Control**	**Findings**
Newcomer, 1999[141–144]	RCT 5254 dyads USA Community	Older people with dementia and their carers	Two case management models with different staffing ratios. Higher and lower community service waivers enabled purchase of a variety of benefits, including: home care (homemaker/chore services, personal care services, companion services) and adult day care	Usual care	Reimbursement provided by the demonstration's Medicare waiver was generally not sufficient to exceed the level of control group service acquired through private payment. No consistent differences between demonstration models were found in service use likelihood or average use among users. There was no between-group difference for informal hours of caring by either primary or secondary carers. The intervention did not reduce rates of nursing home placement
O'Connor, 1991[145]	Quasi-experimental study 159 patients (no. of carers unclear) UK Community	Older people (>75 years) with dementia and their carers	Financial benefits; physical aids; home help; respite admissions; day care; night sitter service; practical advice; psychiatric assessments; support group	Matched controls receiving usual care	Early intervention did not affect admission rates in subjects who lived with supporters. By contrast, two-thirds of subjects with moderate or severe dementia living alone were admitted in the intervention group in the study's second year compared with fewer than one in ten controls ($p = 0.004$). Carer outcomes were not assessed
Oktay, 1990[83]	Quasi-experimental study 191 dyads USA Community	Frail older people and their carers	Post-Hospital Support Program: medical and social services provided by nurse and social worker: assessment; case management; nursing; counselling; referrals; respite; education; support group; medical back-up; on-call help	Usual care	There was a slight reduction in carer stress and a substantial reduction in hospital days used by the treatment group. When baseline differences were taken into account, an average difference of 6.5 days per patient remained. The treatment programme may have postponed some deaths and nursing home placements
Pattie, 1991[146]	Mixed methods 77 patients (no. of carers unclear) UK Community	Older people with mental health needs	Community-based services, including day care; domiciliary support; continuing care; respite care; relaxation class; meals on wheels	Usual care	The service was well received by patients, with subjective impressions of enhanced quality of life and greater independence for patients. Costs were no higher than those of usual care

continued

TABLE 15 *Multidimensional intervention studies excluded from the review* (n = 9) *(cont'd)*

Study	**Study design** ***n*** **Setting**	**Patient group**	**Intervention package(s)**	**Control**	**Findings**
Schulz, 2003[147–150]	RCT 1222 dyads USA Community	Family caregivers of persons with mild or moderate AD	Resources for Enhancing Alzheimer's Caregiver Health (REACH): six sites offering a variety of multicomponent interventions, two sites included respite elements	Control varied by site, comprising 'usual care' or 'minimal support conditions'	There is no single, easily implemented and consistently effective method for eliminating the multiple stresses of providing care to people with dementia. Actively targeting caregiver behaviour is effective in achieving positive outcomes with respect to caregiver depression and burden, but the impact of individual components is unclear

CSP, Caregiver Support Program; GHQ, General Health Questionnaire.

TABLE 16 *Respite studies excluded from the review: no assessment of carer outcomes* (n = 4)

Study	Study design *n* Setting	Patient group	Intervention package	Control	Findings
Chang, 1992[151]	Quasi-experimental (matched controls) 45 patients USA Hospital/community	Older male patients with a variety of medical problems, including cardiac disease, stroke, hypertension and neurological disease. Admitted for respite on account of carer illness or carer vacation	Inpatient respite care	(1) Acute care patients; (2) community-based patients receiving home care	The respite group did not experience an increased risk of mortality or iatrogenesis. There may be a slight benefit associated with hospital-based respite for chronically ill older adults
Strain, 1987[152]	Quasi-experimental (matched controls) 76 patients Canada Community	Older people	Adult day care	No day care and use of home care services (control group 1) No day care and no home care services (control group 2)	At baseline, day-care patients had a significantly lower quality of life, but after the intervention (duration unclear), there was no significant difference in quality of life between the day-care group and either of the control groups
Weissert, 1980[153,154]	RCT 1871 patients USA Community	Older people eligible for Medicare services and in need of continuing health care	Adult day care Adult day care plus homemaker services Homemaker services	Each of the three experimental groups was compared with its own control group (usual care)	Among users of the experimental services, increased use was associated with improved outcomes of care, but other factors better explained variation in outcomes. These included primary diagnosis, impairment prognosis and number of inpatient hospital days. On average, the annual cost of the experimental groups was 70% higher than that of the control groups
Wimo, 1993[155]	Quasi-experimental (matched controls) 99 patients Sweden Community	People with dementia living in the community and with a need for day care, but without severe physical disability	Dementia day care	Waiting list (no day care)	Day care postpones institutionalisation, probably because of less exhaustion of spouses and decreased supervision need

Chapter 6

Results: the economics of respite care

The economic evaluation of respite care services appears to be rare. Only five studies were found, all of which compared day care to usual care. Only two studies were based on RCTs and therefore in spite of including matched controls for the remaining three studies, selection bias may undermine results.

Only one study was undertaken in the UK. The difficulty of transferring results from the remaining four day-care studies is compounded by poor specification of what constitutes usual care and limited documentation of service use data more generally.

Across the economic evaluations, a number of different outcome measures was applied with no single outcome used consistently in each study, undermining the potential to compare outcomes across studies or to aggregate the data. Where multiple outcomes were measured in a single study, there may be trade-offs to be made across the outcomes, but this is not captured if the data are left disaggregated. The practical importance of some of the outcomes used was difficult to interpret, for example, what is the value of alleviating 'role overload and depression' by one unit?

Day care tended to be associated with higher costs and either similar or a slight increase in benefits, relative to usual care. It is not clear whether additional costs are worth any additional benefits. The total cost of care would be influenced by whether day care delays institutionalisation, although there is no reliable evidence that respite can extend care recipients' stay in the community. The cost impact also differs according to which payer's perspective is taken. Encouragingly, there was some evidence to suggest that more needy care recipients were receiving more services.

Included studies

This section presents narrative findings from the included economic evaluations. Forty-five records were identified as being potentially relevant for the economic evaluation of respite care. Once the exclusion criteria were applied, five economic evaluations remained, all of which compared day care with usual care.[35,93,104,114,156] For all but one[35] of these five studies, there were multiple references (an additional 12 papers). Eight additional papers referred to the Hedrick study,[107–110,112,118,157,158] two extra papers referred to Gaugler,[102,115] one extra paper was linked to Artaso Irigoyen[95] and one extra paper was linked to Donaldson.[40] For each study, data were extracted (see Appendix 4, *Tables 30–34*) and quality was assessed (Appendix 5, *Table 37*) and then checked independently by two reviewers (HW, AM).

Included economic evaluations: findings by type of respite

The only economic evidence identified was for day care (five studies); no economic studies of in-home respite, institutional respite, video respite or host family respite were found. Additional details on the main study characteristics are included in the section 'Adult day care' (p. 26) and *Table 29* (Appendix 4).

Day care

Review of Artaso Irigoyen (2002)[95,156]
Cost–consequence analysis of a psychogeriatric day center (article published in Spanish)

Overview This study evaluated the cost consequences of care provided in a psychogeriatric day-care centre compared with community care in Spain. The day-care service included a broad range of group-based activities comprising physical and mental rehabilitation, reality orientation therapy, behavioural skills training, pharmaceutical therapy and family support. Usual care (waiting-list control) involved use of care in the community, including home visits. The study is based on a single quasi-experimental study with matched concurrent controls. However, the day-care group had statistically significantly fewer married patients, and carers had significantly higher levels of income, formal support and quality of life, and were more satisfied with existing care than the usual-care group carers. Patients were followed up for 12 months and the analysis was conducted from a societal perspective.

The study includes a simple comparison of the costs associated with each type of care and a range of different outcomes which are reported separately. Patients were followed up for 12 months, with assessments at baseline and at 6 and 12 months. The analysis was conducted from a societal perspective.

Summary of effectiveness data The outcomes that were measured in the study included the following from the carer viewpoint: carer burden, quality of life and satisfaction. Carer recipient outcomes that were measured included cognitive function, functional capacity and behavioural symptoms. At 12 months, carer satisfaction was statistically significantly different, in favour of the day-care group. No significant differences were found when comparing the other outcomes.

Summary of resource use and cost data Resource-use and unit-cost data were obtained directly from actual sources and were reported separately. The resource-use data were collected prospectively and concurrently with effectiveness data. Unit-cost data were collected from the local health authority (e.g. ambulance costs), local government (e.g. to proxy private transport costs) and market prices (e.g. medications and public transport). Carer time was valued at the cost of an auxiliary nurse, for the nursing time only, and a quarter of this time was spent supervising, or relaxing with, the patient. Productivity losses were valued as perceived loss of net earnings, adjusted for valuations of carer time in leisure/supervision.

The mean monthly cost of day care exceeded that of community care, at €1755 compared with €1238 (cost date 1995), primarily owing to the cost of day care and the greater use of health and social care for the day-care group. Costs of informal care and formal support services were higher for the community-care group, but the differences were not statistically significant.

Summary of cost-effectiveness data Costs and outcomes were not combined. Overall, day care was associated with greater carer satisfaction, similar benefits in terms of all other outcomes and higher patient costs. Therefore, the decision-maker would need to decide whether the outcomes were worth the extra costs of psychogeriatric day care. The authors undertook a subgroup analysis to compare outcomes for incident and prevalent cases; however, no statistically significant differences were found. A further subgroup analysis found that the cost associated with the day-care service was significantly related to care recipient outcomes, including cognitive status and functional status. For the community-care group, it was found that carer burden was positively associated with cost.

Comments It is uncertain whether the results from this study are transferable to the UK setting, since it is not clear whether the sample is representative of the UK population. Findings from the original sample ($n = 96$) were not reported and it is unclear how this may have affected the findings.

Review of Baumgarten and colleagues (2002)[35] Adult day care for the frail elderly: outcomes, satisfaction and cost

Overview This study evaluated the cost consequences of a day-care centre compared with usual care, in a community setting in Canada. Day care involved a broad range of group-based activities, including education, support groups, exercise groups and carer counselling provided in some study sites. Usual care involved a waiting-list control group, and typical health or social services use was tracked. In practice, the usual-care group did not use day care over the study period. The study is based on a single RCT and included carers of older (mean age 77 years) care recipients who were referred to day centres. Patients were followed up for 3 months and the analysis was conducted from the health and social care provider perspective.

Summary of effectiveness data The outcomes that were measured in the study included the Carer Burden Inventory. Care recipient outcomes that were measured included Depression: CES-D; Anxiety: State-Trait Anxiety Inventory (STAI), MMSE and the Older Americans Research and Service (OARS) Multidimensional Functional Assessment Questionnaire (Duke University Center for the Study of Aging and Human Development, 1978). For care recipient anxiety and depression assessments, only care recipients without cognitive impairment contributed data. For functional assessment, carers reported data for cognitively impaired care recipients. At 3 months, no statistically significant differences between the two groups were detected in terms of outcomes.

Summary of resource use and cost data Resource-use data were obtained from the RCT and unit-cost data from actual sources, the published literature and expert opinion. The resource-use data were collected prospectively and concurrently with effectiveness data. Resources used included hospital care, day care, physician care, home care services (e.g. home help, visiting nurse, meals on wheels), outpatient professional services (e.g. physiotherapy, social work), day hospital, long-term care (e.g. respite care, rehabilitation, nursing home) and transportation. The median number of day-care visits was ten throughout the 13-week study period. Full details of the resources used and unit costs were not provided. In terms of total costs, there were no statistically significant differences between the two groups, or in any cost subcategory. At 3 months the mean cost per care recipient was Can$2935 (SD $5536, *n* unclear) (1991) for the day-care group and Can$2138 (SD $4530, *n* unclear) for the usual-care group.

Summary of cost-effectiveness data Costs and outcomes were not combined. The outcomes associated with day care were similar to those in the usual-care group. Day care was associated with higher costs than those of the usual-care group, but the difference was not statistically significant. In summary, day care appears to be more costly and potentially to provide more benefits; however, neither costs nor effects differed significantly across groups. Subgroup analysis of high and low attenders failed to detect statistically significant differences in clinical or demographic characteristics.

Comments The authors note that despite easy accessibility to day care, significant proportions of the intervention group used no (9%) or low (66%) levels of day care. Exploration of baseline characteristics of high and low attendees revealed that low attendees were slightly younger, more likely to be female, less likely to have a spouse caregiver, less impaired cognitively and less functionally impaired, have lower depression levels and were slightly more anxious than high attendees. ('Low' attendees were defined as those who attended the day centre fewer than 13 times over the 13-week study period. 'High' attendees attended the centre 13 times or more over the study period.) Caregivers of low attendees were much more likely to have lower mean burden scores, to be slightly younger and slightly more likely to be male, than caregivers of higher attenders. The description of the types of service used by the usual-care group was limited and resource use was not described separately from costs, and this impacts on the transferability of the findings to the UK setting.

Review of Donaldson and Gregson (1989)[40,104] Prolonging life at home: what is the cost?

Overview This study evaluated the cost-effectiveness of FSU day care compared with usual care, in a community setting in the UK. Day care could include evening care and special occasional residential care to suit carer interests and a range of community services to which the usual-care group also had access, but excluding FSU. The study is based on a single quasi-experimental design with matched concurrent controls and the care recipients were mentally infirm elders. The study covered a 12-month time-frame and was undertaken from the health and social care perspective.

Summary of effectiveness data The outcomes measured from the carer viewpoint included adverse effects of caring (health, job, hobbies, having visitors, normal life, resting, other), opportunity cost of caring (enjoyment of retirement, holidays, social life, looking after family), benefits of day care (freedom/relaxation, good for care recipient, improves care recipient behaviour), benefits of respite care (represents break), benefits of voluntary help (freedom, support) and financial costs of caring (numbers reporting additional costs incurred for ten categories). Carer recipient outcomes that were measured included the Crichton Royal Behavioural Rating Scale (CRBRS) (eight dimensions, scored 0–31; higher score denotes lower ability) assessed at baseline only, and days in the community.

The groups showed no difference in terms of time spent caring for dependent relatives, but the effects on carers were different. Care recipients in the day-care group spent significantly more days in the community compared with usual care. Carers in the day-care group felt that their abilities to have visitors and to rest were more adversely affected by caring compared with those using usual care, and this was statistically significant. In addition, significantly more carers in the day-care group benefited from freedom/relaxation than did usual-care group of carers, and felt that day care improved the care recipient's daytime behaviour. There were no statistically significant differences in the remaining outcomes, including the opportunity cost of caring, perceived financial costs of caring and service benefits.

It should be noted that the authors thought that the outcome measurement for carers and their relatives was the weakest area of the study. Although an attempt was made to match groups, selection bias is possible, thus potentially undermining the results. It is unclear why care recipients receiving FSU care tended to spend more time in the community and yet their carers were more likely to feel that their social life (in terms of their abilities to have visitors and rest) was adversely effected. This was something that was not explored in the study, but may be evidence of the trade-off that carers can make to extend the care of their relative in the community.

Summary of resource use and cost data Resource-use and unit-cost data were obtained from the actual source, including local authority client data file on social services used, frequency and periods of use, health authority medical records on inpatient and day care, and records on client use kept by voluntary agencies. The resource-use data were collected retrospectively and concurrently with effectiveness data. The cost per person per day maintained in the community was £6.62 ($n = 35$) (1986 prices) for the day-care group and £2.34 ($n = 67$) for the usual-care group. The additional cost per additional day spent in the community was £18.80.

Summary of cost-effectiveness data Although the FSU resulted in costs that were three times those of usual-care, it also resulted in, on average, 172 days more in the community than did the usual-care group at a cost of £18.80 per person per extra day, thus saving on, for example, costly long-term care bed usage (i.e. 172 days at a cost of £46 per person per day in a long-term hospital bed). If life at home is preferable to long-term care, FSU can be judged to be cost-effective. Based on the figures, if 30% of people in usual care died while living at home and the remainder were split among long-term hospital care, local authority residential care and private nursing home care, this would result in a cost of £18.70 per person per day.

Comments The study was not randomised, but an attempt was made to avoid selection bias by matching groups. However, important differences between the two groups cannot be ruled out. It is worth noting that a number of people in each group also received respite from local authority day-care services and hospital services.

Review of Gaugler and colleagues (2003)[102,114,115] Evaluating community-based programs for dementia caregivers: the cost implications of adult day services

Overview This study evaluated the cost-effectiveness of US adult day care provided in the community and compared with usual care (see the section 'Adult day care', p. 26). Day care involved providing out of home services, including therapeutic services, health monitoring, socialising, transport and medical care. Usual care excluded the use of day-care services. The evidence was based on the trial by Zarit and colleagues,[102] a quasi-experimental study with matched concurrent controls, and the analysis relies on a subsample of non-randomised effectiveness and resource-use data. The study population included family carers of patients who had dementia, who had not previously used adult day care and had not used more than 8 hours of formal (paid) services per week. However, the day-care group had to use care at least twice a week. Participants who were discharged from day-care services or who were institutionalised were also excluded from the analysis. The study covered a 12-month time-frame and an interim analysis was undertaken at 3 months. The analysis was undertaken from the carer perspective.

Summary of effectiveness data Carer outcomes included in the economic analysis were the Role Overload Scale and the CES-D. Six measures were used in the primary study.[102] Only two of these measures (carer overload and depression) were statistically significantly different from usual care at 12 months.

Summary of resource use and cost data Resource-use and cost data were not reported fully. The resource-use data were collected prospectively and concurrently with effectiveness data. Resource-use data collected included day care, hours of formal (paid) support (home health care), hours of informal support (time spent by primary and secondary carers) and changes in productivity.

At 12 months the total cost per day of day care was US$47.10 (1993), compared with US$41.15 for usual care ($p < 0.05$). The incremental daily cost of day care over usual care was US$5.95. The daily cost of day care (carer charge) was US$17.26. There were statistically significant differences for all of the following costs: daily formal service costs for day care were US$2.01 compared with usual care US$0.41, secondary carer costs for day care were US$6.12 compared with US$4.08 for usual care, primary care costs were US$32.42 for day care compared with US$35.61 for usual care ($p < 0.05$) and employment costs were US$0.30 for day care compared with US$1.05 for usual care ($p < 0.05$).

Summary of cost-effectiveness data The changes in scores for carer role overload and carer depression were reported in incremental cost-effectiveness ratios. Day care was reported to be more costly and potentially also more effective. At 12 months, the additional daily cost of day care was US$4.51 and $2.20 to alleviate role overload and depression by one unit, respectively. The authors suggested that adult day services reduce carer overload and depression over time, with daily costs falling over the 12-month time-frame.

Comments No uncertainty around the cost-effectiveness estimate was expressed. Findings were not reported on an ITT basis. The adjustment to costs and outcomes allowed both for known baseline differences and for factors known to influence attrition. The economic evaluation was confined to costs incurred as out-of-pocket expenses for the carer, but these excluded health and social service use. The implications for health and social care providers are therefore unclear.

Review of Hedrick and colleagues (1993)[93]

Summary and discussion of methods and results of the adult day health care evaluation study

Overview This study evaluated the CCA of ADHC compared with usual care, in a community setting in the USA. The effectiveness study results are reported in a number of articles[93,106–112] and further details of this study are provided in the section 'Adult day care' (p. 26). The study was based on an RCT which compared the Veterans Affairs Adult Day Health Care Centre (DC-V) to usual care, as well as a non-randomised, prospective cohort study (contract ADHC: DC-C). The study included frail older people at high risk of nursing home placement and their carers. Patients included in the study used healthcare services before the study, and 82% were dependent in at least one of the basic ADL, with an average of 2.4 dependencies. Use of the service was quite intensive, with patient schedules being on average 4–8 hours per day for 1–5 days per week. VA ADHC offered included monitoring of complex medication and other treatments, occupational/physical and recreational therapy, personal care and social services. Concurrent use of home-care services for those using DC-V was prohibited by VA regulations. The study covered a 12-month time-frame, with assessments taking place at baseline, and 3, 6 and 12 months. The analysis was undertaken from the healthcare provider perspective. An evaluation was also conducted from the societal perspective, but this is not reported here.

Summary of effectiveness data Carer outcomes included the Psychological Distress Scale (PDS), life satisfaction, ADHC Social Support Scale, Caregiver Impact Scale, perceived seriousness of behaviour problems, caregiver versions of ADHC Patient Satisfaction Questionnaire (PSQ) and ADHC Long-Term Care Patient Satisfaction Questionnaire (LTC PSQ). Care recipient outcomes included survival, SIP, PDS, ADHC PSQ, LTC PSQ, cognitive status and health perceptions.

At 12 months, there were no significant differences between carer outcomes in the DC-V group, the usual care group or the contract adult day care group on physical and psychosocial health status outcomes. However, there were some differences in satisfaction levels: compared with VA ADHC and contract ADHC, the usual-care group carers were less satisfied with usual care provided in nursing homes or ambulatory care clinics, but equally satisfied with home care. Contract ADHC carers were less satisfied with care than were DC-V carers. In terms of care recipient outcomes, at 12 months, there were no statistically significant differences in terms of survival, SIP, psychological distress, cognitive status or health perceptions for DC-V compared with usual care. Contract ADHC patients were significantly more impaired in physical function than those in the DC-V group, even after controlling for baseline differences. No other significant differences in care recipient health status were found. Satisfaction with care was significantly higher for both DC-V groups and contract ADHC than for usual care recipients in nursing homes; however, care recipients in clinics or home care were as satisfied with their care as were those receiving either type of day care.

Summary of resource use and cost data The resource-use data were collected prospectively and concurrently with effectiveness data. Resource-use data collected included institutional care (nursing home, hospital), ambulatory care, day care (labour, 'case finder' costs, transport, administration, overheads), laboratory tests, outpatient pharmacy, special supplies/devices, prosthetics, home care, transportation, home living costs and carer time. The actual resource use was not specified. Unit costs were obtained from the actual source, the published literature and national databases. Additional details of the methods for assessing utilisation and cost of care were provided in Chapko and colleagues.[108]

Patients assigned to DC-V attended VA day care for an average of 45.3 days over 12 months (range 0–246), with 15% having no visits. Mean days' attendance for DC-C patients was 63.8 (range not reported), with 8% having no visits. Usual-care patients used no VA day care, but did attend non-VA day care for an average of 3.6 days annually (for DC-V and DC-C the corresponding figures were 1.6 and 1.5, respectively); between-group differences were not significant.

The mean total (VA and non-VA services) annual costs of care were DC-V US$18,582 (1989 prices), contract ADHC US$18,797 and usual care US$15,931. The cost of contract ADHC was similar to that of DC-V (mean incremental cost of care, adjusted for baseline differences, US$617, 95% CI $–2083 to 3715) and higher than that of the usual-care group (US$2872, 95% CI $–784 to 5684). The cost per day of DC-V (contract ADHC) ranged from US$48 (US$36) to US$103 (US$43). Despite the differences in daily costs, the adjusted mean total cost for attending day care was only US$18 lower at contract ADHC sites, owing to a higher mean number of days spent at contract ADHC (63.8 days) compared with DC-V (45.3 days). DC-V services were substituted for ambulatory services (e.g. clinic visits, home visits), but these cost savings did not offset the additional costs of day care.

Summary of cost-effectiveness data Costs were not combined with outcomes. However, DC-V was associated with higher overall costs and no apparent incremental benefits compared with usual care.

Subgroup analysis was undertaken, based on findings from previous published studies. DC-V was compared with usual care for each outcome using the Student's *t*-test. Unmarried patients, those not hospitalised at enrolment and those very satisfied with social support had significantly better 12-month health outcomes than patients in the control group. Mean annual costs of DC-V were similar to those of usual care for one of the four DC-V sites, the subgroup of patients at high risk of nursing home admission and the subgroup of patients at high risk of hospital admission. Mean annual DC-V costs for the subgroup of high users of ambulatory services were lower than those for similar individuals receiving usual care. Mean annual costs of DC-V were higher than those of usual care for patients with higher levels of physical impairment and for those with lower levels of behavioural problems.

The authors undertook a form of sensitivity analysis by reanalysing the original cost data from the DC-V versus usual care comparison, which was based on a combination of local and national costs, in an analysis based on purely facility-specific costs and an analysis based on purely VA national costs.[159] Based on these reanalyses for individual services, the magnitude and the *p*-values of the differences between costs in ADHC and usual care did not change substantially, compared with the original cost analysis; however, at the 5% level they were no longer significant. In the original analysis, the difference was marginally significant at the 5% level ($p = 0.048$), but non-significant when the data were reanalysed using facility costs ($p = 0.073$) or national average costs ($p = 0.052$). Regression analysis showed that hospital costs alone accounted for 70% of the variation in total costs. Hospital, nursing home, clinic and ADHC in combination accounted for 98% of the variation in total cost per patient.

Comments The evidence suggests that DC-V costs more than usual care, with no apparent incremental benefit to patients or carers. However, the difference in costs bordered on statistical significance at the 5% level, and varied according to whether local or national unit costs were used.[159] The evidence regarding the costs and outcomes associated with contract ADHC is less reliable, given that the data are not based on an RCT. Adult day care could potentially reduce costs if it were targeted at those likely to be high users of ambulatory care. Findings relate to carers of frail older people at risk of nursing home placement and should be interpreted accordingly. Usual care delivered in this trial in the USA may not be transferable to the UK.

Measuring and valuing health outcomes

Table 35 in Appendix 4 reports the outcomes that were measured and valued in the effectiveness and cost-effectiveness studies included in the review.

Respite care programme costs

Besides the economic evaluations, three sources of respite care cost information were found that included costs.[45,160,161] Allen and Wrege[160] assessed the cost of an American community-based day-care centre that was designed for people with Alzheimer's disease and related disorders. The salary of three full-time staff (supplemented with input from community volunteers and student interns) accounted for 72% of the programme costs. The ratio of staff to clients was 1:5 to 1:3, depending on client acuity changes. The rest of the costs were accounted for by meals on wheels (11%), miscellaneous (6%), tax (5%), crafts and activities (3%), and 1% on each of the following: postage, refreshments and travel. The total cost per client per day was US $31.50 (1989 prices).

Curtis and Netten[45] compiled unit costs of health and social care. These costs consider the value of all resources used to provide the services, such as cost of capital (buildings, oncosts, land and equipment and durables) and revenue costs (salary and other revenue costs, capital charges and agency overheads, as well as occupancy rates), and are therefore comprehensive. These costs are service specific, and any out-of-pocket costs to access such services and any loss of income for carers are not included and would need to be added in if the full set of costs were to be considered. Three different types of day care costs are provided, all of which are informed by different studies and none of which relates to a specific age group of people, with the exception of local authority day care for older people. The mean cost of a day-care session ranges from £15 for voluntary sector care to £27 for local authority day care, where a session is a morning, an afternoon or an evening at the day-care facility (price year 2004/05; schemata 1.7, 1.6). The mean daily cost of day care for older people provided by the NHS is £119 (price year 2003/04).[44] There are few published data on the costs of institutional respite for older people, particularly for local authority or independent sector provision. For all types of client, elective NHS institutional respite costs on average £1451 for a 5-day stay, whereas for emergency (non-elective) NHS institutional respite, the corresponding cost is £2041, with a typical average stay of 9 days (price year 2003/04). Although some voluntary organisations report client charges for in-home respite, the costs of this type of respite are less clear. Using prices for home care workers as an approximation, the mean hourly cost of weekday in-home respite would range from £10 for independent sector provision to £15 for local authority provision (price year 2004/05; schemata 10.6, 10.5), with an average cost of all local authority home care, including local authority and independent provision, of £14 per hour.[45] These costs should be inflated by 30% for evenings, by 50% for Saturday services and by 100% for Sunday services. The total annual respite expenditure by the Personal Social Services on day care for older people is £320 million (2004/05).[46] No annual respite expenditure has been found relating to other providers.

Murman and colleagues[161] compared the healthcare utilisation and direct costs of three degenerative dementias: Alzheimer's disease, dementia with Parkinsonism and Huntington's disease. A survey was conducted to collect data on the use of long-term care (i.e. nursing home care or foster home care), hospital care and paid home health care. It is not clear what services were included in home health care, but it seems likely that this would include services that would match the definitions of respite care used in this review. Unit costs were obtained from the published literature and Medicare and Medicaid charges (price year: 1993). Costs were adjusted for differences in duration of symptoms, that is the time from first diagnosis of dementia to the survey, given the expectation that the costs would increase the longer the duration of illness. Based on these, the annual, direct mean costs were US$9000 for those with Alzheimer's disease and those with Huntington's disease, whereas the cost was US$15,000 for those with dementia with Parkinsonism, the latter cost being significantly greater than the costs for the other two groups. Adjusted long-term costs were significantly higher for those with dementia with Parkinsonism; however, adjusted direct costs associated with hospital care and paid home healthcare did not significantly differ across groups. In all groups, over 50% of the total direct costs were due to long-term care costs.

Excluded studies

The information officer searched the published literature to obtain economics data for the review, and these encompassed data on health-related quality of life, the cost of respite care and economic evaluations (see Appendix 3). The searches retrieved 12,927 references, of which 45 studies were marked as potential papers for inclusion in the economic review, which is about three in 1000 of the records in the EndNote library.

Twenty-nine papers were excluded from the economic evaluation review since they did not meet all of the following criteria: conforming to the definition of respite care, inclusion of frail older recipients (aged 65 years or older), comparison of two or more programmes, and assessment of both costs and outcomes. Details of all the evaluations excluded from the review are reported in Appendix 6 (*Table 39*). Two studies did not evaluate respite care,[162,163] evaluating a hospital-based palliative support service, the aim of which was to improve palliation and extend time at home, and the impact of providing radiotherapy on an outpatient (rather than an inpatient) basis, respectively. Whether the study population was frail elderly people was unclear in five studies,[164–168] and clearly not the case in three studies.[163,169,170] Twelve studies were either descriptive, think pieces or methodological, rather than economic evaluations.[98,160,163,164,166,168–174] Costs were not assessed in ten studies[98,119,164,165,167,168,171,174–176] and only partially assessed in two studies.[166,172] Benefits in terms of carer and/or patient outcomes were not assessed in 11 studies.[98,160,165,166,168,171–174,176,177]

In addition, three papers were excluded from the main review since they included an evaluation of multidimensional support packages, and the study design did not allow the impact of the respite care aspect of the programmes to be separated out (see the section ‘Changes to the protocol’, p. 11).[141,147,178]

Besides these studies, three studies included economic evaluations with no assessment of carer outcomes.[153,154,179,180]

Multidimensional support programmes

Three studies evaluated respite care as part of a multidimensional support programme.[140,146,178] Although these studies do not form the mainstay of the review, they have been summarised in the narrative reviews since they more closely reflect usual practice in the UK (‘community care packages’) and findings from these studies may be useful in informing policy for these interventions. Details of the corresponding effectiveness studies for Drummond[140] and Pattie[146] are given in *Table 15* (p. 58) and in Appendix 6 (*Table 38*).

Drummond and colleagues[140] undertook a CUA of multidimensional carer support compared with standard, community care nursing. The study was based on a small RCT ($n = 30$ in each group) in Canada, the length of follow-up was 6 months, and the analysis took a health and social care perspective. The resources used to provide the programmes included nursing visits, respite care, physician visits, homemaker services, day programmes, overnight respite, social worker visits, other paid help and acute hospital care. Some resource-use data were presented in Mohide[139] and unit costs were reported separately.[140] Outcome data were collected for anxiety [state-anxiety portion of the STAI, depression (CES-D) and CQLI]. The CQLI was used to calculate QALYs. No statistically significant differences in costs or consequences were found across the groups, but observed differences suggested that the costs and consequences associated with the support package were higher than for standard care. The additional (incremental) cost per QALY gained from providing day care as opposed to usual care was Can$20,000 or £12,400 (1991 prices).

Pattie and Moxon[146] undertook a CCA of multidimensional carer support comparing three groups in the UK, and taking a health and social care perspective. One group received day care, domiciliary care and continuing care (including respite and holiday relief beds) as part of the local mental health services, for older people; this group and a control group also received local mental health services, and a third group received a variety of services other than mental healthcare and were called the vulnerable group. ‘Subjective impressions’ were that the multidimensional carer support package was associated with improved quality of life and greater independence for patients. In terms of costs, a profile of resource use over 1 year was calculated for each person. The costs per person per year were £6558, £7493 and £2768 (1987 prices) for the intervention, control and vulnerable groups, respectively. Both sets of calculations were described as ‘a crude first attempt’, since the authors believed that considerable development of methods was required to make adequate judgements about cost-effectiveness of the services.

Shulman and Cohen[178] undertook a CUA of multidimensional carer support compared with standard, community care nursing in the USA. A societal perspective was taken, calculating health and social care costs and the cost of informal carer time, based on a synthesis of data obtained from four papers.[140,181–183] Outcomes data for the QALY calculations were taken from Drummond.[140] The incremental cost per patient per year was US$1110 (1988) and the estimate of cost per QALY was US$10,090 per patient per year. The authors undertook a univariate sensitivity analysis, varying the QALYs gained or the incremental cost per patient per year, and this gave a cost–utility ratio of between US$3333 and 28,571.

Economic evaluations with no assessment of carer outcomes

Jonsson[179] undertook a brief review of the cost of illness of dementia patients. Based on a Nordic study in which the costs of care were calculated for 272 Alzheimer’s disease patients (the age of the patients was not provided), 5000 subjects received day care at an annual cost of SEK390 million (price year 2000). Data for the study were collected via a survey at baseline, 6 months and 12 months.

Wan and colleagues[154] and Weissert and colleagues[153] report on the same randomised trial of geriatric day care and homemaker services. The study assessed the effects on patient outcomes and costs. Outcomes were compared for day care, homemaker and combined service groups in terms of sociodemographic factors, psychosocial functioning, physical health status and prognostic measures, as well as health services use. Six types of services were included: (1) skilled nursing facilities, (2) inpatient hospital days, home health care, (3) hospital outpatient services, (4, 5) experimental services (day care or homemaker services), and (6) other ambulatory care.

At the end of the study, day-care patients showed no benefits in physical functioning ability at the end of the study compared with the homemaker group. Institutionalisation in skilled nursing facilities was lower for the day-care group than for the homemaker group, but factors other than the treatment variable explained most of the variance. It appears that life was extended for some day-care patients. The cost of the new services, as well as the cost of existing Medicare services and the cost of the day-care group services, averaged US$6501 (price year unclear) per patient per year, compared with US$3809 for the homemaker group, a difference of US$2692 or 71%, even though hospital and nursing home costs were lower in the day-care group. The mean daily cost of day care was US$52.

The Wimo study,[180] based on the Wimo effectiveness study,[155] compared the cost-effectiveness of day care with a control group who were on the waiting list for day care. Day care was associated with lower costs and less deterioration in the utility indices, and therefore was expected to be cost-effective. As the authors state:

> "although the trend and the sub-group results indicated that day care was cheaper and improved quality of life, the main result was that differences were not significant and the assumption that day care is more cost-effective than a caring organisation without day care was not confirmed".[180]

Economic model

The review of the effectiveness and cost-effectiveness evidence literature demonstrates that there is a considerable amount of information which, potentially, could be synthesised within an economic model. Economic models have a number of benefits. They provide a quantitative framework for synthesising information from difference sources. They provide a mechanism for linking intermediate outcomes (such as changes in carer depression levels) associated with different respite care programmes to long-term outcomes, such as QALYs. Economic models can also be used to enhance the transferability of findings, allowing the analyst to adapt data from one setting to another. This may be particularly useful since the effectiveness and cost-effectiveness reviews show that the large majority of evaluations were based on respite care programmes located outside the UK and may not, therefore, present an accurate picture of provision in the UK. Typically, there is considerable uncertainty associated with the findings from individual studies. Combining data from different studies enhances explanatory power. In addition, study findings from the models may be tested, using sensitivity analysis, to examine the robustness of findings to variation and uncertainty in the model inputs and to quantify this. All of this information may be used as one form of evidence for the decision-maker to consider when judging the value for money of respite care.

As no published cost-effectiveness model of respite care was identified by the review, a *de novo* model would need to be designed, data permitting. The reviewers therefore explored the potential for devising a model that could combine changes in costs with changes in outcomes (preferably quality of life) attributable to respite services.

Evidence on outcomes

As no effectiveness data were found that could be reliably transferred to the current UK setting, the authors considered whether it would be possible to estimate the effect size that a study of respite would need to demonstrate to produce an 'acceptable' cost-effectiveness ratio, for example in terms of the incremental cost per QALY. This would require linking utility values with a measure of carer benefit.

Utility values from preference-based indices of quality of life are useful in that they can be used to aggregate multiple outcomes into a single numeraire. The literature review failed to find any cost-effectiveness studies that met the inclusion criteria and in which health outcomes were linked to utility values. However, one study of a multidimensional support package[78] did generate utilities for use in QALYs, based on data from the CQLI. In the CQLI, caregiver well-being states were based on five dimensions: two social (amount of time to socialise with the family and friends, and quality of the interpersonal friendship between the caregiver and the care recipient), two physical (degree of physical wellness and energy, and adequacy of amount of sleep) and one emotional (degree of happiness and freedom from anxiety and frustration). Each dimension could be described at one of a choice of four levels, from, for example, 'almost always' to 'rarely'. Four standardised hypothetical health states were developed, including the ideal caregiver well-being (reference state where the caregiver was almost always well on each of the dimensions), mild, moderate and severe caregiver well-being states. Twenty-nine family caregivers and ten relatives of well older people described their state of well-being, relative to the standardised states, over the past fortnight. The time trade-off (TTO) technique was used to value their preferences for the caregiver well-being states (see Glossary). The respondents were offered a series of trade-offs between paired states. However, the study by Mohide[78] and the associated economic evaluation[140] were excluded from the main review because the impact of respite care could not be differentiated from other support services provided within the package (see the sections 'Studies excluded from the review', p. 57, and 'Multidimensional support programmes', p. 70). The CQLI was not used in any other study included in the review and the Mohide study[78] did not link the CQLI directly to any other outcome measure reported by the included studies. A further limitation was that the Mohide study[78] used carer preferences for deriving utilities, whereas societal values are the preferred method.[53] However, it is not uncommon to use proxy values such as patient or caregiver values. In addition, the preferences related to Canadian carers, and these may not be transferable to carers in other countries because the subjective preferences that inform utilities may be influenced by contextual effects.[184] The usefulness of the available utility values was diminished still further because only six utility values were generated, namely those for particular carer well-being states (mild, moderate, severe) and those for those carers looking after care recipients with particular health states (cognitive impairment, physical impairment, well older people).

Evidence on resource use

Although the review identified five economic evaluations, only one was set in the UK and this evaluation took place in the late 1980s.[104] The difficulties in transferring findings from economic evaluations from one setting to another are well documented.[185,186] In particular, the transferability of economic findings is contingent upon a number of factors, including the availability of alternative interventions and the comparability of treatment pathways, relative prices, incentives for providers and demographic or epidemiological characteristics of the study population.[53] Special statistical techniques, such as multilevel modelling[187] and metaregression,[188] have been used to address these difficulties. However, these approaches are predicated on the existence of both robust effectiveness data and adequate local resource-use data. In the absence of relevant published data, expert opinion could be sought to fill in the gaps. Therefore, the ERG was asked to complete a short questionnaire on resource use (Appendix 2). However, the small sample size of the ERG and the non-randomised recruitment process meant that findings were insufficiently robust directly to inform a model.

Conclusion

Given the paucity of data, it was concluded that it would not be useful to construct an economic model at this stage. However, such a model would be useful in planning future trials should the present recommendations be taken forward (see Chapter 8). The options being proposed for comparison in the trial could be costed in rough terms and QALYs for the possible outcomes obtained from an expert panel, subject to obtaining ethical approval. Then, an estimate could be made of the clinical effect size required to generate an acceptable cost-effectiveness ratio.

Chapter 7

Discussion

What the literature found

The literature reviewed in this report suggests that respite for carers of frail older people generally has a small effect upon carer burden and carer mental or physical health. There is tentative evidence that some carers benefit more than others. However, carer satisfaction levels for all types of respite are generally high and carers appear to be more satisfied with respite than with usual care. The study found no robust evidence that respite either benefits or adversely affects care recipients, or that it delays entry to residential care. Economic evidence suggests that day care is at least as costly as, and may be considerably 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.

What the literature means

Based on the findings of the review, what implications for policy and practice can be drawn? Can one be confident that respite for carers of frail older people offers small and variable benefits? Should UK government policy, which takes a positive attitude towards respite provision, be revised? Should providers rethink the way in which they offer carers support?

It is the authors' view that the existing evidence base does not allow any firm conclusions on effectiveness or cost-effectiveness to be drawn. Regrettably, much of the existing literature is unable to inform UK policy and practice. There are four reasons for this:

- Where better quality evidence exists, the implications for the UK are unclear.
- There are serious problems with the methodological quality of many studies underpinning the evidence base.
- Even if methodological problems were addressed, trials of respite for this participant group face considerable practical challenges.
- Important gaps in the evidence base remain.

These issues are addressed in more detail below.

Lessons from the 'better quality' evidence

Where better quality evidence exists, the implications for the UK are unclear. There were three better quality studies[35,93,101] (*Table 36*, Appendix 5), all set in North America and all examining day care for older people. Key messages from these studies were that day care in general neither benefited nor harmed the frail older people studied. Just one study found that day care offered carers a significant benefit.[101] Two of the three studies also examined costs: day care was found to be more expensive than usual care, but the importance of this difference was unclear. Neither study reported a summary measure of cost-effectiveness.[35,93]

Are these key messages informative for UK policy and practice? There are four reasons why caution should be exercised. First, regarding the intervention itself, referral practice, care pathways and access issues may differ radically between settings. This means that the study participants may be quite different from those who would receive respite in the UK, and responses may therefore also differ. Furthermore, the intervention may be quite different, perhaps less well resourced or less frequent or offering different services, delivered by different types of staff. Different resource use in the process of service provision will also affect costs and cost-effectiveness, as will differences in price or unit cost.

Secondly, for similar reasons, the comparator of 'usual care' in other settings may be unrepresentative of usual care in the UK. If studies have evaluated the impact of adding respite to usual care, the baseline or starting point against which respite is assessed by definition determines its added value. Study descriptions of usual care were rarely adequate: for example, the descriptions of referral routes, eligibility criteria for normal care and external environments were not clearly specified. Moreover, evidence on what constitutes usual care in the UK – and this might be expected to vary considerably across the country – is sparse.

Thirdly, the external context in which respite is offered may also differ among settings. Availability of information, of other sources of formal or informal support, the existence of financial barriers and eligibility criteria will clearly affect uptake and access, which will in turn influence effectiveness and cost-effectiveness.

Lastly, none of the studies was designed to detect a difference in carer outcomes. Only one study estimated in advance the sample size needed to detect a difference in outcomes, but this was based on a measure of care recipient health.[93] This means that, even for these better quality studies, one cannot be confident of the effectiveness evidence regarding carer benefit.

Lessons from the ‘poorer quality’ evidence

There are serious problems with the methodological quality of many studies underpinning the evidence base (see the section ‘Assessment of study quality’, p. 53). For example, examples were found from the included studies of inconsistent or inadequate reporting of the methods, intervention, comparator and participant characteristics, uptake (of the intervention and of other formal or informal services), outcome results, adverse effects and withdrawal rates. In many cases, the only valid conclusion to be drawn from poorer quality studies is that they do not show whether respite is effective or not. However, many of these quality concerns can be easily remedied in future research. For example, randomised studies could be conducted in accordance with Consolidated Standards on Reporting Trials (CONSORT) guidelines.[189] Non-randomised studies could prespecify how differences in baseline characteristics between groups will be analysed. For any type of study, primary and secondary outcomes could be prespecified and outcomes assessors blinded, so that they remain unaware of allocation group. Study findings could be analysed on an ITT basis, reported clearly and comprehensively.

Lessons from the practical problems faced by trials

Even if these methodological problems were to be addressed, trials of respite for this participant group may face considerable practical challenges.

First, studies of older people present particular challenges.[190] For example, there may be problems recruiting frail older people [94,124] and studies may also suffer high attrition rates.[76,93,101,124] Frail older people are a heterogeneous group, varying in health status as well as in ethnic, cultural and social characteristics. Co-morbidity is common among older people, which makes study of a particular disease area more complex.[190] Moreover, many older people, whose carers are eligible for respite, are likely to have dementia. This makes recruitment to trials and securing of informed consent more problematic. Secondly, carers’ characteristics may influence the effectiveness of respite. For example, respite may benefit male carers more or less than female carers; the same may be true of carers from different ethnic groups. The systematic investigation of these differences could help to inform service provision. Carers may also suffer guilt or present with psychological barriers that hamper their ability to accept support. For example, the study by Lawton and co-authors[33] found that:

> “Most of the project participants did not know what respite service was and initially did not view it as a real alternative … Very few understood respite as a means of preventing or mitigating their ongoing burdens and strains. Rather, most thought of it as a service to be used only when they could no longer manage at all.”

The researchers identified a subgroup of non-users with high levels of unmet need, but who appeared to be very reluctant to accept offers of support.[33] This finding is supported by other evidence which suggests that ‘engulfed’ carers find it very difficult to accept help.[23] In other words, the very factor that gives rise to a need for support also impairs the ability to access it. There is some evidence that respite may be particularly beneficial for these carers.[97] Thirdly, the relationship between the older person and their carer presents a particular challenge for outcome assessment and may also affect uptake or recruitment. Adult child carers may have different needs and responses to those of spouse carers.[117] More importantly, the impact of respite upon the dyad’s relationship, although clearly critical to the effectiveness of the service, is difficult to assess: the ERG spoke of the challenge to ‘square the circle’, providing tailored person-centred support to older people *and* their carers (see Appendix 1). Lastly, respite itself is a complex and heterogeneous intervention, with structural and process issues key in determining acceptability and quality. For example, one study found that volunteer respite staff were unable to cope with the needs of the frail older people.[124] These issues are discussed in further detail below.

What do we still need to know?

Important gaps in the evidence base remain. There is a lack of UK-relevant, good-quality, controlled evaluations for all types of respite care and no economic evidence for any type of respite other than day care. The most recent effectiveness evidence identified relates to 2003 and most of the higher quality evidence relates to day care in North America. The only economic evidence from the UK was published in 1989. Many existing UK respite services have not yet been subject to a controlled evaluation. These include the services provided by the Crossroads organisation,[191] the Macmillan carers schemes[84] and the Scottish host family respite service.[91]

No controlled study was found that explored the impact of ethnicity, socio-economic status, age or gender upon carer or care recipient outcomes. It is possible that economic and cultural changes in society could affect the uptake of day care by certain types of carer. For example, employed adult child carers may have to rely on the provision of adult day care. There has been an enormous growth in adult day care in the USA,[98,99] but it is less clear how adult day care has developed in the UK or how important the role of day care is in supporting carers in their economic role.

All controlled studies included in this review involved at least some people with cognitive impairment. This makes it difficult to discern the differential impact of care recipient impairments upon the respite experience for carers. For example, do carers of people with no cognitive impairment primarily need a physical break, while those caring for people with dementia require ‘mental’ respite? No controlled study was found focusing on carers of people with particular diseases such as cancer, Parkinson’s disease or stroke.

Little evidence was found on how respite affects the quality of life of carers or care recipients.[34,95,103,117] The existing evidence base makes little attempt to synthesise findings for carers and care recipients, with only one study included in the review directly assessing the impact upon the dyad’s relationship.[101] Outcomes need to be relevant and meaningful both to older people[190] and to their carers. The ERG highlighted the importance of ethical issues relating to ‘dyadic conflict situations’ and suggested some outcomes that may be relevant for further research (see Appendix 1, *Box 4*).

Most studies assessed the impact of the intervention upon care recipients, but findings were not always clearly or consistently reported. Even if respite is unlikely to benefit the health of frail older people, it is vital that at the very least, no harm is done. Although no reliable evidence was found that any harm occurred, one cannot be confident that this is the case unless findings are routinely and consistently assessed and reported.

Where do we go from here?

Studying the effectiveness and cost-effectiveness of respite care using conventional RCT designs is complex and difficult.[192] This was highlighted by some members of the ERG. First, the intervention itself takes many different forms. Moreover, the boundaries between ‘respite’ and other types of service are very unclear. Thus, respite may be provided in the form of home-based services or institutional care, for example, as well as through services with entirely different names (and sometimes different purposes), such as day care or intermediate care. The specification of ‘standard’ services for the control group is equally problematic; potential users of respite care services are likely to have relatively high support needs and are therefore likely also to be receiving a range of different formal and informal services and support. Moreover, to the extent that respite care is used in response to imminent or actual crises, there may be ethical problems in the random assignment of potential clients to a control group.

In the UK at least, professional assessment and gatekeeping play a significant role in accessing respite care services. Thus, typically, an older person may be referred for respite care by a social worker or other social care worker, or by a hospital doctor or nurse if respite care services form part of rapid response services designed to prevent inappropriate hospital admission. Carers who receive funding such as direct payments with which to purchase their own respite care will also have undergone a professional assessment of their needs. Such gatekeeping activities are crucial in determining access to publicly funded respite care services. However, they also have implications for potential recruitment to an RCT. Thus, it will be necessary to ensure that professional assessment processes, eligibility criteria and referrals are consistent with the aims of particular types of respite service.

As noted above, the acceptability of respite care is a key issue, both in its take-up and use and in relation to its impact and outcomes. However, specifying what is, or may be, acceptable is not easy, not least because of the diversity of informal care-giving situations. Thus, what is 'acceptable' to a working daughter caring for an older physically infirm parent may be very different from what is 'acceptable' to an older man caring for a wife with severe dementia. In addition, what is 'acceptable' to the carer will also take account, to a greater or lesser extent, of what is perceived to be 'acceptable' to the person receiving respite. This makes the measurement of outcomes difficult because there is likely to be considerable interaction and interdependence between the outcomes for the carer and the older person.

In view of the complexity of the intervention, the difficulty in establishing an acceptable, ethical comparator, 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 (carer and care recipient dyads) suitable for study, establish clear definitions of the services to be compared (e.g. usual care versus intensive respite) and determine the main outcomes to be measured, such as carer quality of life or resources consumed. Once these have been agreed, the prospects of successfully conducting a full-scale, well-controlled trial would be greatly enhanced.

Chapter 8

Conclusions

Implications for healthcare

Much of the existing literature fails to meet basic quality standards in terms of study design and analytical approach (see the section 'Assessment of study quality', p. 53). From the more reliable evidence (most of which does not easily translate into lessons for the UK), it is clear that if respite for carers of frail older people does work, then the overall effect is small. However, the effect size does not seem to be uniform, with some groups of carers apparently benefiting more than others. Nevertheless, many studies report high levels of carer satisfaction.

There is no reliable evidence that respite adversely affects care recipients or that it delays entry to residential care, although this may in part reflect poor or inconsistent reporting. Economic evidence suggests that day care is at least as costly as usual care and may be considerably more expensive than usual care. Regrettably, much of the existing literature is unable to inform policy and practice: there are many important gaps in the evidence base, with a lack of UK-relevant, good-quality, controlled evaluations for all types of respite care and no economic evidence for any type of respite other than day care.

Recommendations for research

Existing studies provide evidence of the barriers to undertaking successful trials of complex interventions. Recruitment difficulties (participants or staff), low levels of uptake or compliance, high attrition rates, use of respite by the comparison group and staffing problems strongly indicate that pilot studies are needed to inform full-scale trials of respite in the UK. Pilot studies need to clarify and prioritise the objectives of respite care, identify one or more target groups (carer and care recipient dyads) suitable for study, establish clear definitions of the services to be compared (e.g. usual care versus intensive respite) and determine the main outcomes to be measured, such as carer quality of life or resources consumed. Pilot work may then inform methodologically rigorous trials that can establish the effectiveness and cost-effectiveness of UK respite services. Given the complexity and intersectoral nature of respite care, it is likely that a range of methodological approaches will be needed to address the gaps in the evidence base.

Objectives

Overarching any further research is the primary need to clarify the objectives of respite services. While this review focuses on respite as a form of carer relief, some respite services may have broader objectives; for example, day care may also reduce isolation and enhance social participation of older people. One way forward would be to use literature reviews and stakeholder consultations to clarify and prioritise objectives. Further research should explicitly state the objectives chosen, recognising that these will affect both how services are provided and how outcomes are measured.

Target groups

The term 'frail older (people)' encompasses a wide range of conditions and needs, such as cognitive impairment, dependence in eating or bathing, terminal illness and incontinence.[193] Adult child carers may have needs for and attitudes to respite that differ from those of spouse carers, and demographic characteristics may also influence carer response. Existing research suggests that some carers and care recipients benefit more than others. Further research should therefore clearly specify the study population and ensure that study samples are adequately sized to inform any planned subgroup analyses.

Clear definitions of the services

There is a need to identify the essential components of respite services, clarifying boundaries between respite and intermediate care, crisis response, day care, rehabilitation and palliative care.

Study respite services need to be culturally, socially and demographically appropriate for the study population. Services will need to be flexible and tailored for individual carer and care recipient needs. An appropriate comparison intervention, comprising an agreed (i.e. socially acceptable) basic package, could then be tested against a more intensive package of care that includes respite. Study respite services should be delivered by competent staff, recognising that medium-dependency support may be inadequate for those with high-dependency needs. Respite services should be delivered by staff with an appropriate level of competence in terms of skill, experience or training.

There are difficulties recruiting frail older people: trials may suffer high attrition rates either because of the death or institutionalisation of the care recipient or because of carer exhaustion. Lessons from trials of palliative care may help to inform this issue.

Outcomes

Primary and secondary outcomes should accommodate both the carer, and the care recipient, and be meaningful to both. Measures should aim to target outcomes that are relevant to carers and people receiving respite care, while recognising that individuals in a care-giving relationship will simultaneously have not only joint but also separate interests and aspirations.

Once pilot work has been undertaken, methodologically rigorous trials are needed to establish effectiveness and cost-effectiveness of UK respite services for carers of frail older people. Trials should seek to balance the need for real-world assessments with adequate control. Primary and secondary outcomes, subgroup analyses and methods for handling missing data should be prespecified. Randomised trials should ideally comply with CONSORT guidelines and be undertaken on an ITT basis. Reporting standards in this research area have generally been poor. For all types of trial, adequate descriptions are needed for baseline demographic/clinical characteristics (reporting mean, standard deviation and range), numbers enrolled in each group, numbers contributing data in each group, intervention/comparator (who did what to whom when, how often and with what resources), compliance/uptake rates (in absolute numbers), outcome instruments with appropriate change and/or end-point statistics for each group (including health, social and other relevant outcomes, adverse events, time to institutionalisation and resource use) and use of other support services (formal and informal).

Future studies

As any single approach is unlikely to provide satisfactory data, there is scope for mixed methods studies to enable both qualitative and quantitative approaches to compensate for their respective shortcomings. In addition, long-term surveillance data could complement findings from these trials, enabling regression analyses of robust and comprehensive observational data sets. These measures may begin to close the gap in the evidence base regarding the real-world effectiveness and economic viability of respite care for frail older people.

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Contribution of authors

Joy Adamson (Research Fellow) has expertise in observational and qualitative studies. She was involved with the screening of abstracts and acted as moderator for any disagreements raised relating to the inclusion or exclusion of studies into or from the review. She collaborated in the meta-analysis and also provided comments on both the protocol and the final report. Hilary Arksey (Research Fellow) took the lead in setting up the ERG and maintaining contact with members throughout the various stages of the research. She organised the Feedback Workshop at the King's Fund in London; she also provided feedback on the protocol, the draft report for the King's Fund workshop and the draft final report. Mike Drummond (Professor of Health Economics) acted as an advisor on the economic aspects of the project. He participated in the design of the study and commented on the final report. Caroline Glendinning (Professor of Social Policy) contributed expert advice on current policies for family carers and on the organisation and funding of respite care services. She also contributed to the identification of appropriate people to invite to the ERG and chaired the one-day seminar with the ERG that was held in December 2005.
Su Golder (Information Officer) was responsible for developing the search strategies and retrieving references. She managed the Endnote library and the ordering of papers, was responsible for writing the literature search sections of the protocol and report, and also provided comments on both the protocol and the final report. Anne Mason (Research Fellow) had overall responsibility for project coordination. She was the lead reviewer responsible for writing the protocol, contributed to all aspects of the effectiveness evaluation (study selection, data extraction and quality assessment and analysis), collaborated on the economic review and costing, integrated the contribution from the ERG and coordinated the final report. Karen Spilsbury (Research Fellow) assisted with study selection, quality assessment and data extraction of controlled and uncontrolled studies, and interpretation for effectiveness evaluations, and also assisted with producing the protocol and preparing the final report. Helen Weatherly (Research Fellow) assisted in screening, data extraction and quality assessment for the effectiveness and cost-effectiveness review, and led the cost-effectiveness review of the published literature. She led the development of the cost questionnaire and collected relevant respite care costs. She explored options for the economic modelling and collaborated in producing the final report.

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Appendix 1

Key issues from the expert reference group

Twelve of the 13 ERG members provided written reviews of the draft report and nine ERG members attended the workshop. Nine economic questionnaires were received, with one ERG member declining to complete the questionnaire. A description of the methods used to recruit the ERG can be found in the section 'Expert reference group' (p. 10). The themes summarised here represent the subjective views of the group and should be interpreted accordingly.

The ERG identified a lack of planning for respite. The ERG felt that carers ideally need access to low-level input by proactive (preventive) services, rather than reactive services (e.g. acute care): "a stitch in time saves nine!" However, a medical crisis, either for the carer or the care recipient, was seen as a common reason for 'respite' episodes. In this context, respite may serve as an alternative to hospital admission and be undertaken for assessment purposes, rather than for carer support.

The ERG commented on the lack of variety of respite and stressed the need to ensure the availability of choice in respite care: "access is frequently service-driven rather than needs-led". There was perceived to be a lack of specialist services for people of different ages and ethnicities, and for those requiring specialist nursing care. A number of ERG members spoke of the closure of respite services in their own localities, which had made it very difficult for carers to plan ahead. The ERG felt that there was a need for joined-up planning and delivery of flexible, person-centred respite services. However, the group also highlighted the difficulty of recruiting and retaining care workers (particularly for overnight respite services, and/or services in rural locations) that needed to be addressed.

Access to respite services is currently chiefly through the Community Care or Carers Assessment processes. The Single Assessment Process is gradually replacing these, but information technology (IT) incompatibilities between health and social service systems (and other cross-organisations) have still to be overcome. The ERG identified a number of barriers to access (*Box 2*).

BOX 2 *ERG views on barriers to accessing respite services*

Emotional barriers
- Carers feel it is their duty to care, and feel guilty about wanting a break and about spending household income on respite.
- Carers worry whether respite services will offer appropriate care for the care recipient.
- Out of home respite may be seen as a step towards long-term institutional care by carers and care recipients.

Informational barriers
- Carers find it difficult to access information
  - on available respite services
  - on carer rights to an assessment.
- Carers needs are poorly assessed.

Financial barriers
- Charges may particularly discourage older carers
- Direct payments are used less frequently by older carers and those from lower socio-economic groups

Regulatory/statutory barriers
- FACS (Fair Access to Care Services), was thought to have led to rationing and restricting of respite services for care recipients
- There was anecdotal evidence that legislation designed to improve the quality of respite services had had unintended consequences, adversely affecting provision.

Practical barriers
- There is a lack of transport/escort services
- There is a lack of culturally/socially/clinically appropriate services
- There are shortages of respite staff in rural areas and for night services.

Several ERG members provided examples of local solutions to local problems and stressed the importance of local innovation, ownership and implementation (*Box 3*). These include cases where direct access to services has been introduced.

The ERG expressed their views on issues for further research (*Box 4*). The group thought that the challenge of evaluating a 'soft service' (as opposed to a 'discrete' intervention) such as respite care relates to difficulties of classification and quantification, particularly with regard to overlaps with the following types of care:

- emergency respite
- intermediate care

BOX 3 *Examples of good respite practice, cited by the ERG*

- One member spoke of her experience of a local day-care centre established in a small town in the 1970s. Still operating, the centre is staffed by volunteers and provides day care 2 days per week for ten people. Transport and meals are provided for a small user charge (£5). It is perceived as being very effective, useful and non-threatening; users do not see it as a stepping stone to institutional care.
- In another part of the country, flexible respite services are being introduced for £2.50 per hour for 3 hours per week. Respite time that is not used in one week can be 'rolled over' for future use. Facilitated by social services and funded by the Carer's Grant, unusually there is direct access to this service (i.e. not via social services).
- In one part of the country, the Alzheimer's Society has commissioned Crossroads to provide flexible sitting services for carers, costing £9 per hour for weekdays and £10 per hour for weekends. This in-home respite, which usually occurs in 4-hour sessions, was considered valuable because care is individualised.
- An example of carer choice shaping the provision of institutional respite was given. The lease by the local PCT of a bed in a private residential home, chosen by a group of carers of people with dementia, ensures that there is a bed available throughout the year in a home of carers' choosing.
- A type of 'host-family respite' was described. The Neighbourhood Day Care Scheme operates in the home of employed 'hosts', who are supervised and supported by a service coordinator. The service is available 6 hours a day, with transport provided.

- rehabilitation
- palliative care.

Some ERG members questioned whether regular day care should be viewed as part of a package of care to address the social needs of the care recipient, rather than as a form of respite for the carer.

The issue of study design was raised. The scope of the present systematic review was questioned: evidence on the effectiveness of respite that pre-dated the search limit of 1980 was cited and these studies were subsequently checked for relevance. Concerns were also raised about the appropriateness and validity of RCTs and, indeed, of systematic reviews in this area. For example, one member commented: "there is a danger in continuing to try and fit models for systematic reviews that are not best placed to capture the essence of a service." The ERG considered RCTs to be problematic for a number of reasons:

- Respite includes a range of services, rather than a widget, and meets a range of needs and circumstances.

BOX 4 *Issues for further research: suggestions from the ERG*

Defining respite

- Clear taxonomy for respite services, clarifying boundaries between respite and intermediate care, crisis response, day care, rehabilitation and palliative care.

Study design issues

- Key question to be addressed is 'what works for whom in which circumstances and in which locality?'
- Systematic reviews may fail to capture the essence of a service.
- Qualitative studies could inform the questions to be addressed by RCTs.
- Audits may provide process information and resource-use estimates.
- The NHS National Programme for Information Technology may provide potentially useful data.

Suggested outcome measures

- 'A good death'
- 'Any targets in the NHS improvement plan'
- Averted hospitalisation/delayed admission to long-term care
- Choice and control to live your life (carer/care recipient)
- Meaningful activity, time for self/free hours
- Process measures, clarifying:
  - service composition (intervention/comparator), including service delivery
  - carers' formal and informal support networks
- Quality of life/life fulfilment/dignity
- Reduced stress
- Relief from caring responsibility

Gaps in the evidence base

- Studies assessing existing UK respite provision, particularly services provided by the voluntary sector
- Studies focusing on specific groups of older people and carers:
  - care recipients requiring specialist nursing care
  - carers/care recipients of different ages
  - carers/care recipients of different ethnic backgrounds
  - services for male carers of female care recipients
- Studies addressing barriers to access:
  - financial barriers
  - transport and escort service issues
  - validation/support/encouragement for carers
  - informational/service navigation
- Studies addressing barriers to provision:
  - impact of policy, regulation and legislation
  - workforce issues for recruiting and retaining respite service carers

- RCTs may be unsuitable for evaluating complex interventions and unable "to place users and carers at the heart of the process".
- There may be ethical issues for comparisons of respite against 'no respite'.

Outcome measurement was another issue raised the group. Given the late stage of entry and the chronic nature of conditions often suffered by this patient group, some members of the ERG questioned whether standard outcomes were unachievable: “respite care does not take away the burden of being a carer, responsibilities still remain”. The potential for respite to avert hospitalisation was thought to be important. Although the review team had found no reliable evidence for the ERG draft report that respite could avert hospital care or delay institutionalisation, some members of the ERG disputed the finding, believing that it reflected limitations of existing studies and available methodology. The need to measure process was highlighted, taking account of the acceptability of the service, and studies should therefore adequately describe the services assessed, to help to identify an acceptable basic level of care. The group felt that quality of life measures may be inadequate and stressed the need to consider the ‘big picture’, stressing the need to be more creative and flexible in capturing how respite care works. Several members of the ERG cited anecdotal evidence of harm to frail elderly people attending day care or institutional care, and recommended that studies should record short- and long-term adverse events.

Drawing on the themes discussed, the ERG cited a number of gaps in the evidence base, which are summarised in *Box 4*.

Appendix 2

UK respite services: economic survey of the ERG

Methods

To inform an assessment of the cost-effectiveness of respite services, data on the configuration and delivery of services, their utilisation and cost are required. Ideally, these data would be collected from a large sample of representative respite purchasers. However, primary research of this nature was outside the scope of this project. Therefore, ERG members were asked to complete a brief questionnaire to provide expert opinion on the respite care services that are available in the UK. The questionnaire contained four sections. The first section asked what type of services were available in the respondents' locality, as well as whether or not any services had been withdrawn and whether any services were planned but unlikely to be implemented. Respondents were asked to focus on one of three types of respite with which they were familiar, namely day care, in-home respite or institutional respite. The second section asked about funding arrangements, obtaining information on payment for and provision of the services. The third section asked about issues relating to the accessibility of the service. Respondents were asked to indicate where the service was provided, the characteristics of people and their carers using the service, and (for day care and institutional respite care services) whether transportation was provided and, if so, whether and what type of user charges were made. The final section asked respondents to describe how the service was configured. For day care and institutional respite care services, respondents were asked for the maximum number of care recipients that could use the service at a single point in time, as well as the typical number of care recipients using the service at a single point in time. In addition, respondents were asked what days and times the service was available, the staff-mix, the ratio of full-time equivalent (FTE) staff to care recipients, the length of the waiting list, details on the length of a typical respite care session and an estimate of how many sessions a user would typically receive annually. This information was used to calculate unit costs of services and, where data were missing, estimates were obtained from the Personal Social Services Research Unit (PSSRU, 2005).[45] Unless otherwise stated, costs reported relate to 2004/05.

Results

Nine of the 13 (69%) ERG members responded to the questionnaire. One individual declined to respond. There were some missing data, primarily because some ERG members did not work directly with respite care services and were therefore unable to provide responses to the more detailed questions.

A range of different types of respite care services was available in the respondents' localities. Most commonly, in-home respite (day and/or overnight) ($n = 8/9$) was available, followed by day care ($n = 7/9$), institutional respite (overnight) ($n = 6/9$), respite programmes ($n = 4/9$), multidimensional support packages ($n = 2/9$) and host family respite ($n = 1/9$). Respondents were unaware of any video respite services within their localities. One respondent mentioned a further service that they called "flexible home care respite".

The majority (6/9) of respondents knew of respite care services that had been withdrawn and one respondent knew of services that were planned but were unlikely to be implemented. Reasons that were given for the withdrawal of services were:

- service reconfiguration with respite care hospital beds being used for rehabilitation services instead
- service reconfiguration whereby it was no longer possible to book respite care in the local hospice, although some ad hoc care was available occasionally
- a general reduction in institutional care services owing to financial constraints
- a reduction in inpatient respite care beds for people with dementia with the reduction in Mental Health Trust NHS funding available locally. In substitution, respite beds were available in nursing homes, but these beds could not be booked and were not always available on demand. The training of carers in the nursing homes was less likely to meet the needs of the patients with dementia, a common result being that patients entering such nursing homes returned to hospital
- difficulties encountered in recruiting and retaining staff who were able to provide care at times that were suitable for care recipients and their carers.

The remaining responses relate to funding arrangements, access issues and descriptions of services, and are specific to day care, in-home respite or institutional respite care. These are summarised in *Tables 17* and *18*.

Day care

Two out of nine respondents focused on day care. One respondent was unable to provide many details since they did not work directly with services. The other respondent was familiar with two day-care programmes. Both of these services were multiagency funded, receiving the majority of monies from the voluntary sector and with contributions from the carer's grants from the local authority, care recipients and carers. The local authority charges a subsidised rent for the accommodation. No other funding is provided by local government.

The day-care services and accommodation were provided by the voluntary sector. Recipients of day care accessed the service via their GP or social workers, or based on self-referral.

Both services catered for people with learning difficulties, or mild or moderate dementia, but were unable to accommodate those with severe dementia. In terms of carer characteristics, access to one service required a doctor's recommendation.

Both services provided some transportation. One service charged care recipients £3.50 for transport to and from day care. The transport costs of the other service were included within the day care user charge of £5.

The day-care services could accommodate a maximum of 18–20 people. On a typical day or night, 15 or 16 people used the services. Both services were staffed by volunteer carers, some of whom were retired nurses, and one of the services also used trained, paid care staff. The ERG

TABLE 17 *Respite care funding and access issues*

Type of respite care	Day care	In-home respite	Institutional respite
No. of services to which data relate	2	2	5
Funding for the service	Multiagency Carer's grant via local authority, voluntary sector, patients/carers	Multiagency Local authority, voluntary sector, patients/carers	Multiagency NHS, local authority, patients/carers
Service provision	Local authority, voluntary	Local authority, voluntary sector, people/carers	NHS, local authority, patients/carers
Where the service is provided	Multiagency Voluntary, local authority, care trust	In-home	NHS (inpatient or outpatient), local authority, people/carer home, nursing home, voluntary facility, day centre
Patient characteristics for those people using the service	People with learning disabilities, mild dementia, moderate physical disability and chronic illness such as Parkinson's disease	People with dementia, people who are older and physically frail, those who are heavily disabled and older, those who have mental health problems and are older	Physically frail (e.g. stroke victims), older (one scheme was for people aged $\geqslant$65 years), one scheme was mostly for those requiring palliative care for cancer, one for older people with dementia, and one for older people with mental health problems in general
Carer characteristics for those people using the service	Doctor's recommendation	Providing regular, substantial amounts of care	–
Examples of transport facilities, including user charges	Transport provided, user charge £3.50 per day for transporting to and from the centre	Not stated	Transport provided, ranging from taxi to ambulance. Paid for by a range of sources: local authority, NHS charity

TABLE 18 *Respite care service delivery*

Type of respite care	Day care	In-home respite	Institutional respite
No. of services to which data relate	2	2	5
Maximum no. of people using the service at a single point in time	18–20	6–10	40
Typical no. of people using the service at a single point in time	15–16	3–4	40
Service times	Available 2 days per week, from around 10.00 to 14.00 or 15.30 h	Available 24 hours, but typically from 09.00 to 22.00 h. From 08.00 to 22.00 h	Monday to Friday, 24/7
Types of staff involved	Care support workers and volunteers	Home care agency staff, care support workers	Nurses, physiotherapists, occupational therapists, social workers, volunteers
Ratio of staff to care recipients	From one carer to two patients to one carer to seven patients, dependent on need	One carer to one patient	One carer to eight patients
Length of waiting list	From one vacancy to 2-week waiting list	7–8 week, but can be shorter depending on need	3 weeks, provided as and when needed
Typical length of a session	4–5.5 hours	Typically 2–4 hours. Range 1–12	4 hours to 1 week, or 1–3 days per week or 1–2 weeks
Typical no. of sessions received per year per person	One per week	Typically 40–156 per year. Range 2–60 per year	Range 4–8 sessions per year

member noted that care provided across units may differ depending on the quality of the care provided. For one service, the two sessions of day care per week were provided by a pool of 18 volunteers. For each session, two voluntary organisers worked the entire session and, depending on need, between four and six volunteers were involved for shorter periods. The ratio of staff to care recipients is estimated to be from one carer for seven patients, to one carer for two patients, depending on patient need. It is estimated that each session is based on approximately 18 hours of care. Information on support staff with, for example, administrative or financial management responsibilities was not provided.

Both services were open 2 days per week for 4–5.5 hours a session (one was available from 10.00 to 15.30 hours and the other from 10.00 to 14.00 hours). Registered care recipients typically receive one session per week. The ERG member noted that the services recognised the need for a long day respite care to enable carers to have a full day out.

The waiting list was about a fortnight long for one service; however, the respondent noted that the local authority had one respite bed in a private nursing home for emergency admission if respite care was required urgently. An administrative officer filtered the waiting list on a carer benefit and a waiting list priority basis. The other day-care unit had one vacant position at the time the questionnaire was completed.

In terms of the cost of day care, one service charged £10 per session, excluding transport, and the other cost £5, including transport (as mentioned above) (*Table 19*). It is useful to include the full cost of the service since this reflects the true value of the resources used to provide the services. Based on the literature, a cost per session of day care for older people appears to be around £30 per session,[45] although there is considerable variation; hence, it is likely that the above costs are

TABLE 19 Unit costs and charges for day care for older people

2004/05 value (mean/average)	Unit	Source	Notes
£21	Per session	ERG responses	Based on synthesis of ERG data and PSSRU unit costs.[45] Unit cost assumes that service operates at full capacity. Full capital and revenue costs are not included in the cost as these data were not collected
£10	Per session	ERG questionnaire	This is a user charge and was subsidised by the voluntary sector with a contribution from the local authority. It does not include people's transport costs
£5	Per session	ERG questionnaire	This is a user charge and was subsidised by the voluntary sector with a contribution from the local authority. It includes people's transport costs

highly subsidised, primarily through voluntary sector service provision. It should be noted that the units for which costs are reported vary. Based on the data that were obtained it was not possible to explore the influence of, for example, patient characteristics, day-care quality and location on costs.

Based on the information provided, the cost of day care per session was £21, assuming full occupancy and excluding revenue costs and the cost of capital charges.

A few comments were provided by respondents. For one of the day-care centres, carers received no formal training and this is likely to make carers very vulnerable if they are involved in any accident associated with their work, for instance back problems that may emerge from lifting patients. It was suggested therefore that any future trial that examined the costs of the voluntary sector should include training and insurance costs, and that this type of cover is essential for carers.

In-home respite

Two out of nine respondents focused on in-home respite care and both questionnaires were completed. Both services received local authority funding. In addition, one of the services was funded by the voluntary sector and by user charges.

One in-home service was paid for and provided by the local authority, in conjunction with the voluntary sector and the private sector. The other service was provided by the local authority and the voluntary sector.

One service was provided for people with dementia. No carer characteristics were described. The other in-home service was provided for those who were older and physically frail and/or heavily disabled and/or who have mental health problems. To be eligible for this service, carers were required to provide regular, substantial amounts of care.

For the in-home service that provided care to people with dementia, it was estimated that a maximum of six to ten people could receive the service at a single point in time. On a typical day or night, three or four people used the service. The service was typically available every day from 09.00 to 22.00 hours; however, the service was occasionally available at other times. The service was staffed by care support workers and the number of FTE was unknown. The ratio of FTE staff to care recipients was 1:1.

The waiting list for the service was on average 7–10 weeks, but emergency cases could be accommodated more rapidly.

A typical in-home care session lasted for 3–4 hours, ranging from 2 to 10 hours. Each registered care recipient usually received 40–52 sessions per year, with a range of two to 60 sessions per year.

Based on the resource-use information provided, the service cost about £27 per session or £8 per hour. It should be noted that hourly rates tend to vary, depending on the day and time when in-home respite care is supplied.

The second in-home service was provided every day of the week from 08.00 to 22.00 hours, although the service was also available at other times. It was staffed by home care agency staff and volunteers. The number of FTE was unknown. The ratio of FTE staff to care recipients was 1:1. No information was provided about any waiting list.

TABLE 20 *Unit costs of in-home care for older people*

2004/05 value (mean/average)	Unit	Source	Notes
£47	Per night	ERG member	Night sitting
£27	Per session	ERG member and estimates obtained from PSSRU, 2005	Local authority day care for older people. A session is 3.5 hours long on average
£11	Per hour	ERG member	This is a user charge and it is unclear how this was calculated. The charge was subsidised by using the carer's grant money from the local authority
£8	Per hour	ERG member and estimates obtained from PSSRU, 2005[45]	Local authority day care for older people

A typical in-home care session lasted for 2 hours, ranging from 1 to 12 hours. Each registered care recipient usually received three sessions per week or 156 sessions per year.

The respondent provided data on service charges. Home care is charged at £11.20 per hour up to a maximum of £250. Night sitting and night sleeping services are charged at £47 per night up to a maximum of £250 (*Table 20*).

This respondent noted that a new scheme has been proposed in their locality, in addition to existing schemes. The scheme would be directly accessed, sitting outside the care management system, and giving carers up to 3 hours' sitting service per week at an hourly charge of £2.50. The proposal is that the weekly hours can be rolled up and taken in a block on a monthly basis if the carer wishes and additional hours can be purchased at full cost. Carers' organisations in the voluntary sector would be tasked with the 'brokerage' role of overseeing access to the scheme, by means of a limited assessment of need prior to referral to an appropriate care provider.

Institutional respite care

Five out of nine respondents focused on institutional respite care. One service was paid for and provided solely by the local authority. Three services were funded jointly by the NHS, the local authority and patients/carers, and two of these services were also provided by these agencies. The other service was provided by the private sector. The remaining respite care programme was paid for by the NHS and the local authority without a patient/carer charge and was provided by these agencies as well as the private sector.

In terms of their location, one was provided in a private facility, one in a hospital outpatient ward, one in a local authority facility and one in a day centre in an NHS/local authority-funded nursing home. The remaining service was provided in a combination of places, including, primarily, in an NHS/local authority inpatient facility, as well as care taking place in people's homes and a voluntary care facility.

One service was provided to physically frail people (e.g. stroke victims); one for people aged 65 and over, mostly requiring palliative care for cancer; one for older people with dementia, but sometimes other groups of older people in different institutional settings; and one for older people with mental health problems, especially dementia. No other patient characteristics were reported.

Three out of five respondents provided information on transport facilities. One service relied on NHS or taxi transportation. For another service, an ambulance was available as required. For another service, transport was sometimes paid for by the local authority the NHS or voluntary agencies, but most care recipients relied on relatives for transportation. One respondent remarked that transport is nearly always an issue for accessing respite, with a need for appropriate and timely transport with suitable patient escorts.

One respondent reported that the institutional care service tended to operate at full capacity, with 40 people using the service at a single point in time. The services differed somewhat in their opening hours. Three services were available all day every day, and another was open for 24 hours, but only from Monday to Friday: institutional care was not provided at the weekend. The opening hours of the other service were not provided. One service was operated by nursing staff only, two by care workers alongside nursing staff, one by a team of specialist nurses, physiotherapists and social workers, and one by social care staff only. One respondent reported on the ratio of staff to patients: one member of staff per eight patients. Staff FTE were not provided by the respondents.

The length of the waiting list was 3 weeks for one service. Details were not provided for the other services. A typical session lasted for (1) 4 hours to 1 week, (2) 1–2 weeks, (3) 2 weeks, and (4) 1–3 days per week or 2 weeks in 6–8 weeks.

For those stating the typical number of respite care sessions per year, this was four to six sessions for one service and seven to eight for another.

A few comments were provided by the questionnaire respondents. One ERG member's answers related to cancer patients who were usually in the palliative care phase of their disease. Different types of patients require different types of care, and this is likely to impact on the type of resources used and the costs of the care received. Another ERG member noted that for many people particular episodes of care or programmes of respite are components of an overall package of care. This may include episodes of day care and episodes of inpatient care, which may give way to home care and so on. Some care recipients may receive only one service, others a combination of the above services.

Summary

- Data collected in the survey provide some useful insight into how services are funded, accessed and delivered. Limited costing work was possible, based on the brief survey. No assessment of the benefits of the services was elicited in the survey, although this issue is important.
- There is a range of services available in respondents' localities.
- Within each type of service, there is considerable variation in funding, access and service delivery.
- The economic survey focused on how respite care services are delivered, rather than why they were delivered, as they were. Therefore, the responses are primarily descriptive rather than interpretive. Insufficient data were collected to undertake analyses to explore factors associated with any differences across services.
- The survey results provide a snapshot of how services are delivered currently. At the same time, it is clear that the respite care system is dynamic. Respondents noted that there is an underlying shift from institutional service provision to more care being provided in the community.

Appendix 3

Searching methods

Databases searched

Databases of systematic reviews

Cochrane Database of Systematic Reviews (CDSR) (Cochrane Library: http://www.nelh.nhs.uk/cochrane.asp)
Database of Abstracts of Reviews of Effects (DARE) (CRD Internal Database)

Databases on old age and ageing

AgeInfo (Centre for Policy on Ageing: http://www.cpa.org.uk/ageinfo/ageinfo2.html)
AgeLine (DIALOG)

Health/medical-related databases

Allied and Complementary Medicine Database (AMED) (OvidWeb)
British Nursing Index (BNI) (OvidWeb)
Cumulative Index to Nursing and Allied Health Literature (CINAHL) (OvidWeb)
Cochrane Central Register of Controlled Trials (CENTRAL) (Cochrane Library: http://www.nelh.nhs.uk/cochrane.asp)
EMBASE (OvidWeb)
Health Management Information Consortium (HMIC) (HELMIS, DHdata and the King's Fund databases) (OvidWeb)
Health Technology Assessment Database (HTA) (CRD Internal Database)
MEDLINE (OvidWeb)
MEDLINE In Process and other non-indexed citations (OvidWeb)
PsycINFO (BIDS: http://www.bids.ac.uk/)

Social care databases

Applied Social Sciences Index and Abstracts (ASSIA) (CSA Illumina: http://uk1.csa.com/)
Caredata (electronic library for social care eLSC: http://195.195.162.66/elsc/caredata/caredatasearch.htm)
International Bibliography of the Social Sciences (IBSS) (BIDS: http://www.bids.ac.uk/)
Interventions and Policy Evaluation (C2 – RIPE) (Campbell Collaboration: http://www.campbellcollaboration.org/frontend.asp)
Social Science Citation Index (SSCI) (Web of Science: http://wos.mimas.ac.uk/)
Social Services Abstracts (CSA Illumina: http://uk1.csa.com/)
Social, Psychological, Educational and Criminological Trials Register (C2-SPECTR) (Campbell Collaboration: http://128.91.199.101/)
Sociological Abstracts (CSA Illumina: http://uk1.csa.com/)

Economic databases

EconLit (BIDS: http://www.bids.ac.uk/)
Health Economics Evaluation Database (HEED) (http://www.ohe-heed.com/)
Internet Documents in Economics Access Service (IDEAS) (working papers sections only) (http://ideas.uqam.ca)
NHS Economic Evaluation Database (NHS EED) (CRD Internal Database)

Databases of conference proceedings

Inside Conferences (DIALOG)
ISI Proceedings: science and technology (Web of Knowledge: http://wos.mimas.ac.uk/)
ISI Proceedings: social sciences and humanities (Web of Knowledge: http://wos.mimas.ac.uk/)

Databases of reports, dissertations and other grey literature

Dissertation Abstracts (http://wwwlib.global.umi.com/dissertations/)
Index to Theses (http://www.theses.com/)
System for Information on Grey Literature in Europe (SIGLE) (BIDS: http://www.bids.ac.uk/)

Databases for ongoing and recently completed research

ClinicalTrials.gov
ESRC SocietyToday Database (http://www.esrc.ac.uk/ESRCInfoCentre/index.aspx)
MetaRegister of Controlled Trials (http://www.controlled-trials.com/)
National Research Register (NRR) (http://www.update-software.com/national/)
Research Findings Electronic Register (ReFeR) (http://www.info.doh.gov.uk/doh/refr_web.nsf/Home?OpenForm)

Generic search strategies

The search terms were chosen to achieve a balance between recall and precision. The 'soft' nature of this topic makes producing a search strategy with high precision difficult. Many of the keywords relevant to the topic have multiple meanings and/or are commonly used words in other contexts. Social science databases often lack abstracts or have little or no indexing. This can restrict sophisticated searching. The search strategies are therefore as comprehensive as possible within the restrictions of the interfaces.

Databases of systematic reviews

Cochrane Database of Systematic Reviews (CDSR) (Cochrane Library)

Issue 1, 2005
Searched: 21 March 2005
This search strategy retrieved 219 reviews (186 completed and 33 ongoing).

#1. (caregiv* or (care next giv*) or carer* or (informal next care) or befriending)
#2. (caretaker* or (care next taker*) or (children next caring) or (families next caring))
#3. (sons near/2 care)
#4. (sons near/2 caring)
#5. (daughters near/2 care)
#6. (daughters near/2 caring)
#7. (friends near/2 care)
#8. (friends near/2 caring)
#9. (husband* near/2 support)
#10. (husband* near/2 supporting)
#11. (husband* near/2 care)
#12. (husband* near/2 caring)
#13. (wives near/2 support)
#14. (wives near/2 supporting)
#15. (wives near/2 care)
#16. (wives near/2 caring)
#17. (wife near/2 support)
#18. (wife near/2 supporting)
#19. (wife near/2 care)
#20. (wife near/2 caring)
#21. (spouse* near/2 care)
#22. (spouse* near/2 caring)
#23. (spouse near/2 support)
#24. (spouse near/2 supporting)
#25. (grandparent* near/2 care)
#26. (grandparent* near/2 caring)
#27. (grandparent* near/2 support)
#28. (grandparent* near/2 supporting)
#29. (grandchild* near/2 care)
#30. (grandchild* near/2 caring)
#31. (grandchild* near/2 support)
#32. (grandchild near/2 supporting)
#33. (neighbor* near/2 care)
#34. (neighbor* near/2 caring)
#35. (neighbor* near/2 support)
#36. (neighbor* near/2 supporting)
#37. (neighbour* near/2 care)
#38. (neighbour* near/2 caring)
#39. (neighbour* near/2 support)
#40. (neighbour* near/2 supporting)
#41. (relatives near/2 care)
#42. (relatives near/2 caring)
#43. (relatives near/2 support)
#44. (relatives near/2 supporting)
#45. (parent near/2 caring)
#46. (parents near/2 caring)
#47. (mother near/2 caring)
#48. (mothers near/2 caring)
#49. (father near/2 caring)
#50. (fathers near/2 caring)
#51. (families near/2 support*)
#52. (#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 or #20 or #21 or #22 or #23 or #24 or #25 or #26 or #27 or #28 or #29 or #30 or #31 or #32 or #33 or #34 or #35 or #36 or #37 or #38 or #39 or #40 or #41 or #42 or #43 or #44 or #45 or #46 or #47 or #48 or #49 or #50 or #51)
#53. CAREGIVERS explode all trees (MeSH)
#54. (#52 or #53)
#55. RESPITE CARE single term (MeSH)
#56. DAY CARE single term (MeSH)
#57. ((care next attendant*) or (support next service*) or (support next program*) or (support next scheme*) or (home next support) or (short next stay*) or break or breaks or (buddy next scheme*) or befriending or (night next care))
#58. (relief near/3 support)
#59. (relief near/3 caring)
#60. (relief near/3 carer)
#61. (relief near/3 caregiv*)
#62. (relief near/3 (care next giv*))
#63. (sitting or holiday* or vacation* or (residential next home*) or (day next centre*) or (day next center*)
#64. respite
#65. (day next care) or daycare or (day next program*) or (day next service*) or (day next away) or crossroads or hotel* or outing* or (personal next assistant*) or leisure*
#66. (time next off)
#67. (visitor* or (social next club*) or (friendship next club*) or (home next based) or inhome or (temporary next relief) or (home next care))
#68. (homecare or (domicillary next service*) or (domicillary next care) or (domicil* near/2 service*) or (domicil* near/2 care) or homemaker* or (home next help*) or (home next healthcare))

#69. ((home next health next care) or (home next nursing) or (night next nursing) or (home near/2 service*) or (home near/2 treatment*))
#70. (#55 or #56 or #57 or #58 or #59 or #60 or #61 or #62 or #63 or #64 or #65 or #66 or #67 or #68 or #69)
#71. (#54 and #70)

Database of Abstracts of Reviews of Effects (DARE) (CRD Internal database)

Searched: 18 March 2005
This search strategy produced 54 records.

s carer$ or care(w)giv$ or caregiv$ or informal(w)care or befriending or care(w)taker or care(w)taking or children(w)caring or parent (2w)caring or parents(2w)caring or mother(2w)caring or mothers(2w)caring or father(2w)caring or fathers(2w)caring or sons(2w)care or sons(2w)caring or daughters(2w)care or daughters(2w)caring or friends(2w)care
s friends(2w)caring or wives(2w)care or wife(2w)care or spouse$(2w)care or grandparent$(2w)care or grandchild(2w)care or neighbour$(2w)care or neighbour(2w)care or relatives(2w)care or wives(2w)caring or wife(2w)caring or spouse$(2w)caring or grandparent$(2w)caring or grandchild$(2w)caring or neighbour$(2w)caring or neighbour$(2w)caring or relatives(2w)caring or husband$(2w)support or wives(2w)support or wife(2w)support
s spouse$(2w)support or grandparent$(2w)support or grandchild$(2w)support or neighbour$(2w)support or neighbour$(2w)support or relatives(2w)support or wives(2w)supporting or wife(2w)supporting or spouse$(2w)supporting or grandparent$(2w)supporting or grandchild$(2w)supporting or neighbour$(2w)supporting or neighbour$(2w)supporting or relatives(2w)supporting or families(w)caring or families(2w)support
s s1 or s2 or s3
s care(w)attendant$ or support(w)service$ or support(w)program$ or support(w)scheme$ or home(w)support or short(w)stay$ or break or breaks or respite or buddy(w)scheme or befriending or night(w)care or temporary(w)relief or relief(2w)support or relief(2w)caring or relief(2w)carer or relief(2w)caregiv$ or relief(2w)care(w)giv$ or sitting or holiday$ or vacation$ or residential(w)home$ or day(w)centre$ or day(w)center$ or day(w)care or day(w)service$ or day(w)away or day(w)program$ or daycare or crossroads or hotel$ or outing$ or personal(w)assistant$ or leisure time(w)off or visitor$ or social(w)club$ or friendship(w)club$ or home(w)based or inhome or home(w)care or homecare or domicil$(2w)service$ or domicil$(2w)care or homemaker$ or home(w)help$ or home(w)healthcare or home(w)health(w)care or home(w)nursing or night(w)nursing or home(2w)service$ or home(2w)treatment$
s s4 and s5

Databases on old and ageing

AgeInfo

Searched: 31 March 2005 by N Lievesley at Centre for Policy on Ageing
This search was limited to papers published from 1980 onwards and retrieved 855 records.

#1 Keywords informal care@
#2 Text carer*
#3 Text caregiv*
#4 Text care giv*
#5 Text informal care
#6 Text befriending
#7 Text caretak* or care tak*
#8 Text son* .2. (care* or caring or support*)
#9 Text daughter* .2. (care* or caring or support*)
#10 Text friend* .2. (care* or caring or support*)
#11 Text famil* .2. (care* or caring or support*)
#12 Text husband .2. (care* or caring or support*)
#13 Text (wife or wives) .2. (care* or caring or support*)
#14 Text spouse .2. (care* or caring or support*)
#15 Text neighbo* .2. (care* or caring or support*)
#16 Text (grandmother or grandfather or grandparent) .2. (care* or caring or support*)
#17 Text grandchild* .2. (care* or caring or support*)
#18 Text relative* .2. (care* or caring or support*)
#19 Text (mother* or father* or parent*) .2. (care* or caring or support*)
#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 Keywords boarding out schemes@
#22 Text respite or relief
#23 Text care attendant*
#24 Text support service* or support program* or support scheme* or home support
#25 Text short stay*
#26 Text break or breaks

#27 Text buddy scheme*
#28 Text befriending
#29 Text night care
#30 Text sitting
#31 Text holiday* or vacation*
#32 Text residential home* or residential care*
#33 Text day cent*
#34 Text day care or daycare
#35 Text day service* or day program*
#36 Text crossroads
#37 Text hotel* or outing*
#38 Text personal assistant*
#39 Text leisure or time off
#40 Text visitor*
#41 Text social club* or friendship club*
#42 Text home based or inhome or home care or homecare
#43 Text domicillary or domicilary or homemaker* or home help*
#44 Text home healthcare or home health care or home nursing or night nursing
#45 Text home .2. (service or treatment)
#46 - #21 or #22 or #23 or #24 or #25 or #26 or #27 or #28 or #29 or #30 or #31 or #32 or #33 or #34 or #35 or #36 or #37 or #38 or #39 or #40 or #41 or #42 or #43 or #44 or #45
#47 - #20 and #46

AgeLine (DIALOG)

1980 to February 2005
Searched: 30 March 2005
This search strategy retrieved 2451 records.

s caregiv?
s care(w)giver or care(w)givers or care(w)giving
s carer?
s informal(2w)care
s befriending
s caretak?
s care(2w)taker?
s care(2w)taking
s children(2w)caring
s ((parent or parents or mother or mothers or father or fathers) (2w) caring)
s ((sons or daughters or friends)(2w)(care or caring))
s ((husband? or wives or wife or spouse? or grandparent? or grandchild? or neighbour? or neighbor? or relatives)(2w)(care or caring or support or supporting))
s families(w)caring
s families(2w)support
s care(w)attendant?
s (support(w)service? or support(w)program? or support(w)scheme? or home(w)support)
s (short(w)stay? or break or breaks)
s (buddy(w)scheme? or befriending)
s night(w)care
s (relief(3w)(support or caring or carer or caregiv? or care giv?))
s sitting
s holiday? or vacation?
s residential(w)home?
s respite
s day(w)centre? or day(w)center?
s (day(w)care or daycare or day(w)program? or day(w)service? or day(w)away)
s crossroads
s (hotel? or outing?)
s personal(w)assistant?
s leisure
s time(w)off
s visitor?
s social(w)club?
s friendship(w)club?
s (home(w)based or inhome)
s temporary(w)relief
s home(w)care
s homecare
s (domicil?(2w)service?)
s (domicil?(2w)care)
s homemaker?
s (home(w)help? or home(w)healthcare or home(w)health(w)care)
s (home(w)nursing or night(w)nursing)
s (home(2w)service?)
s (home(2w)treatment?)
s s1:s14
s s15:s45
s s46 and s47

Health/medical-related databases

Allied and Complementary Medicine Database (AMED) (OvidWeb)

1985 to March 2005
Searched: 10 March 2005
This search strategy retrieved 419 records.

1. caregiv$.ti,ab.
2. care giv$.ti,ab.
3. carer$.ti,ab.
4. informal care.ti,ab.
5. befriending.ti,ab.
6. caretak$.ti,ab.
7. care taker$.ti,ab.
8. care taking.ti,ab.
9. children caring.ti,ab.
10. ((parent or parents or mother or mothers or father or fathers) adj2 caring).ti,ab.
11. ((sons or daughters or friends) adj2 (care or caring)).ti,ab.

12. ((husband$ or wives or wife or spouse$ or grandparent$ or grandchild$ or neighbour$ or neighbor$ or relatives) adj2 (care or caring or support or supporting)).ti,ab.
13. families caring.ti,ab.
14. (families adj2 support).ti,ab.
15. Caregivers/
16. Respite Care/
17. care attendant$.ti,ab.
18. (support service$ or support program$ or support scheme$ or home support).ti,ab.
19. (short stay$ or break or breaks).ti,ab.
20. day care/
21. (buddy scheme$ or befriending).ti,ab.
22. night care.ti,ab.
23. (relief adj2 (support or caring or carer or caregiv$ or care giv$)).ti,ab.
24. sitting.ti,ab.
25. (holiday$ or vacation$).ti,ab.
26. residential home$.ti,ab.
27. respite.ti,ab.
28. (day centre$ or day center$).ti,ab.
29. (day care or daycare or day program$ or day service$ or day away).ti,ab.
30. crossroads.ti,ab.
31. (hotel$ or outing$).ti,ab.
32. personal assistant$.ti,ab.
33. leisure.ti,ab.
34. time off.ti,ab.
35. visitor$.ti,ab.
36. social club$.ti,ab.
37. friendship club$.ti,ab.
38. (home-based or inhome).ti,ab.
39. temporary relief.ti,ab.
40. home care.ti,ab. or home care services/
41. homecare.ti,ab.
42. (domicil$ adj2 service$).ti,ab.
43. (domicil$ adj2 care$).ti,ab.
44. homemaker$.ti,ab.
45. (home help$ or home healthcare or home health care).ti,ab.
46. (home nursing or night nursing).ti,ab.
47. (home adj2 service$).ti,ab.
48. (home adj2 treatment$).ti,ab.
49. or/1-15
50. or/16-48
51. 49 and 50

British Nursing Index (BNI) (OvidWeb)
1985 to February 2005
Searched: 11 March 2005
This search strategy retrieved 313 records.

1. caregiv$.ti,ab.
2. care giv$.ti,ab.
3. carer$.ti,ab.
4. informal care.ti,ab.
5. befriending.ti,ab.
6. caretak$.ti,ab.
7. care taker$.ti,ab.
8. care taking.ti,ab.
9. children caring.ti,ab.
10. ((parent or parents or mother or mothers or father or fathers) adj2 caring).ti,ab.
11. ((sons or daughters or friends) adj2 (care or caring)).ti,ab.
12. ((husband$ or wives or wife or spouse$ or grandparent$ or grandchild$ or neighbour$ or neighbor$ or relatives) adj2 (care or caring or support or supporting)).ti,ab.
13. families caring.ti,ab.
14. (families adj2 support).ti,ab.
15. Carers/
16. Respite Care/
17. care attendant$.ti,ab.
18. (support service$ or support program$ or support scheme$ or home support).ti,ab.
19. (short stay$ or break or breaks).ti,ab.
20. day care/ or mental health services/
21. (buddy scheme$ or befriending).ti,ab.
22. night care.ti,ab.
23. (relief adj3 (support or caring or carer or caregiv$ or care giv$)).ti,ab.
24. sitting.ti,ab.
25. (holiday$ or vacation$).ti,ab.
26. residential home$.ti,ab.
27. respite.ti,ab.
28. (day centre$ or day center$).ti,ab.
29. (day care or daycare or day program$ or day service$ or day away).ti,ab.
30. crossroads.ti,ab.
31. (hotel$ or outing$).ti,ab.
32. personal assistant$.ti,ab.
33. leisure.ti,ab.
34. time off.ti,ab.
35. visitor$.ti,ab.
36. social club$.ti,ab.
37. friendship club$.ti,ab.
38. (home-based or inhome).ti,ab.
39. temporary relief.ti,ab.
40. home care.ti,ab.
41. homecare.ti,ab.
42. (domicil$ adj2 service$).ti,ab.
43. (domicil$ adj2 care).ti,ab.
44. homemaker$.ti,ab.
45. (home help$ or home healthcare or home health care).ti,ab.
46. (home nursing or night nursing).ti,ab.
47. (home adj2 service$).ti,ab.
48. (home adj2 treatment$).ti,ab.
49. or/1-15
50. or/16-48
51. 49 and 50

Cumulative Index to Nursing and Allied Health Literature (CINAHL) (OvidWeb)

1982 to March week 2 2005
Searched: 17 March 2005
This search strategy retrieved 1998 records.

1. caregiv$.ti,ab.
2. care giv$.ti,ab.
3. carer$.ti,ab.
4. informal care.ti,ab.
5. befriending.ti,ab.
6. caretak$.ti,ab.
7. care taker$.ti,ab.
8. care taking.ti,ab.
9. children caring.ti,ab.
10. ((parent or parents or mother or mothers or father or fathers) adj2 caring).ti,ab.
11. ((sons or daughters or friends) adj2 (care or caring)).ti,ab.
12. ((husband$ or wives or wife or spouse$ or grandparent$ or grandchild$ or neighbour$ or neighbor$ or relatives) adj2 (care or caring or support or supporting)).ti,ab.
13. families caring.ti,ab.
14. (families adj2 support).ti,ab.
15. Caregivers/
16. Respite Care/
17. care attendant$.ti,ab.
18. (support service$ or support program$ or support scheme$ or home support).ti,ab.
19. (short stay$ or break or breaks).ti,ab.
20. day care/
21. (buddy scheme$ or befriending).ti,ab.
22. night care.ti,ab.
23. (relief adj3 (support or caring or carer or caregiv$ or care giv$)).ti,ab.
24. sitting.ti,ab.
25. (holiday$ or vacation$).ti,ab.
26. residential home$.ti,ab.
27. respite.ti,ab.
28. (day centre$ or day center$).ti,ab.
29. (day care or daycare or day program$ or day service$ or day away).ti,ab.
30. crossroads.ti,ab.
31. (hotel$ or outing$).ti,ab.
32. personal assistant$.ti,ab.
33. leisure.ti,ab.
34. time off.ti,ab.
35. visitor$.ti,ab.
36. social club$.ti,ab.
37. friendship club$.ti,ab.
38. (home-based or inhome).ti,ab.
39. temporary relief.ti,ab.
40. home care.ti,ab.
41. homecare.ti,ab.
42. (domicil$ adj2 service$).ti,ab.
43. (domicil$ adj2 care).ti,ab.
44. homemaker$.ti,ab.
45. (home help$ or home healthcare or home health care).ti,ab.
46. (home nursing or night nursing).ti,ab.
47. (home adj2 service$).ti,ab.
48. (home adj2 treatment$).ti,ab.
49. or/1-15
50. or/16-48
51. 49 and 50

Cochrane Central Register of Controlled Trials (CENTRAL) (Cochrane Library)

Issue 1, 2005
Searched: 21 March 2005
The same search strategy was used as for the Cochrane Database of Systematic Reviews (CDSR). This resulted in 348 records.

EMBASE (OvidWeb)

1980 to week 10 2005
Searched: 10 March 2005
This search strategy retrieved 2229 records.

1. caregiv$.ti,ab.
2. care giv$.ti,ab.
3. carer$.ti,ab.
4. informal care.ti,ab.
5. befriending.ti,ab.
6. caretak$.ti,ab.
7. care taker$.ti,ab.
8. care taking.ti,ab.
9. children caring.ti,ab.
10. ((parent or parents or mother or mothers or father or fathers) adj2 caring).ti,ab.
11. ((sons or daughters or friends) adj2 (care or caring)).ti,ab.
12. ((husband$ or wives or wife or spouse$ or grandparent$ or grandchild$ or neighbour$ or neighbor$ or relatives) adj2 (care or caring or support or supporting)).ti,ab.
13. families caring.ti,ab.
14. (families adj2 support).ti,ab.
15. Caregivers/
16. home care/
17. care attendant$.ti,ab.
18. (support service$ or support program$ or support scheme$ or home support).ti,ab.
19. (short stay$ or break or breaks).ti,ab.
20. day care/
21. (buddy scheme$ or befriending).ti,ab.
22. night care.ti,ab.
23. (relief adj3 (support or caring or carer or caregiv$ or care giv$)).ti,ab.
24. sitting.ti,ab.
25. (holiday$ or vacation$).ti,ab.
26. residential home$.ti,ab.
27. respite.ti,ab.

28. (day centre$ or day center$).ti,ab.
29. (day care or daycare or day program$ or day service$ or day away).ti,ab.
30. crossroads.ti,ab.
31. (hotel$ or outing$).ti,ab.
32. personal assistant$.ti,ab.
33. leisure.ti,ab.
34. time off.ti,ab.
35. visitor$.ti,ab.
36. social club$.ti,ab.
37. friendship club$.ti,ab.
38. (home-based or inhome).ti,ab.
39. temporary relief.ti,ab.
40. home care.ti,ab.
41. homecare.ti,ab.
42. (domicil$ adj2 service$).ti,ab.
43. (domicil$ adj2 care).ti,ab.
44. homemaker$.ti,ab.
45. (home help$ or home healthcare or home health care).ti,ab.
46. (home nursing or night nursing).ti,ab.
47. (home adj2 service$).ti,ab.
48. (home adj2 treatment$).ti,ab.
49. or/1-15
50. or/16-48
51. 50 and 49

Health Management Information Consortium (HMIC) (OvidWeb)

HELMIS 1984–1998, DHdata 1983 to January 2005 and the King's Fund database 1979 to January 2005
Searched: 11 March 2005
This search strategy retrieved 1179 records.

1. caregiv$.ti,ab.
2. care giv$.ti,ab.
3. carer$.ti,ab.
4. informal care.ti,ab.
5. befriending.ti,ab.
6. caretak$.ti,ab.
7. care taker$.ti,ab.
8. care taking.ti,ab.
9. children caring.ti,ab.
10. ((parent or parents or mother or mothers or father or fathers) adj2 caring).ti,ab.
11. ((sons or daughters or friends) adj2 (care or caring)).ti,ab.
12. ((husband$ or wives or wife or spouse$ or grandparent$ or grandchild$ or neighbour$ or neighbor$ or relatives) adj2 (care or caring or support or supporting)).ti,ab.
13. families caring.ti,ab.
14. (families adj2 support).ti,ab.
15. carers/ or informal care/
16. exp Respite Care/
17. care attendant$.ti,ab.
18. (support service$ or support program$ or support scheme$ or home support).ti,ab.
19. (short stay$ or break or breaks).ti,ab.
20. day care/
21. (buddy scheme$ or befriending).ti,ab.
22. night care.ti,ab.
23. (relief adj3 (support or caring or carer or caregiv$ or care giv$)).ti,ab.
24. sitting.ti,ab.
25. (holiday$ or vacation$).ti,ab.
26. residential home$.ti,ab.
27. respite.ti,ab.
28. (day centre$ or day center$).ti,ab.
29. (day care or daycare or day program$ or day service$ or day away).ti,ab.
30. crossroads.ti,ab.
31. (hotel$ or outing$).ti,ab.
32. personal assistant$.ti,ab.
33. leisure.ti,ab.
34. time off.ti,ab.
35. visitor$.ti,ab.
36. social club$.ti,ab.
37. friendship club$.ti,ab.
38. (home-based or inhome).ti,ab.
39. temporary relief.ti,ab.
40. home care.ti,ab.
41. homecare.ti,ab.
42. (domicil$ adj2 service$).ti,ab.
43. (domicil$ adj2 care).ti,ab.
44. homemaker$.ti,ab.
45. (home help$ or home healthcare or home health care).ti,ab.
46. (home nursing or night nursing).ti,ab.
47. (home adj2 service$).ti,ab.
48. (home adj2 treatment$).ti,ab.
49. or/1-15
50. or/16-48
51. 49 and 50
52. limit 51 to yr=1980-2005

Health Technology Assessment Database (HTA) (CRD Internal Database)

Searched: 18 March 2005
The same search strategy was used as for DARE.
This search produced 14 records.

MEDLINE (OvidWeb)

1966 to March week 1 2005
Searched: 10 March 2005
This search strategy retrieved 2811 records.

1. caregiv$.ti,ab.
2. care giv$.ti,ab.
3. carer$.ti,ab.
4. informal care.ti,ab.
5. befriending.ti,ab.
6. caretak$.ti,ab.

7. care taker$.ti,ab.
8. care taking.ti,ab.
9. children caring.ti,ab.
10. ((parent or parents or mother or mothers or father or fathers) adj2 caring).ti,ab.
11. ((sons or daughters or friends) adj2 (care or caring)).ti,ab.
12. ((husband$ or wives or wife or spouse$ or grandparent$ or grandchild$ or neighbour$ or neighbor$ or relatives) adj2 (care or caring or support or supporting)).ti,ab.
13. families caring.ti,ab.
14. (families adj2 support).ti,ab.
15. Caregivers/
16. Respite Care/
17. care attendant$.ti,ab.
18. (support service$ or support program$ or support scheme$ or home support).ti,ab.
19. (short stay$ or break or breaks).ti,ab.
20. day care/
21. (buddy scheme$ or befriending).ti,ab.
22. night care.ti,ab.
23. (relief adj3 (support or caring or carer or caregiv$ or care giv$)).ti,ab.
24. sitting.ti,ab.
25. (holiday$ or vacation$).ti,ab.
26. residential home$.ti,ab.
27. respite.ti,ab.
28. (day centre$ or day center$).ti,ab.
29. (day care or daycare or day program$ or day service$ or day away).ti,ab.
30. crossroads.ti,ab.
31. (hotel$ or outing$).ti,ab.
32. personal assistant$.ti,ab.
33. leisure.ti,ab.
34. time off.ti,ab.
35. visitor$.ti,ab.
36. social club$.ti,ab.
37. friendship club$.ti,ab.
38. (home-based or inhome).ti,ab.
39. (temporary relief).ti,ab.
40. home care.ti,ab.
41. homecare.ti,ab.
42. (domicil$ adj2 service$).ti,ab.
43. (domicil$ adj2 care).ti,ab.
44. homemaker$.ti,ab.
45. (home help$ or home healthcare or home health care).ti,ab.
46. (home nursing or night nursing).ti,ab.
47. (home adj2 service$).ti,ab.
48. (home adj2 treatment$).ti,ab.
49. or/1-15
50. or/16-48
51. 49 and 50
52. limit 51 to yr=1980 - 2005

MEDLINE In-Process, Other Non-Indexed Citations (OvidWeb)

9 March 2005
Searched: 10 March 2005
This search strategy retrieved 69 records.

1. caregiv$.ti,ab.
2. care giv$.ti,ab.
3. carer$.ti,ab.
4. informal care.ti,ab.
5. befriending.ti,ab.
6. caretak$.ti,ab.
7. care taker$.ti,ab.
8. care taking.ti,ab.
9. children caring.ti,ab.
10. ((parent or parents or mother or mothers or father or fathers) adj2 caring).ti,ab.
11. ((sons or daughters or friends) adj2 (care or caring)).ti,ab.
12. ((husband$ or wives or wife or spouse$ or grandparent$ or grandchild$ or neighbour$ or neighbor$ or relatives) adj2 (care or caring or support or supporting)).ti,ab.
13. families caring.ti,ab.
14. (families adj2 support).ti,ab.
15. care attendant$.ti,ab.
16. (support service$ or support program$ or support scheme$ or home support).ti,ab.
17. (short stay$ or break or breaks).ti,ab.
18. (buddy scheme$ or befriending).ti,ab.
19. night care.ti,ab.
20. (relief adj3 (support or caring or carer or caregiv$ or care giv$)).ti,ab.
21. sitting.ti,ab.
22. (holiday$ or vacation$).ti,ab.
23. residential home$.ti,ab.
24. respite.ti,ab.
25. (day centre$ or day center$).ti,ab.
26. (day care or daycare or day program$ or day service$ or day away).ti,ab.
27. crossroads.ti,ab.
28. (hotel$ or outing$).ti,ab.
29. personal assistant$.ti,ab.
30. leisure.ti,ab.
31. time off.ti,ab.
32. visitor$.ti,ab.
33. social club$.ti,ab.
34. friendship club$.ti,ab.
35. (home-based or inhome).ti,ab.
36. (temporary relief).ti,ab.
37. home care.ti,ab.
38. homecare.ti,ab.
39. (domicil$ adj2 service$).ti,ab.
40. (domicil$ adj2 care).ti,ab.
41. homemaker$.ti,ab.
42. (home help$ or home healthcare or home health care).ti,ab.

43. (home nursing or night nursing).ti,ab.
44. (home adj2 service$).ti,ab.
45. (home adj2 treatment$).ti,ab.
46 or/1-14
47 or/15-45
48 46 and 47

PsycINFO (BIDS)

1972 to March week 1 2005
Searched: 18 March 2005
This search strategy retrieved 3306 records.

#1 caregiv* or care giv* or carer* or informal care or befriending or caretaker* or care taker* or care taking or children caring or families caring
#2 (parent or parents or mother or mothers or father or fathers) near2 caring
#3 (sons or daughters or friends) near2 (care or caring)
#4 (husband* or wives or wife or spouse* or grandparent* or grandchild* or neighbor* or neighbour* or relatives) near2 (support or supporting or care or caring)
#5 families near2 support
#6 (respite or care attendant* or support service* or support program* or support scheme* or home support or short stay* or break or breaks or buddy scheme* or befriending or night care or relief or sitting or holiday* or vacation* or residential home* or day centre* or day center* or day care or daycare or day program* or day service* or day away or crossroads or hotel* or outing* or personal assistant* or leisure or time off or visitor* or social club* or friendship club* or home based or inhome or home care or homecare or domicil* near2 service* or domicil* near2 care or homemaker* or home help* or home healthcare or home health care or home nursing or night nursing or home near2 service* or home near2 treatment*)
#7 #1 or #2 or #3 or #4 or #5
#8 #5 and #6

Social care databases

Applied Social Sciences Index and Abstracts (ASSIA) (CSA Illumina)

1987 to March 2005
Searched: 18 March 2005
This search strategy retrieved 781 records.

(carer* or caregiv* or care giv* or informal care or befriending or caretaker* or care taker* or care taking or children caring or sons n2 care or sons n2 caring or daughters n2 care or daughters n2 caring or friends n2 care or friends n2 caring or families caring or husband* n2 support or wives n2 support or wife n2 support or spouse* n2 support or grandparent* n2 support or grandchild* n2 support or neighbour* n2 support or neighbor* n2 support or relatives n2 support or wives n2 supporting or wife n2 supporting or spouse* n2 supporting or grandparent* n2 supporting or grandchild* n2 supporting or neighbour* n2 supporting or neighbor* n2 supporting or relatives n2 supporting or wives n2 care or wife n2 care or spouse* n2 care or grandparent* n2 care or grandchild* n2 care or neighbour* n2 care or neighbor* n2 care or relatives n2 care or wives n2 caring or wife n2 caring or spouse* n2 caring or grandparent* n2 caring or grandchild* n2 caring or neighbour* n2 caring or neighbor* n2 caring or relatives n2 caring or parent n2 caring or parents n2 caring or mother n2 caring or mothers n2 caring or father n2 caring or fathers n2 caring or families n2 support) and (respite or care attendant* or support service* or support program* or support scheme* or home support or short stay* or break or breaks or buddy scheme* or befriending or night care or relief or sitting or holiday* or vacation* or residential home* or day centre* or day center* or day care or daycare or day program* or day service* or day away or crossroads or hotel* or outing* or personal assistant* or leisure or time off or visitor* or social club* or friendship club* or home based or inhome or home care or homecare or domicillary or domicilary or homemaker* or home help* or home healthcare or home health care or home nursing or night nursing or home n2 service* or home n2 treatment*)

Caredata (electronic Library for Social Care eLSC)

1980 to March 2005
Searched: 16 March 2005
Indexing terms are denoted by capitals and textwords by lower case. This search strategy retrieved 655 records.

CARERS / carer* or caregiv* / care giv* / informal care / befriending / caretaker* / care taker* / care taking / children caring / sons w2 care /sons w2 caring / daughters w2 care / daughters w2 caring / friends w2 care / friends w2 caring / families caring / husband* w2 support / wives w2 support / wife w2 support / spouse* w2 support / grandparent* w2 support / grandchild* w2 support / neighbour* w2 support / neighbor* w2 support / relatives w2 support / wives w2 supporting / wife w2 supporting / spouse* w2 supporting / grandparent* w2 supporting / grandchild* w2 supporting / neighbour* w2 supporting / neighbor* w2 supporting / relatives w2 supporting / wives w2 care / wife w2 care / spouse* w2 care / grandparent* w2 care / grandchild* w2 care / neighbour* w2 care / neighbor* w2 care / relatives w2 care / wives w2 caring / wife w2 caring / spouse* w2 caring / grandparent* w2 caring / grandchild* w2 caring / neighbour* w2 caring / neighbor* w2 caring / relatives w2 caring / parent w2 caring / parents w2 caring / mother w2 caring / mothers w2 caring / father w2 caring / fathers w2 caring / families w2 support) & (RESPITE CARE / DAY CARE / ADULT TRAINING CENTRES / DAY CENTRES / DAY HOSPITALS / DROP IN CENTRES / LUNCH CLUBS / PSYCHIATRIC DAY CENTRES / respite / care attendant* / support service* / support program* / support scheme* / home support / short stay* / break / breaks / buddy scheme* / befriending / night care / relief / sitting / holiday* / vacation* / residential home$ / day centre* / day center* / day care / daycare / day program* / day service* / day away / crossroads / hotel* / outing* / personal assistant* / leisure / time off / visitor* / social club* / friendship club* / home based / inhome / home care / homecare / domicillary / domicilary / homemaker* / home help* / home healthcare / home health care / home nursing / night nursing / home w2 service* / home w2 treatment*)

International Bibliography of the Social Sciences (IBSS) (BIDS)
1980 to 15 March 2005
Searched: 21 March 2005
These search strategies retrieved 122 records in total.

children caring or sons care or sons caring or daughters care or daughters caring or friends care or friends caring or families caring or husband* support or wives support or wife support or spouse* support or grandparent* support or grandchild* support or neighbour* support or neighbor* support or relatives support or wives supporting
This search strategy retrieved 35 records.

wife supporting or spouse* supporting or grandparent* supporting or grandchild* supporting or neighbour* supporting or neighbor* supporting or relatives supporting or wives care or wife care or spouse* care or grandparent* care or grandchild* care or neighbour* care or neighbor* care or relatives care or wives caring or wife caring or spouse* caring or grandparent* caring or grandchild* caring or neighbour* caring or neighbor* caring or relatives caring or parent caring or parents caring or mother caring or mothers caring or father caring or fathers caring or families support
This search strategy retrieved 27 records.

(carer* or caregiv* or care giv* or informal care or befriending or caretaker* or care taker* or care taking) and (respite or care attendant* or support service* or support program* or support scheme* or home support or short stay* or break or breaks or buddy scheme* or befriending or night care or relief or sitting or holiday* or vacation* or residential home* or day centre* or day center* or day care or daycare or day program*)
This search strategy retrieved 30 records.

(carer* or caregiv* or care giv* or informal care or befriending or caretaker* or care taker* or care taking) and (day service* or day away or crossroads or hotel* or outing* or personal assistant* or leisure or time off or visitor* or social club* or friendship club* or home based or inhome or home care or homecare or domicil* or homemaker* or home help* or home healthcare or home health care or home nursing or night nursing or home service* or home treatment*)
This search strategy retrieved 34 records.

Interventions and Policy Evaluation (C2 – RIPE) (Campbell Collaboration)
March 2005
Searched: 22 March 2005
This website was browsed for relevant studies.
No relevant studies were identified.

Social Science Citation Index (SSCI) (Web of Science)
1980–2005
Searched: 18 March 2005
This search strategy retrieved 1839 records. This interface does not accept terms such as ‘taking’ in ‘care taking’ or ‘off’ in ‘time off’, so these terms were excluded from the search strategy.

carer* or caregiv* or care giv* or informal care or befriending or caretaker* or care taker*
OR
children caring or sons care or sons caring or daughters care or daughters caring or friends care or friends caring or families caring or husband* support or wives support or wife support or spouse* support or grandparent* support or grandchild* support or neighbour* support or neighbor* support or relatives support or wives supporting or wife supporting or spouse* supporting or grandparent* supporting or grandchild* supporting or neighbour* supporting or neighbor* supporting or relatives supporting or

wives care or wife care or spouse* care or grandparent* care or grandchild* care or neighbour* care or neighbor* care or relatives care or wives caring or wife caring or spouse* caring or grandparent* caring or grandchild* caring or neighbour* caring or neighbor* caring or relatives caring or parent caring or parents caring or mother caring or mothers caring or father caring or fathers caring or families support
AND
respite or care attendant* or support service* or support program* or support scheme* or home support or short stay* or break or breaks or buddy scheme* or befriending or night care or relief or sitting or holiday* or vacation* or residential home* or day centre* or day center* or day care or daycare or day program* or day service* or day away or crossroads or hotel* or outing* or personal assistant* or leisure or visitor* or social club* or friendship club* or home based or inhome or home care or homecare or domicillary or domicilary or homemaker* or home help* or home healthcare or home health care or home nursing or night nursing or home service* or home treatment*

Social Services Abstracts (CSA Illumina)

1980 to March 2005
Searched: 18 March 2005
This database was searched with the same search strategy as ASSIA and retrieved 635 records.

Social, Psychological, Educational and Criminological Trials Register (C2-SPECTR) (Campbell Collaboration)

Searched: 22 March 2005
Because this database is small and has a simple search interface, only the ‘carers’ terms were searched for in indexed and non-indexed fields and automatic truncation was selected. This search strategy retrieved 71 records (published in 1980 or later).

Terms searched in Indexed fields: caregiv
OR
Terms searched in non-indexed fields: carer or care giv or caregiv or informal care or befriending or care tak or families caring or children caring or sons care or sons caring or daughters care or daughters caring or friends care or friends caring or families caring or husband support or wives support or wife support or spouse support or grandparent support or grandchild support or neighbour support or neighbor support or relatives support or wives supporting or wife supporting or spouse supporting or grandparent supporting or grandchild supporting or neighbour supporting or neighbor supporting or relatives supporting or wives care or wife care or spouse care or grandparent care or grandchild care or neighbour care or neighbor care or relatives care or wives caring or wife caring or spouse caring or grandparent caring or grandchild caring or neighbour caring or neighbor caring or relatives caring or parent caring or parents caring or mother caring or mothers caring or father caring or fathers caring or families support

Sociological Abstracts (CSA Illumina)

1980 to March 2005
Searched: 18 March 2005
This database was searched with the same search strategy as ASSIA and retrieved 435 records.

Economic databases

EconLit (BIDS)

1980 to February 2005
Searched: 23 March 2005
The same search strategy was used as for PsycINFO. This search retrieved two records.

Health Economics Evaluation Database (HEED)

Issue: May 2005
Searched: 13 May 2005
This search strategy retrieved 201 records.

carer* or caregiv* or 'care giving' or 'care giver or 'care givers' or 'informal care' or befriending or caretaker* or 'care taker' or 'care takers' or 'care taking' or
‘children caring’ or ‘sons care’ or ‘sons caring’ or ‘daughters care’ or ‘daughters caring’ or ‘friends care’ or ‘friends caring’ or ‘families caring’ or ‘husband support’ or ‘husbands support’ or ‘wives support’ or ‘wife support’ or ‘spouse support’ or ‘grandparent support’ or ‘grandparents support’ or ‘grandchild support’ or ‘grandchildren support’ or ‘neighbour support’ or ‘neighbours support’ or ‘neighbor support’ or ‘neighbors support’ or ‘relatives support’ or ‘wives supporting’ or ‘wife supporting’ or ‘spouse supporting’ or ‘grandparent supporting’ or ‘grandparents supporting’ or ‘grandchild supporting’ or ‘grandchildren supporting’ or ‘neighbour supporting’ or ‘neighbours supporting’ or ‘neighbors supporting’ or ‘neighbor supporting’ or ‘relatives supporting’ or ‘wives care’ or ‘wife care’ or ‘spouse care’ or ‘grandparent care’ or ‘grandparents care’ or ‘grandchild care’ or ‘grandchild care’ or ‘neighbour care’ or ‘neighbours care’ or ‘neighbor care’ or ‘neighbors care’ or ‘relatives care’ or ‘wives caring’ or ‘wife caring’ or ‘spouse caring’ or ‘grandparents caring’

or 'grandparent caring' or 'grandchildren caring' or 'grandchild caring' or 'neighbours caring' or 'neighbour caring' or 'neighbors caring' or 'neighbor caring' or 'relatives caring' or 'parent caring' or 'parents caring' or 'mother caring' or 'mothers caring' or 'father caring' or 'fathers caring' or 'families support'
AND
respite or attendant* or support or stay or stays or break* or buddy or befriending or relief or sitting or holiday* or vacation* or home* or day or crossroads or hotel* or outing* or assistant* or leisure or visitor* or club or clubs or inhome or domicillary or domicilary or night

Internet Documents in Economics Access Service (IDEAS) (working papers sections only)
Searched: 29 March 2005
After deduplicating the results of a number of searches, 76 records were retrieved.

This database was searched in a number of stages using only 'carer' terms. First any of the following terms were searched:
carer carers caregiver caregivers befriending caretakers caretaker caretaking
This search retrieved 38 records

Then, additional searches using the following terms were conducted:
informal and care
care and taker
care and takers
This search retrieved 53 records.

NHS Economic Evaluation Database (NHS EED) (CRD Web Pages)
Searched: 18 March 2005
The same search strategy was used as for DARE. This search produced 115 records.

Databases of conference proceedings

Inside Conferences (DIALOG)
1993 to March 2005
Searched: 30 March 2005
The same search strategy was used as for AgeLine and retrieved 47 records.

ISI Proceedings: science and technology (Web of Knowledge)
1990 to 2005
Searched: 23 March 2005
The same search strategy was used as for SSCI and retrieved 153 records.

ISI Proceedings: social sciences and humanities (Web of Knowledge)
1990 to 2005
Searched: 23 March 2005
The same search strategy was used as for SSCI and retrieved 101 records.

Databases of reports, dissertations and other grey literature

Dissertation Abstracts
2003–2005
Searched: 29 March 2005
This search strategy retrieved 20 records.

1 (carer? or caregiv? or care giv? or informal care or befriending or caretaker? or care taker? or care taking or children caring)
2 (sons w/2 care) or (sons w/2 caring) or (daughters w/2 care) or (daughters w/2 caring)
3 (friends w/2 care) or (friends w/2 caring)
4 (families caring) or (husband? w/2 support)
5 (wives w/2 support) or (wife w/2 support)
6 (spouse? w/2 support) or (grandparent? w/2 support)
7 (grandchild? w/2 support) or (neighbour? w/2 support)
8 (neighbor? w/2 support) or (relatives w/2 support)
9 (wives w/2 supporting)
10 (wife w/2 supporting) or (spouse? w/2 supporting)
11 (grandparent? w/2 supporting)
12 (grandchild? w/2 supporting) or (neighbour? w/2 supporting) or (neighbor? w/2 supporting)
13 (relatives w/2 supporting) or (wives w/2 care) or (wife w/2 care) or (spouse? w/2 care) or (grandparent? w/2 care)
14 (grandchild? w/2 care) or (neighbour? w/2 care) or (neighbor? w/2 care) or (relatives w/2 care) or (wives w/2 caring)
15 (wife w/2 caring) or (spouse? w/2 caring) or (grandparent? w/2 caring) or (grandchild? w/2 caring) or (neighbour? w/2 caring) or (neighbor? w/2 caring)
16 (relatives w/2 caring) or (parent w/2 caring) or (parents w/2 caring) or (mother w/2 caring) or (mothers w/2 caring) or (father w/2 caring) or (fathers w/2 caring) or (familiesw/2 support)
17 respite or care attendant? or support service? or support program? or support scheme? or home support
18 short stay? or break or breaks or buddy scheme? or befriending or night care or relief or sitting or holiday? or vacation? or residential home? or day centre? or day center? or day care or daycare or day program? or day service? or day away

19 crossroads or hotel? or outing? or personal assistant? or leisure or time off or visitor? or social club? or friendship club? or home based or inhome or home care or homecare or domicillary or domicilary or homemaker? or home help?
20 home healthcare or home health care or home nursing or night nursing
21 home w/2 service?
22 home w/2 treatment?
23 #17 or #18 or #19 or #20 or #21 or #22
24 #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
25 #23 and #24

Index to Theses
1980 to 19 January 2005
Searched: 24 March 2005
A series of searches was conducted and the subsequent results were deduplicated. This resulted in 25 records being identified.

(carer* or caregiv* or "care giv*" or "informal care" or caretaker*) and (respite or "care attendant*" or "support service*" or "support program*" or "support scheme*" or "home support")
This search retrieved eight records.

(carer* or caregiv* or "care giv*" or "informal care" or caretaker*) and ("short stay*" or break or breaks or "buddy scheme*" or befriending or "night care" or relief or sitting or holiday*)
This search retrieved four records.

(carer* or caregiv* or "care giv*" or "informal care" or caretaker*) and (vacation* or "residential home*" or "day centre*" or "day center*" or "day care" or "daycare" or "day program*")
This search retrieved no records.

(carer* or caregiv* or "care giv*" or "informal care" or caretaker*) and ("day service*" or "day away" or crossroads or hotel* or outing* or "personal assistant*" or leisure)
This search retrieved four records.

(carer* or caregiv* or "care giv*" or "informal care" or caretaker*) and ("time off" or visitor* or "social club*" or "friendship club*" or "home based" or inhome or "home care" or homecare)
This search retrieved four records.

(carer* or caregiv* or "care giv*" or "informal care" or caretaker*) and (domicillary or domicilary or homemaker* or "home help*" or "home healthcare" or "home health care")
This search retrieved no records.

(carer* or caregiv* or "care giv*" or "informal care" or caretaker*) and ("home nursing" or "night nursing" or (home w2 service*) or (home w2 treatment*))
This search retrieved no records.

("children caring" or "care taking" or "care taker*" or befriending)
This search retrieved six records.

(sons W/2 care) or (sons W/2 caring) or (daughters W/2 care) or (friends W/2 care) or (friends W/2 caring) or (wives W/2 support) or (wife W/2 support) or (grandparent* W/2 support)
This search retrieved no records.

(neighbor* W/2 support) or or (wives W/2 supporting) or (wife W/2 supporting) or (spouse* W/2 supporting) or (grandparent* W/2 supporting) or (grandchild* W/2 supporting)
This search retrieved no records.

(neighbour* W/2 supporting) or (neighbor* W/2 supporting) or (relatives W/2 supporting) or (wives W/2 care) or (wife W/2 care) or (spouse* W/2 care) or (grandparent* W/2 care)
This search retrieved no records.

(grandchild* W/2 care) or (neighbour* W/2 care) or (neighbor* W/2 care) or (relatives W/2 care) or (wives W/2 caring) or (wife W/2 caring) or (grandchild* W2 support)
This search retrieved one record.

(grandparent* W/2 caring) or (grandchild* W/2 caring) or (neighbour* W/2 caring) or (neighbor* W/2 caring) or or (parent W/2 caring)
This search retrieved no records.

(mother W/2 caring) or (father W/2 caring) or (fathers W/2 caring)
This search retrieved no records.

((neighbour* W/2 support) or (mothers W/2 caring)) and (respite or "care attendant*" or "support service*" or "support program*" or "support scheme*" or "home support")
This search retrieved no records.

((families W/2 support) or (parents W/2 caring)) and (respite or "care attendant*" or "support service*" or "support program*" or "support scheme*" or "home support")
This search retrieved three records.

((relatives W/2 caring) or (spouse* W/2 caring)) and (respite or "care attendant*" or "support

service*" or "support program*" or "support scheme*" or "home support")
This search retrieved no records.

((relatives W/2 support) or (daughters W/2 caring)) and (respite or "care attendant*" or "support service*" or "support program*" or "support scheme*" or "home support")
This search retrieved no records.

(families caring) or (husband* W/2 support) and (respite or "care attendant*" or "support service*" or "support program*" or "support scheme*" or "home support")
This search retrieved one record.

(spouse* W/2 support) or (families W/2 support) and (respite or "care attendant*" or "support service*" or "support program*" or "support scheme*" or "home support")
This search retrieved three records.

(neighbour* W/2 support) or (mothers W/2 caring) and ("short stay*" or break or breaks or "buddy scheme*" or befriending or "night care" or relief or sitting or holiday*)
This search retrieved no records.

(families W/2 support) or (parents W/2 caring) and ("short stay*" or break or breaks or "buddy scheme*" or befriending or "night care" or relief or sitting or holiday*)
This search retrieved two records.

(relatives W/2 caring) or (spouse* W/2 caring) and ("short stay*" or break or breaks or "buddy scheme*" or befriending or "night care" or relief or sitting or holiday*)
This search retrieved no records.

(relatives W/2 support) or (daughters W/2 caring) and ("short stay*" or break or breaks or "buddy scheme*" or befriending or "night care" or relief or sitting or holiday*)
This search retrieved no records.

(families caring) or (husband* W/2 support) and ("short stay*" or break or breaks or "buddy scheme*" or befriending or "night care" or relief or sitting or holiday*)
This search retrieved one record.

(spouse* W/2 support) or (families W/2 support) and ("short stay*" or break or breaks or "buddy scheme*" or befriending or "night care" or relief or sitting or holiday*)
This search retrieved two records.

(neighbour* W/2 support) or (mothers W/2 caring) and (vacation* or "residential home*" or "day centre*" or "day center*" or "day care" or "daycare" or "day program*")
This search retrieved no records.

(families W/2 support) or (parents W/2 caring) and (vacation* or "residential home*" or "day centre*" or "day center*" or "day care" or "daycare" or "day program*")
This search retrieved no records.

(relatives W/2 caring) or (spouse* W/2 caring) and (vacation* or "residential home*" or "day centre*" or "day center*" or "day care" or "daycare" or "day program*")
This search retrieved no records.

(relatives W/2 support) or (daughters W/2 caring) and (vacation* or "residential home*" or "day centre*" or "day center*" or "day care" or "daycare" or "day program*")
This search retrieved no records.

(families caring) or (husband* W/2 support) and (vacation* or "residential home*" or "day centre*" or "day center*" or "day care" or "daycare" or "day program*")
This search retrieved no records.

(spouse* W/2 support) or (families W/2 support) and (vacation* or "residential home*" or "day centre*" or "day center*" or "day care" or "daycare" or "day program*")
This search retrieved no records.

(neighbour* W/2 support) or (mothers W/2 caring) and ("day service*" or "day away" or crossroads or hotel* or outing* or "personal assistant*" or leisure)
This search retrieved one record.

(families W/2 support) or (parents W/2 caring) and ("day service*" or "day away" or crossroads or hotel* or outing* or "personal assistant*" or leisure)
This search retrieved no records.

(relatives W/2 caring) or (spouse* W/2 caring) and ("day service*" or "day away" or crossroads or hotel* or outing* or "personal assistant*" or leisure)
This search retrieved no records.

(relatives W/2 support) or (daughters W/2 caring) and ("day service*" or "day away" or crossroads or hotel* or outing* or "personal assistant*" or leisure)
This search retrieved no records.

(families caring) or (husband* W/2 support) and (“day service*” or “day away” or crossroads or hotel* or outing* or “personal assistant*” or leisure)
This search retrieved no records.

(spouse* W/2 support) or (families W/2 support) and (“day service*” or “day away” or crossroads or hotel* or outing* or “personal assistant*” or leisure)
This search retrieved no records.

(neighbour* W/2 support) or (mothers W/2 caring) and (“time off ” or visitor* or “social club*” or “friendship club*” or “home based” or inhome or “home care” or homecare)
This search retrieved one record.

(families W/2 support) or (parents W/2 caring) and (“time off ” or visitor* or “social club*” or “friendship club*” or “home based” or inhome or “home care” or homecare)
This search retrieved one record.

(relatives W/2 caring) or (spouse* W/2 caring) and (“time off ” or visitor* or “social club*” or “friendship club*” or “home based” or inhome or “home care” or homecare)
This search retrieved no records.

(relatives W/2 support) or (daughters W/2 caring) and (“time off ” or visitor* or “social club*” or “friendship club*” or “home based” or inhome or “home care” or homecare)
This search retrieved no records.

(families caring) or (husband* W/2 support) and (“time off ” or visitor* or “social club*” or “friendship club*” or “home based” or inhome or “home care” or homecare)
This search retrieved no records.

(spouse* W/2 support) or (families W/2 support) and (“time off ” or visitor* or “social club*” or “friendship club*” or “home based” or inhome or “home care” or homecare)
This search retrieved one record.

(neighbour* W/2 support) or (mothers W/2 caring) and (domicillary or domicilary or homemaker* or “home help*” or “home healthcare” or “home health care”)
This search retrieved no records.

(families W/2 support) or (parents W/2 caring) and (domicillary or domicilary or homemaker* or “home help*” or “home healthcare” or “home health care”)
This search retrieved no records.

(relatives W/2 caring) or (spouse* W/2 caring) and (domicillary or domicilary or homemaker* or “home help*” or “home healthcare” or “home health care”)
This search retrieved no records.

(relatives W/2 support) or (daughters W/2 caring) and (domicillary or domicilary or homemaker* or “home help*” or “home healthcare” or “home health care”)
(families caring) or (husband* W/2 support) and (domicillary or domicilary or
This search retrieved no records.

((spouse* W/2 support) or (families W/2 support)) and (domicillary or domicilary or homemaker* or “home help*” or “home healthcare” or “home health care”)
This search retrieved no records.

(neighbour* W/2 support) or (mothers W/2 caring) and (“home nursing” or “night nursing” or (home w/2 service*) or (home w2 treatment*))
This search retrieved no records.

(families W/2 support) or (parents W/2 caring) and (“home nursing” or “night nursing” or (home w/2 service*) or (home w2 treatment*))
This search retrieved no records.

(relatives W/2 caring) or (spouse* W/2 caring) and (“home nursing” or “night nursing” or (home w/2 service*) or (home w2 treatment*))
This search retrieved no records.

(relatives W/2 support) or (daughters W/2 caring) and (“home nursing” or “night nursing” or (home w/2 service*) or (home w2 treatment*))
This search retrieved no records.

(families caring) or (husband* W/2 support) and (“home nursing” or “night nursing” or (home w/2 service*) or (home w2 treatment*))
This search retrieved no records.

(spouse* W/2 support) or (families W/2 support) and (“home nursing” or “night nursing” or (home w/2 service*) or (home w2 treatment*))
This search retrieved no records.

System for Information on Grey Literature in Europe (SIGLE) (BIDS)

Searched: 23 March 2005
The same search strategy was used as for PsycINFO and retrieved 63 records.

Databases for ongoing and recently completed research

ClinicalTrials.gov

Searched: 19 July 2005
A series of searches was conducted on this database and the results were deduplicated. This retrieved 20 records.

caregiver OR caregiving OR caregivers OR befriending OR caretaker OR caretakers OR caretaking OR "care taker" OR "care givers" OR "informal care" OR "children caring" OR "families caring" OR “care giver”

"care giving" OR “sons care” OR “sons caring” OR “daughters care” OR “daughters caring” OR “friends care” OR “friends caring” OR “families caring” OR “husband support” OR “husbands support” OR “wives support” OR “wife support” OR “spouse support”

OR “grandparent support” OR “grandparents support” OR “grandchild support” OR “grandchildren support” OR “neighbour support” OR “neighbor support” OR “relatives support” OR “wives supporting “ OR “wife supporting”

OR “spouse supporting” OR “grandparent supporting” OR “grandchild supporting” OR “neighbour supporting” OR “neighbor supporting” OR “grandparents supporting” OR “grandchildren supporting” OR “neighbours supporting”

OR “neighbors supporting” OR “relatives supporting” OR “wives care” OR “wife care” OR “spouse care” OR “grandparent care” OR “grandchild care” OR “neighbour care” OR “neighbor care” OR “grandparents care” OR “grandchildren care”

OR “neighbours care” OR “neighbors care” OR “relatives care” OR “wives caring” OR “wife caring” OR “spouse caring” OR “grandparent caring” OR “grandchild caring” OR “grandchildren caring” OR “grandparents caring” OR “neighbour caring”

OR “neighbor caring” OR “neighbours caring” OR “neighbors caring” OR “relatives caring” OR “parent caring” OR “parents caring” OR “mother caring” OR “mothers caring” OR “father caring” OR “fathers caring” OR “families support”

MetaRegister of Controlled Trials

Searched: 19 July 2005
All registers were searched using a series of searches. This retrieved 254 records in total.

Carer OR caregiver OR caregiving OR caregivers OR befriending OR caretaker OR caretakers OR caretaking OR "care taker" OR "care givers" OR "informal care" OR "children caring" OR "families caring" OR “care giver”

"care giving" OR “sons care” OR “sons caring” OR “daughters care” OR “daughters caring” OR “friends care” OR “friends caring” OR “families caring” OR “husband support” OR “husbands support” OR “wives support” OR “wife support” OR “spouse support”

OR “grandparent support” OR “grandparents support” OR “grandchild support” OR “grandchildren support” OR “neighbour support” OR “neighbor support” OR “relatives support” OR “wives supporting “ OR “wife supporting”

OR “spouse supporting” OR “grandparent supporting” OR “grandchild supporting” OR “neighbour supporting” OR “neighbor supporting” OR “grandparents supporting” OR “grandchildren supporting” OR “neighbours supporting”

OR “neighbors supporting” OR “relatives supporting” OR “wives care” OR “wife care” OR “spouse care” OR “grandparent care” OR “grandchild care” OR “neighbour care” OR “neighbor care” OR “grandparents care” OR “grandchildren care”

OR “neighbours care” OR “neighbors care” OR “relatives care” OR “wives caring” OR “wife caring” OR “spouse caring” OR “grandparent caring” OR “grandchild caring” OR “grandchildren caring” OR “grandparents caring” OR “neighbour caring”

OR “neighbor caring” OR “neighbours caring” OR “neighbors caring” OR “relatives caring” OR “parent caring” OR “parents caring” OR “mother caring” OR “mothers caring” OR “father caring” OR “fathers caring” OR “families support”

ESRC SocietyToday Database

Searched: 20 July 2005
This search strategy retrieved 1204 records.

caregiver OR caregiving OR caregivers OR befriending OR caretaker OR caretakers OR caretaking OR "care taker" OR "care givers" OR "informal care" OR "children caring" OR "families caring" OR “care giver” OR carer OR carers

National Research Register (NRR)

Issue 2, 2005
Searched: 20 July 2005
This search strategy retrieved 2154 records, many of which were duplicates within the database.

#1 carer* or caregiv* or care giv* or informal care or befriending or caretaker* or care taker* or care taking or children caring or sons care or sons caring or daughters care or daughters caring or friends care or friends caring or families caring or husband* support or wives support or wife support or spouse* support or grandparent* support or grandchild* support or neighbour* support or neighbor* support or relatives support or wives supporting or wife supporting or spouse* supporting or grandparent* supporting or grandchild* supporting or neighbour* supporting or neighbor* supporting or relatives supporting or wives care or wife care or spouse* care or grandparent* care or grandchild* care or neighbour* care or neighbor* care or relatives care or wives caring or wife caring or spouse* caring or grandparent* caring or grandchild* caring or neighbour* caring or neighbor* caring or relatives caring or parent caring or parents caring or mother caring or mothers caring or father caring or fathers caring or families support
#2 Respite or care attendant* or support service* or support program* or support scheme* or home support or short stay* or break or breaks or buddy scheme* or befriending or night care or relief or sitting or holiday* or vacation* or residential home* or day centre* or day center* or day care or daycare or day program* or day service* or day away or crossroads or hotel* or outing* or personal assistant* or leisure or visitor* or social club* or friendship club* or home based or inhome or home care or homecare or domicillary or domicilary or homemaker* or home help* or home healthcare or home health care or home nursing or night nursing or home service* or home treatment* or time off
#3 #1 and #2

Research Findings Electronic Register (ReFeR)

Searched: 20 July 2005
This database was searched in a series of stages using solely the 'carer' terms and the subsequent results were deduplicated. This resulted in 136 records.

caregiver OR caregiving OR caregivers OR befriending OR caretaker OR caretakers OR caretaking OR "care taker" OR "care givers" OR "informal care" OR "children caring" OR "families caring" OR “care giver” OR carer* OR "care giving"

“sons care” OR “sons caring” OR “daughters care” OR “daughters caring” OR “friends care” OR “friends caring” OR “families caring” OR “husband support” OR “husbands support” OR “wives support” OR “wife support” OR “spouse support” OR “grandparent support” OR “grandparents support” OR “grandchild support” OR “grandchildren support” OR “neighbour support” OR “neighbor support” OR “relatives support” OR “wives supporting “ OR “wife supporting”

OR “spouse supporting” OR “grandparent supporting” OR “grandchild supporting” OR “neighbour supporting” OR “neighbor supporting” OR “grandparents supporting” OR “grandchildren supporting” OR “neighbours supporting” OR “neighbors supporting” OR “relatives supporting” OR “wives care” OR “wife care” OR “spouse care” OR “grandparent care” OR “grandchild care” OR “neighbour care” OR “neighbor care” OR “grandparents care” OR “grandchildren care” OR

“neighbours care” OR “neighbors care” OR “relatives care” OR “wives caring” OR “wife caring” OR “spouse caring” OR “grandparent caring” OR “grandchild caring” OR “grandchildren caring” OR “grandparents caring” OR “neighbour caring” OR “neighbor caring” OR “neighbours caring” OR “neighbors caring” OR “relatives caring” OR “parent caring” OR “parents caring” OR “mother caring” OR “mothers caring” OR “father caring” OR “fathers caring” OR “families support”

Tables of records retrieved

TABLE 21 *Databases of systematic reviews*

Database	Host	Dates covered	Date searched	Records retrieved
CDSR	Internet	2005, Issue 1	21 March 2005	219
DARE	CRD Internal Database	March 2005	18 March 2005	54

TABLE 22 *Databases on old age and ageing*

Database	Host	Dates covered	Date searched	Records retrieved
Ageinfo	Centre for Policy on Ageing	1980–2005	31 March 2005	855
Ageline	DIALOG	1980 to February 2005	30 March 2005	2451

TABLE 23 *Health/medical-related databases*

Database	Host	Dates covered	Date searched	Records retrieved
AMED	OvidWeb	1985 to March 2005	10 March 2005	419
BNI	OvidWeb	1985 to February 2005	11 March 2005	313
CENTRAL	Internet	2005, Issue 1	21 March 2005	348
CINAHL	OvidWeb	1982 to March 2005	17 March 2005	1998
EMBASE	OvidWeb	1980 to 2005 week 10	10 March 2005	2229
HMIC – King's Fund Database, and Dhdata HMIC – HELMIS	OvidWeb	January 2005	11 March 2005	1179
HTA	CRD Internal Database	March 2005	18 March 2005	14
MEDLINE	OvidWeb	1980 to March week 1 2005	10 March 2005	2811
MEDLINE in process	OvidWeb	9 March 2005	10 March 2005	69
PsycINFO	BIDS	1980–2005	18 March 2005	3306

TABLE 24 *Social care databases*

Database	Host	Dates covered	Date searched	Records retrieved
ASSIA	CSA illumina	1987 to March 2005	18 March 2005	781
Caredata	Internet	1980 to March 2005	16 March 2005	655
IBSS	BIDS	1980 to 15 March 2005	21 March 2005	122
C2 – RIPE	Internet	March 2005	22 March 2005	0
C2 – SPECTR	Internet	1980 to March 2005	22 March 2005	71
Social Services Abstracts	CSA illumina	1980 to March 2005	18 March 2005	635
SSCI	Web of Science	1980 to March 2005	18 March 2005	1839
Sociological Abstracts	CSA illumina	1980 to March 2005	18 March 2005	435

TABLE 25 *Economic databases*

Database	Host	Dates covered	Date searched	Records retrieved
NHS EED	Internet	Up to 2005	18 March 2005	115
HEED	CD-ROM	Up to 2005	25 March 2005	201
IDEAS	Internet	Up to 2005	29 March 2005	76
EconLit	BIDS	1980 to February 2005	23 March 2005	2

TABLE 26 *Databases of conference proceedings*

Database	Host	Dates covered	Date searched	Records retrieved
Inside Conferences	DIALOG	1993 to March 2005	30 March 2005	47
ISI Proceedings: Social Sciences and Humanities	Web of Science	1990–2005	23 March 2005	101[a]
ISI Proceedings: Science and Technology	Web of Science	1990–2005	23 March 2005	153[a]

[a] 223 in both ISI proceedings.

TABLE 27 *Databases of reports, dissertations and other grey literature*

Database	Host	Dates covered	Date searched	Records retrieved
Dissertation Abstracts	Internet	2003–2005	29 March 2005	20
SIGLE	BIDS	1980 to December 2004	23 March 2005	63
Index to Theses	Internet	1980 to 19 January 2005	24 March 2005	25

TABLE 28 *Databases for ongoing and recently completed research*

Database	Host	Date searched	Records retrieved
Meta Register of Controlled Trials	Internet	19 March 2005	254
NRR	Internet	20 March 2005	2154
Clinicaltrials.gov	Internet	19 March 2005	20
ReFeR	Internet	20 March 2005	136
ESRC	Internet	20 March 2005	1204

Appendix 4

Findings from the literature review

TABLE 29 *Effectiveness studies included in the review: summary characteristics*

Study	Respite type Country	Methods	Participants	Intervention	Comparator(s)
Artaso Irigoyen, 2002[95]	DC Spain	**Design** Quasi-experimental with matched controls ID: 12 months; FU: 12 months **Method of randomisation** NA **Concealment** NA **Blinding** NR **Withdrawal/dropout** Carers: unclear; care recipients: 27	***n* (enrolled)** Carers: unclear; care recipients: 96 **Baseline characteristics** Similar between groups: demographic: no (intervention care recipients were significantly less likely to be married, more likely to be separated, and received higher levels of formal support; intervention carers had lower income than controls); clinical: no (intervention carers had significantly higher quality of life than control carers and were more satisfied with caring) % Male: carer: 23%; care recipient: 25% Mean age (years): carer: 54.1; care recipient: 75.8 **Inclusion criteria** People with psychiatric disorders (DSM-IIIR or affective disorder) and consequent loss of autonomy, aged ⩾65 years and with a principal carer **Exclusion criteria** NR	**Description** Psychogeriatric day care (DC): services include prosthetics, physical and mental rehabilitation, reality orientation therapy, behavioural skills training, pharmaceutical therapy and family support **Uptake** Mean number of days used by intervention group not reported	Usual care (C)
Baumgarten, 2002[35]	DC Canada	**Design** Parallel group RCT with waiting list control ID: 3 months; FU: 3 months **Method of randomisation** Randomisation by study coordinator, once eligibility determined and consent obtained. Stratified randomisation; randomisation by permuted blocks of six	***n* (enrolled)** Carers: unclear; Care recipients: 251 **Baseline characteristics** Similar between groups: demographic: yes; clinical: yes % Male: carer: 26.4%; care recipient: 28.0%. Mean age (years): carer: 56.3 (SD 15.8, $n = 178$); care recipient: 77.2 (SD 7.3, $n = 212$). **Inclusion criteria** All care recipients (aged ⩾60 years) referred to participating day centre. To be eligible to participate, day centres had to have waiting times of ⩾3 months, to offer group programmes for functional and psychosocial rehabilitation, to include care recipients with cognitive disorders, to offer respite for carers and transportation for care recipients; and to admit at least four care recipients per month	**Description** Day-centre care of multipurpose: broad range of group-based activities aimed at functional, psychological and social rehabilitation, with care tailored to need and ability. Education, support groups, exercise groups and carer counselling may be provided. Recommended participation: 6 hours per day, once or twice per week. Small daily fee to cover transportation and meal costs (DC) **Uptake** Actual attendance: median number of visits: 10; 35 (34%) care recipients attended at least	Usual care (waiting-list control); no day care used (C)

continued

TABLE 29 *Effectiveness studies included in the review: summary characteristics (cont'd)*

Study	Respite type Country	Methods	Participants	Intervention	Comparator(s)
		Concealment Adequate **Blinding** NR **Withdrawal/dropout** Carers: unclear; care recipients: 39	**Exclusion criteria** Care recipients <60 years; those who could not speak English/French; those too cognitively impaired to be interviewed and did not have an informal carer; those referred to day centre for individualised treatments such as rehabilitation treatment for Parkinson's disease; care recipients with urgent need (receive more than 20 hours per week home care or informal carer experiencing acute ill-health) where it would be unethical to randomise; paid carers	13 times; 9 (8.7%) never attended	
Burch, 2001[89,109]	DC UK	**Design** Parallel-group RCT ID: 3 months; FU: 12 months. Results reported at 3 months **Method of randomisation** Randomised by blocks of 20, using sequence of labelled tickets in sealed opaque envelope held by independent individual **Concealment** Adequate **Blinding** Single-blind (assessor) **Withdrawal/dropout** Carers: unclear; care recipients: 29	***n* (enrolled)** Carers: unclear; care recipients: 105 **Baseline characteristics** Similar between groups: demographic: no (intervention carers younger and higher proportion female); clinical: yes % Male: carer: NR; care recipient: 47.6% Mean age (years): carer: NR; care recipient: 80.4 (SD 7.6, $n = 105$) **Inclusion criteria** All older people referred as outpatients or inpatients for day hospital rehabilitative therapy, living within the study catchment areas **Exclusion criteria** Care recipients suffering from dysphagia; care recipients whose care needs could not be met by day-centre facilities	**Description** Day-centre care: physiotherapy; education; informal personalised plans; use of limited equipment; transportation provided; 2 days per week (DC) **Uptake** Median number of treatments over 3 months: 10 (IQR 5–14)	Day hospital: offer of occupational therapy (with leisure activities), physiotherapy; use of specialist equipment (heat, ice, ultrasound, parallel bars, mechanical aid); education and personalised plans; transportation provided. Median number of treatments over 3 months: 11.5 (IQR 5–20.5) (DH)

continued

TABLE 29 *Effectiveness studies included in the review: summary characteristics (cont'd)*

Study	Respite type Country	Methods	Participants	Intervention	Comparator(s)
Clark, 2000[84]	Multidimensional package UK	**Design** Uncontrolled descriptive study using qualitative and quantitative, retrospective and prospective, methods ID: 7 visits of 3.5 hours (approx.); FU: 12 months **Method of randomisation** NA **Concealment** NA **Blinding** NA **Withdrawal/dropout** Referrals data: NA. Macmillan carers' survey: NA. Informal carer survey: carers: 97 non-responders	***n* (enrolled)** Referrals data: carers: 542; care recipients: 624. Macmillan carers' survey: carers: NR; care recipients: 235. Informal carer survey: carers: 218; care recipients: NA **Baseline characteristics** Similar between groups: NA % Male: referral data: carer: NR; care recipient: 43%. Carer survey data: carer: 23%; care recipient: NR Mean age (years): referrals data: carer: 41% >60; care recipient: 73% >60, 20% >80; carer survey data: 58% of respondents >60 **Inclusion criteria** Family carers of elderly people with cancer, referred to one of seven Macmillan carers schemes in England between July 1996 and June 1997 **Exclusion criteria** NR	**Description** Multidimensional package, including in-home respite option. The schemes offered personal care, social and emotional support, and practical help. Respite the key reason for referral (42% of carers; $n = 542$) and the service most commonly used **Uptake** % Using respite: 24%; $n = 542$. Mean visit duration (hours): 3.5 (range 4–20+); mean number of visits: 7 (range 1–56)	
Conlin, 1992[94]	RP (INR, IR) USA	**Design** Quasi-experimental study (waiting-list control) with controls matched by dementia severity score ID: 10 weeks; FU: 10 weeks (for rate of institutionalisation only: 18 weeks) **Method of randomisation** Stratified allocation (non-random). Within each dementia severity level (mild, moderate, severe), people allocated alternately to intervention or control based on order of study entry **Concealment** Inadequate **Blinding** NR **Withdrawal/dropout** Unclear	***n* (enrolled)** 15 dyads **Baseline characteristics** Similar between groups: demographic: unclear; clinical: yes % Male: carer: 13%; care recipient: NR Mean age (years): carer: 60.4 (range 37–87); care recipient: NR **Inclusion criteria** Older people with AD or related dementia, where carer was applying for free respite care provided by new state-sponsored programme **Exclusion criteria** NR	**Description** Respite care provided in adult assisted living facility or at home, according to carer preference. Respite care for 6–8 hours per day, 2 days per week for 10 weeks (R) **Uptake** Mean hours respite use over study period: 15.3. 5/7 used in-home respite, 2/7 chose institutional respite	Usual care (no meal delivery, home help or home health services) (C)

continued

TABLE 29 *Effectiveness studies included in the review: summary characteristics (cont'd)*

Study	Respite type Country	Methods	Participants	Intervention	Comparator(s)
Donaldson, 1989[40,104]	DC UK	**Design** Quasi-experimental with matched controls ID: unclear; FU: unclear (from assessment to admission to long-term care or death) **Method of randomisation** NA **Concealment** NA **Blinding** NR **Withdrawal/dropout** Carers: 52; care recipients: 3	***n* (enrolled)** 105 dyads **Baseline characteristics** Similar between groups: demographic: yes; clinical: unclear (severity of illness not reported) % Male: carer 42%; care recipient: 40% Mean age (years): carer: 25% <60, 53% >70; care recipient: 6% <65, 43% 65–74, 40% 75–84, 11% ⩾85 **Inclusion criteria** Elderly mentally infirm people, suffering from chronic organic brain disease, and their carers; visitors to the FSU were matched to a control group of non-FSU users on the basis of age, sex, psychiatric diagnosis, physical state, behavioural ability, whether living alone or not **Exclusion criteria** Factors relating to "mobility, aggressiveness and age" may make admission to the FSU inappropriate, as resources unable to accommodate client (assessment by CPN)	**Description** FSU: tailor-made service including day care, evening care, special occasional residential care to suit carer interests, plus "mix of community services" (see Comparator). Transportation by minibus (F) **Uptake** Days of utilisation per person: FSU day care: F 70 ($n = 35$), C 3 ($n = 67$); FSU respite: F 19 ($n = 35$), C 0.2 ($n = 67$)	Usual care (C): "mix of community services" without FSU. Community services included day care (provided by local authority, NHS or voluntary sector), day hospital, home help, meals on wheels, institutional respite (local authority, NHS or private) and other social services (not specified). In practice, care recipients received some non-FSU day care, but much less than those in the intervention arm
Grant, 2003[97]	INR USA	**Design** Parallel-group RCT ID: 10 days; FU: 40 days **Method of randomisation** Random numbers table **Concealment** Unclear **Blinding** NR **Withdrawal/dropout** Unclear	***n* (enrolled)** 55 dyads **Baseline characteristics** Similar between groups: demographic: unclear; clinical: yes % Male: carer: 38.1%; care recipient: NR Mean age (years): carer: 73.3 (SD 5.3, $n = 55$), care recipient: NR **Inclusion criteria** Spousal carers of people with diagnosis of probable or possible AD; dyad living at home; carer in receipt of <8 hours respite per week **Exclusion criteria** Carers receiving medications known to alter plasma catecholamine levels	**Description** In-home respite care: 10 days of in-home help (up to 6 hours per day) over a 2-week period. Carers could leave, do chores, hobbies or anything else they chose (R) **Uptake** Mean use 43.0 hours (SD 20.8); five carers (all non-vulnerable) used none of the interventions	Usual care (C)

continued

TABLE 29 *Effectiveness studies included in the review: summary characteristics (cont'd)*

Study	**Respite type Country**	**Methods**	**Participants**	**Intervention**	**Comparator(s)**
Hedrick, 1993[93,106–112]	DC USA	**Design** Parallel-group RCT ID: 12 months; FU: 12 months **Method of randomisation** Centrally randomised by computerised random number generator using blocks (block size also varied randomly) **Concealment** Adequate **Blinding** NR **Withdrawal/dropout** 297 (including contract day-care study)	***n* (enrolled)** Carers: 586; care recipients: 826 **Baseline characteristics** Similar between groups: demographic: yes; clinical: yes % Male: carer: NR; care recipient: 96% Mean age (years): carer: 62.5 (SD 12.9), range 20–100;[109] care recipient: mean: 72, 33% aged ≥75, 12% >84 **Inclusion criteria** Elderly people at high risk of nursing home placement ('very frail'); meeting at least one of the following conditions: residing in, or admitted via hospital to, a nursing home; requiring personal assistance/supervision for ambulation/dressing/toilet use; significant cognitive impairment (MMSE: disorientation/recall; bowel incontinence) **Exclusion criteria** Persons ineligible for VA services or unacceptable to day-care staff	**Description** ADHC (Department of Veterans Affairs): intensive health and social services, professionally staffed. Concurrent use of home care services for those using VDC prohibited by VA regulations. Sites selected as "the most well established" "best developed programs in the largest Medical Centers" and representing dispersed geographical locations. Transportation provided at some sites. Mean use over 12 months: 45 visits (range 0–246); 15% had no visits (DC-V) **Uptake** Average number of weekly visits: 2.75; mean number of annual days in VA day care: 63.81	Usual care (C): care recipients had some non-VA day care, but not significantly more than those in the intervention arms
Holm, 2003[90]	HFR Australia	**Design** Uncontrolled qualitative study ID: 12 months; FU: 12 months **Method of randomisation** NA **Concealment** NA **Blinding** NA **Withdrawal/dropout** 7	***n* (enrolled)** Carers: unclear; care recipients: 25 **Baseline characteristics** Similar between groups: NA % Male: carer: 14% ($n = 7$); care recipient: 17% ($n = 18$) Mean age (years): carer: NR; care recipient: 81.5 ($n = 18$) **Inclusion criteria** Older people with dementia and disordered behaviour, for whom centre-based respite was difficult or inappropriate **Exclusion criteria** NR	**Description** Short-break service: service provider's home used for up to six care recipients for 6 hours per day, once a week. Services included games, tea and lunch, exercise, crafts, conversation and occasional outings. Transport to and from respite provided. Fee of AUS$8 per session **Uptake** Average annual attendance: 17 weeks (range 1–45)	

continued

TABLE 29 *Effectiveness studies included in the review: summary characteristics (cont'd)*

Study	Respite type Country	Methods	Participants	Intervention	Comparator(s)
Johnson, 1988[85]	INR UK	**Design** Uncontrolled, retrospective descriptive study of referral data ID: 3 hours over 7 weeks (approx.); FU: 24 months **Method of randomisation** NA **Concealment** NA **Blinding** NA **Withdrawal/dropout** 56 (patients discharged from scheme over study period)	***n* (enrolled)** Carers: $n = 190$; care recipients: $n = 244$ **Baseline characteristics** Similar between groups: NA % Male: carer: 27%; care recipient: NR Mean age (years): carer: 59.7, 30% $\geqslant 70$; care recipient: 68.3 **Inclusion criteria** Family carers of terminally ill patients referred to the scheme from May 1984 to May 1986 **Exclusion criteria** Referrals judged to be 'inappropriate' were referred elsewhere	**Description** Relative Support Scheme: in-home respite **Uptake** Mean use (hours): 3.1 (range 0.5–6). Median number of visits: 2.5 (range 0–50). Mean total hours' respite: 14.4. 30% of appropriate referrals received one or no visits	
Kosloski, 1993[76]	RP (DC, INR) USA	**Design** Quasi-experimental 'non-equivalent' control group design ID: 6 months; FU: 6 months **Method of randomisation** NA **Concealment** NA **Blinding** NR **Withdrawal/dropout** 69	***n* (enrolled)** 116 dyads **Baseline characteristics** Similar between groups: demographic: no (care recipients differed on racial composition and household income); clinical: yes % Male: carer: 26%; care recipient: 47% Mean age (years): carer ($n = 72$): mean value NR (range 38–89); 67% >60, 40% >70, 18% >80. Care recipient ($n = 72$): mean value NR (range NR); >60: 96%; >70: 75%; >80: 32% **Inclusion criteria** Carers of persons with AD or related dementia; participants providing baseline and follow-up assessment data **Exclusion criteria** NR	**Description** Respite programme: adult day care (2/7 sites; 5 days per week, 9 hours per day); in-home respite (2/7 sites: day/evenings on weekdays, provision flexible); adult day care and in-home respite (3/7 sites) (R) **Uptake** Mean use (hours): 220 (range 4–1137, median 130)	No respite (waiting-list control) (C)

continued

TABLE 29 *Effectiveness studies included in the review: summary characteristics (cont'd)*

Study	Respite type Country	Methods	Participants	Intervention	Comparator(s)
Lawton, 1989[33,116,122,123]	RP (DC, INR, IR) USA	**Design** Parallel-group RCT ID: 12 months; FU: 12 months **Method of randomisation** Random numbers table; where participants were recruited through support groups, randomisation was at the level of the group. 45% of sample recruited through support groups; number of support groups not reported **Concealment** Unclear **Blinding** NR **Withdrawal/dropout** 11	***n* (enrolled)** 632 dyads **Baseline characteristics** Similar between groups: demographic: yes; clinical: no (care recipients in control group had significantly lower cognitive impairment; carers in the control group were significantly less depressed) % Male: carer: 20.6%; care recipient: 40.4% Mean age (years): carer: 59.9 (?SD, $n = 632$); care recipient: 76.2 (?SD, $n = 632$) **Inclusion criteria** Family carers; diagnosis of AD or related dementia [carer-reported physician diagnosis; Mental Status Questionnaire (Khan, 1961) >7]; residence in a six-county greater Philadelphia area **Exclusion criteria** NR	**Description** Three types of subsidised respite care offered in context of 12-month ongoing package (case management, counselling, informational and educational services): (1) in-home involving a sitter, a person to perform homemaker services or provide personal care, available regularly or occasionally, during the day or evening or weekend; (2) adult day care, 1–5 days per week (transportation/medical services provided according to need); or (3) institutional respite, emergency or planned (limited to a stay of ≤21 days). Participants offered respite services at baseline and, where respite was not taken up, at 2 months, with a 'flexible' subsidy capped at $1000 per family per year (R) **Uptake** % Using intervention at 12 months: respite (in-home): 46.1%, $n = 301$ (median use 63 hours per year); day care: 7.6%, $n = 301$ (median use 10 days per year); nursing home: 15.9%, $n = 301$ (median use: 11 days per year, range: 3 days to 3 weeks); all respite: 58.1[33]	At baseline interview, control group carers assessed, counselled and provided with a list of local agencies and resources that offered services to impaired elders and their families (C)

continued

TABLE 29 *Effectiveness studies included in the review: summary characteristics (cont'd)*

Study	Respite type Country	Methods	Participants	Intervention	Comparator(s)
Lund, 1995[92]	VR USA	**Design** Uncontrolled within-patient study ID: 1 month; FU: 1 month **Method of randomisation** NA **Concealment** NA **Blinding** Open **Withdrawal/dropout** 0	***n* (enrolled)** 31 dyads **Baseline characteristics** Similar between groups: demographic: yes; clinical: yes % Male: carer: 32%; care recipient: 45% Mean age (years): carer: 66 (range 38–89); care recipient: 78 (range 58–98) **Inclusion criteria** Carers of non-institutionalised persons with AD **Exclusion criteria** NR	**Description** Video respite tape, to be used by carer as required: "Favourite Things" (33 minutes), designed for people with AD to encourage participation and attention (V) **Uptake** 67% of carers used the tapes over the study period: mean use 14 times per month (range 0–60)	US TV programme ("Laurence Welk"): length of programme NR (C)
Montgomery, 1985[124]	RP (DC: INR, IR) USA	**Design** Parallel-group RCT ID: 12 months; FU: 20 months **Method of randomisation** NR **Concealment** Unclear **Blinding** NR **Withdrawal/dropout** Unclear	***n* (enrolled)** Carers: 541 (some caring for two people); care recipients: 576 **Baseline characteristics** Similar between groups: demographic: unclear; clinical: unclear % Male: carer: 21%; care recipient: 33% Mean age (years): carer: NR; care recipient: median: 81.6, 75% >75 **Inclusion criteria** Impaired elderly people living in the community in King County, Washington; family carer living within 1-hour driving distance of older person **Exclusion criteria** NR	**Description** Respite services: provided on fee-for-service basis through Medicare waivers ($882 Medicare funds available to each eligible family, equivalent to 14 days' institutional respite). Families could buy any combination of respite: in-home: 2–3 hours or overnight; day care: up to 5 hours per day; overnight extended stay in nursing home (R) **Uptake** Actual use: all respite: uptake: 64.6%, $n = 189$; in-home respite: uptake: 82%, $n = 122$ (29/100 used overnight in home respite; for short-stay visits: mean hours per visit: 3.32); day care: uptake: 13%, $n = 122$ (median number of visits: 21; mean hours per visit:	Multidimensional package 1: seminars for carers (2 hours per week for 6 weeks); support groups (continuation of seminar attendees, frequency determined by study participants); family consultation services (individualised training session to develop carer case management skills); respite services (in-home: 2–3 hours or overnight; day care: up to 5 hours per day; overnight extended stay in nursing home) (M1) Multidimensional package 2: seminars for carers (2 hours per week for 6 weeks); support groups (continuation of seminar attendees, frequency determined by study participants); family consultation services (individualised training session to develop carer case management) (M2) Multidimensional package 3: seminars for carers (2 hours per week for 6 weeks); support groups (continuation of seminar

continued

TABLE 29 *Effectiveness studies included in the review: summary characteristics (cont'd)*

Study	Respite type Country	Methods	Participants	Intervention	Comparator(s)
				5.0); overnight nursing home respite: uptake: 15%; $n = 122$ (mean days per visit: 8.4) (R)	attendees, frequency determined by study participants) (M3) Family consultation services (individualised training session to develop carer case management skills) (F) Control: no study services offered; unclear whether in receipt of non-study respite services (Kosloski 1995, p. 69)[194] (C)
Montgomery 1989[117,119–121]	INR USA	**Design** Parallel-group RCT ID: 12 months; FU: 12 months **Method of randomisation** NR **Concealment** Unclear **Blinding** NR **Withdrawal/dropout** Carers (primary): 30; carers (secondary): 0; care recipients: 95	***n* (enrolled)** Carers (primary): 298 (eight caring for two people); carers (secondary): 40; care recipients: 306 **Baseline characteristics** Similar between groups: demographic: unclear; clinical: unclear % Male: carer (primary): 21%; carer (secondary): 35%; care recipient: 40% Mean age (years): carer (primary): median 58, with 38% aged ⩾65; carer (secondary): median 59; care recipient: median 81; mean 82 **Inclusion criteria** Impaired elderly people living in the community in King County, Washington; family carer living within 1-hour driving distance of older person and providing regular care or assistance **Exclusion criteria** NR	**Description** Volunteer in-home respite services: provision of temporary relief from caring tasks for carers for up to 4 hours per week, twice per week (R) **Uptake** Uptake: mean use of volunteer respite: 12 visits (range 1–37); mean use of paid respite: 11 visits (range 1–32); % of eligible: 35%	Family education services: seminars for carers (2 hours per week for 6 weeks) covering changing family roles, legal issues, community resources, communication skills, decision-making, healthcare and self-care; support groups (continuation of seminar attendees, frequency determined by study participants); family consultation services (individualised training session to develop carer case management skills). 'Free respite care' provided to facilitate attendance Uptake: seminars: 73%; support groups: 55%; family coordination: 89% (E) In-home respite and family education services. Uptake: seminars: 76%; support groups: 61%; family coordination: 90%; respite: 26% (RE) Control group: usual care (unclear?) (C)

continued

TABLE 29 *Effectiveness studies included in the review: summary characteristics (cont'd)*

Study	Respite type Country	Methods	Participants	Intervention	Comparator(s)
Niebuhr, 1989[96]	INR USA	**Design** Quasi-experimental study with non-equivalent controls (from neighbouring county with no volunteer respite provision) ID: 3 months; FU: 3 months **Method of randomisation** NA **Concealment** NA **Blinding** NR **Withdrawal/dropout** 10 dyads	***n* (enrolled)** 57 dyads **Baseline characteristics** Similar between groups: demographic: no (control group had higher incomes); clinical: no (control group had lower incidence of cardiovascular disease and dementia, and higher incidence of neurological disease and arthritis, diabetes and pulmonary disease). Statistical significance NR. No significant between-group differences for carer clinical outcomes % Male: carer: 12%; care recipient: 50% Mean age (years): carer: 63 (range 30–81); care recipient: 66 (16% <65, 70% >70) **Inclusion criteria** Family carers of persons whose level of impairment requires care comparable to intermediate or skilled nursing care. Carers had to be the primary carer, co-reside with the care recipient, be a close relative and experience at least mild burden (Burden Interview; Zarit and Zarit, 1983) and depressive symptoms (Geriatric Depression Scale; Yesavage and Fring, 1983) **Exclusion criteria** NR	**Description** In-home respite two to four times per week for 3 months (R) **Uptake** NR	No volunteer respite services (C)

continued

TABLE 29 *Effectiveness studies included in the review: summary characteristics (cont'd)*

Study	Respite type Country	Methods	Participants	Intervention	Comparator(s)
Quayhagen, 2000[101]	DC USA	**Design** Parallel-group RCT ID: 8 weeks; FU: 12 weeks **Method of randomisation** NR **Concealment** Unclear **Blinding** Single-blind (assessor) **Withdrawal/dropout** Unclear	***n* (enrolled)** 103 dyads **Baseline characteristics** Similar between groups: demographic: yes; clinical: yes % Male: carer: 36.9%; care recipient: 63.1% Mean age (years): carer: 71.8 (SD 8.1, $n = 103$); care recipient: 74.5 (SD 7.1, $n = 103$) **Inclusion criteria** Patients with possible or probable dementia; mild to moderate dementia; Mattis Dementia Rating Scale >100 **Exclusion criteria** NR	**Description** Early-stage day care (DC): 4 hours per week for 8 weeks. Patients participated in structured activities, including social time, physical exercise, outings and community involvement. Transportation not provided. Carers attended two monthly support group meetings for peer and counselling support (duration NR). **Uptake** NR	Cognitive stimulation (CS): 1 hour per day, 5 days per week for 8 weeks of active cognitive stimulation Dyadic counselling (DY): 1.5 hours; sessions per week NR; 8 weeks. Includes problem identification, stress reduction, anger management, communication enhancement and conflict resolution, using systems and cognitive behavioural approach and 'take-home' task Dual seminar (DS): 1.5 hours per week for 8 weeks. Group and individual meetings, to discuss, support and problem solve. Focused on specific topics Waiting list control group (C): 8 weeks
Robertson, 2002[17,91]	HFR UK	**Design** Uncontrolled qualitative study ID: 5–7 days; FU: variable **Method of randomisation** NA **Concealment** NA **Blinding** Open **Withdrawal/dropout** 0	***n* (enrolled)** Carers: 6; care recipients: 4 **Baseline characteristics** Similar between groups: NA % Male: carer: NR; care recipient: NR Mean age (years): carer: NR; care recipient: NR **Inclusion criteria** Service users (past and current) **Exclusion criteria** Those whose health was not good enough to participate in the study	**Description** Short-break service: service provider's home used for carer and care recipient to have a joint break for 5–7 days, approximately every 2 months **Uptake** NR	

continued

TABLE 29 *Effectiveness studies included in the review: summary characteristics (cont'd)*

Study	Respite type Country	Methods	Participants	Intervention	Comparator(s)
Wells, 1987[34,125]	IR Australia	**Design** Parallel-group RCT, with waiting-list control group ID: 12 weeks; FU: 12 weeks **Method of randomisation** Reported as 'ballot' **Concealment** Unclear **Blinding** NR **Withdrawal/dropout** 4	***n* (enrolled)** 26 dyads **Baseline characteristics** Similar between groups: demographic: unclear; clinical: no (intervention group carers had significantly more psychological problems, with higher GHQ, anxiety and grief scores) % Male: NR Mean age (years): NR **Inclusion criteria** Persons with a formal diagnosis of dementia; 'reasonable' physical health **Exclusion criteria** NR	**Description** Community care with option of respite (C) **Uptake** NR	Special nursing home unit (institutional care): based around rectangular corridor to facilitate severe wandering behaviour; single bedrooms; 'home-like' garden/furnishings (patient's own); multipurpose living areas; kitchen/dining room (I)
Wishart, 2000[79]	INR Canada	**Design** Parallel-group RCT, with waiting-list control group ID: 6 weeks; FU: 6 weeks **Method of randomisation** Computer-generated randomisation by blocks of four, placed in sealed opaque envelopes **Concealment** Unclear **Blinding** NR **Withdrawal/dropout** 3	***n* (enrolled)** 24 dyads **Baseline characteristics** Similar between groups: demographic: no (carers in control group had higher educational level); clinical: yes % Male: carer: 14%; care recipient: 20% Mean age (years): carer: 57.6 (SD 14.0, $n = 20$); care recipient: 80.2 (SD 7.9: $n = 20$) **Inclusion criteria** People with cognitive impairment and their carers **Exclusion criteria** NR	**Description** "Special Steps" visiting/walking programme to provide assistance and companionship for care recipient; target of 2 hours per week. Dropouts were due to death or illness (S) **Uptake** 11/13 used the service (hours per week NR)	Usual care (waiting list) (C)

continued

TABLE 29 *Effectiveness studies included in the review: summary characteristics (cont'd)*

Study	Respite type Country	Methods	Participants	Intervention	Comparator(s)
Zank, 2002[103,116]	DC Germany	**Design** Quasi-experimental with matched controls ID: 9 months; FU: 15 months **Method of randomisation** NA **Concealment** NA **Blinding** Open **Withdrawal/dropout** 65	***n* (enrolled)** Carers: unclear (not all care recipients had carers); care recipients: $n = 148$ **Baseline characteristics** Similar between groups: reported only for treatment completers at 9 months: demographic: no (control group care recipients more likely to have children); clinical: yes % Male: reported only for treatment completers at 9 months: carer: 16.0%; care recipient: 26.3% Mean age (years): reported only for treatment completers at 9 months: carer: 57.1 (?SD, $n = 42$); care recipient: 79.5 (SD 9.5, $n = 83$) **Inclusion criteria** Intervention group: day-care use at least twice weekly; intention to continue day care use for $\geqslant 3$ months; use of home-based community care. Control group: no day-care use; use of home-based community care. Matched by physical and mental health, age, gender and socio-economic characteristics **Exclusion criteria** Those using day care or other forms of respite within previous year	**Description** Geriatric day care plus usual home-based community care (morning and evening assistance with personal care). Day care tailored for individual care recipient may include rehabilitative and educational activities, outings and leisure. Transportation provided. Attendees visit 8 hours per day, one to five times per week. Prescribed by physician and funded through general care insurance, social welfare or patient payments (or combination) (DC) **Uptake** Mean use (days per week): 3.4 for 9 months	Usual home-based community care: morning and evening assistance with personal care 7 days per week, up to five times daily. Includes assistance with ADL, medication or basic housework. Actual use: 4.4 hours per week.[195] Prescribed by physician and funded through health insurance, care insurance, social welfare or patient payments (or combination) (C)

continued

TABLE 29 *Effectiveness studies included in the review: summary characteristics (cont'd)*

Study	Respite type Country	Methods	Participants	Intervention	Comparator(s)
Zarit, 1998[102,117,118]	DC USA	**Design** Quasi-experimental study with controls taken from a state with similar demographics ID: 12 months; FU: 12 months **Method of randomisation** NA **Concealment** NA **Blinding** NR **Withdrawal/dropout** At 3 months: 242/566; at 12 months: 373/566	***n* (enrolled)** 566 dyads **Baseline characteristics** Similar between groups: demographic: no (intervention group had higher family income); clinical: no [intervention group had more behaviour problems and required more help with ADL; their carers were more burdened (worry/overload/negative affect)] % Male (note: per-protocol only): 3-month analysis: carer: 19.6%, care recipient: 39.5%; 12-month analysis: carer: 22.8%; care recipient: 35.8% Mean age (note: per-protocol only): 3-month analysis: carer: 60.1 (SD 13.7, $n = 324$); care recipient: 77.6 (SD 8.3, $n = 324$); 12-month analysis: carer: 59.2 (SD 13.2, $n = 193$); care recipient: 76.7 (SD 8.4, $n = 193$). **Inclusion criteria** Principal carers of relatives with a diagnosis of dementia; no use of day-care services within previous 3 months; carer using ≤8 hours paid help per week; care recipient independently mobile or mobile with assistive devices (control group only); would be willing to use day-care services if available and affordable **Exclusion criteria** Exclusions from the analysis: dyads with missing follow-up data; carer ceasing to be principal carer; intervention group: use of services less than twice a week; control group: use of day-care services or >8 hours paid help per week or care recipient no longer able to participate in day care during the study period (e.g. institutionalised/died)	**Description** Day-care services, mostly providing care on 5 days per week, 7 hours per day. Offered transportation and "a variety of therapeutic activities sensitive to the needs of dementia patients"[115] (DC) **Uptake** Only those using day care for at least 2 days per week for at least 3 months were assessed: mean days per week: 3.07 (SD 1.16); mean hours per day: 6.01 (SD 0.72)	No day-care services and ≤8 hours per week paid help (C)

CPN, community psychiatric nurse; DC, day care; FU, follow-up (includes ID); HFR, host family respite; ID, duration of intervention; INR, in-home respite; IR, institutional respite; NA, not applicable; NR, not reported; RP, respite package; VR, video respite.

TABLE 30 *Economic evaluation data extraction form: Artaso Irigoyen, 2002*

Artaso Irigoyen, 2002[95,156]	
Study population	Carers (n = 69; DC: n = 34; C: n = 35): mean age (years): 54.1; 23% male; duration of caring (months): 37.4; Burden (Zarit): 51.1 (SD 12.5, n = 69); quality of life (CCV: Cuestionario de Calidad de Vida): 140.2 (SD 21.1, n = 69); satisfaction (Cuestionario de Satisfacción del Cliente): 27.4 (SD 3.94, n = 69). Care recipients (n = 69; DC: n = 34; C: n = 35): people with psychiatric disorders and consequent loss of autonomy, with a principal carer and aged $\geqslant$65 years; mean age (years): 75.8; 25% male; 13% living alone; cognitive status (Minexamen Cognoscitivo): 16.4 (SD 7.8, n = 69); functional capacity (ECA: Ritchie scale): 123.3 (SD 21.9, n = 69); behavioural symptoms (BEHAVE-AD): 7.3 (SD 5.0, n = 69). Control group matched on age, gender, cognitive status and functional status. Intervention group had statistically significantly fewer married patients, and intervention group carers had significantly higher levels of income, formal support and quality of life, and were more satisfied with existing care than control group carers. 27 patients lost to follow-up (original sample: n = 96), mainly due to institutionalisation (DC: n = 13/51; C: n = 3/45)
Outcome results	At 12 months: Carers Burden (Zarit): DC: 53.6 (SD 15.4, n = 34); C: 50.5 (SD 11.4, n = 35). Quality of life (CCV: Cuestionario de Calidad de Vida): DC: 139.8 (SD 25.6, n = 34); C: 132.0 (SD 17.5, n = 35); satisfaction (Cuestionario de satisfacción del Cliente): DC: 29.2 (SD 2.4, n = 34); C: 27.0 (SD 4.9, n = 35). Care recipients: cognitive status (Minexamen Cognoscitivo): DC: 13.4 (SD 8.3, n = 34); C: 15.1 (SD 9.1, n = 35); functional capacity (ECA: Ritchie scale): DC: 104.4 (SD 36.9, n = 34); C: 104.7 (SD 32.5, n = 35); behavioural symptoms (BEHAVE-AD): DC: 5.7 (SD 4.5, n = 34); C: 7.0 (SD 4.31, n = 35)
Cost data handled appropriately	Measures of variance for cost data were not reported. Discounting was not applied as the duration of follow-up was 12 months
Uptake of intervention and control	27 patients lost to follow-up (original sample: n = 96), mainly due to institutionalisation (DC: n = 13/51; C: n = 3/45)
Subgroup analysis	Outcomes for incident (those admitted within previous month) and prevalent (those admitted more than 1 month previously) cases were compared; no statistically significant differences were found. For the intervention group, cost was found to be significantly related to the patient's clinical outcomes (cognitive and functional status) and for the control group, only carer burden was found to influence cost
Statistical analysis for patient-level stochastic data	χ^2 and Student's t-tests (baseline comparability); repeated measures ANOVA (for clinical outcome measures carer/care recipient); non-parametric tests (costs); multiple linear regression (costs)

ANOVA, analysis of variance.

TABLE 31 *Economic evaluation data extraction form: Baumgarten, 2002*

Baumgarten, 2002[35]	
Study population	Carers ($n = 178$) of elderly care recipients ($n = 212$) referred to day centres. Age (years): carer: 56.3 (SD 15.8, $n = 89$); care recipient: 77.2 (SD 7.3, $n = 108$). % male: carers: 26.4%; care recipients: 28.0%
Outcome results	No statistically significant differences between intervention and control groups detected. Carers: Carer Burden Inventory (0–96): DC: 21.0 (SD 18.4, $n = 88$); C: 19.8 (SD 19.3, $n = 90$). Care recipients: depression: (CES-D) (0–60): DC: 16.5 (SD 10.9, $n = 61$); C: 14.6 (SD 11.9, $n = 62$); anxiety: STAI (20–100): DC: 39.2 (SD 14.4, $n = 59$); C: 36.4 (SD 14.6, $n = 60$); MMSE (0–30): DC: 23.4 (SD 6.1, $n = 103$); C: NR; OARS Multidimensional Functional Assessment Questionnaire (1 = excellent to 6 = completely impaired): DC: 4.3 (SD 1.2, $n = 104$); C: 4.2 (SD 1.3, $n = 100$)
Cost data handled appropriately	Cost data were handled appropriately. Discounting was not applied as the duration of follow-up was less than 12 months
Uptake of intervention and control	Median number of visits: 10; 35 (34%) care recipients attended at least 13 times; 9 (8.7%) never attended
Subgroup analysis	Clinical outcomes and demographic characteristics for the intervention group were analysed by high ($\geqslant$13 visits) or low (<13 visits) day-care attendance over the study period. Although carer burden fell for carers in the high attendance group, the difference relative to low attenders was not statistically significant when controlled for potential confounders
Statistical analysis for patient-level stochastic data	Multiple linear regression used to adjust for potential confounders

TABLE 32 *Economic evaluation data extraction form: Donaldson, 1989*

Donaldson, 1989[40,104]	
Study population	Carers ($n = 53$; E: $n = 24$; C: $n = 29$): 75.5% aged >60 years; 41.5% male. Care recipients: mentally infirm elders ($n = 105$; E: $n = 35$; C: $n = 70$); 94.3% aged $\geqslant$65 years; 40.0% male. 11.4% of patients living alone, 65.7% living with spouse, 22.9% living with relatives. 68.6% of patients had some kind of dementia and 51.4% were in good physical health. Control group matched on age, gender, psychiatric diagnosis, physical health, dependency and domestic status
Outcome results	Carers: adverse effects: E: carers abilities to have visitors and to rest were significantly more adversely affected than C ($p < 0.001$). Opportunity cost of caring: no significant between-group differences; perceived financial costs of caring: no significant between-group differences; service benefits: day care: significantly more E carers (100%, $n = 24$) benefited from freedom/relaxation than did C carers (62.1%, $n = 29$) and felt that day care improved the care recipient's daytime behaviour (E: 91.7%; C: 62.1%). Mean number of days spent in the community: E: 664, $n = 35$; C: 492, $n = 67$ ($p < 0.05$) (E – C = 172)
Cost data handled appropriately	Measures of variance for cost data were not reported. Discounting was not applied as the duration of follow-up was 12 months
Cost results	Cost per person: E: £4390.82 ($n = 35$); C: £1158.36 ($n = 67$). Cost per person per day maintained in the community: E: £6.62 ($n = 35$); C: £2.34 ($n = 67$). Additional cost per additional day (E:C) spent in the community: £18.80.
Uptake of intervention and control	Costs were based on 100% occupancy. Days of utilisation per person: FSU day care: E: 70 ($n = 35$); C: 3 ($n = 67$); FSU respite: E: 19 ($n = 35$); C: 0.2 ($n = 67$); local authority day care: E: 32 ($n = 35$); C: 3 ($n = 67$); hospital respite: E: 40 ($n = 35$); C: 10 ($n = 67$)
Subgroup analysis	Not undertaken
Statistical analysis for patient-level stochastic data	Mann–Whitney *U*-test (days spent at home in the community); Pearson's correlation (baseline characteristics); Fisher's exact test (carer outcomes); statistical analysis of costs not undertaken

TABLE 33 *Economic evaluation data extraction form: Gaugler, 2003*

Gaugler, 2003[102,114,115]	
Study population	Family carers of patients who had dementia. Eligible caregivers had not previously used adult day care, and used no more than 8 hours of formal (paid) services per week. To be eligible for inclusion in the 3-month and 12-month analyses, entry inclusion criteria had to be upheld and the intervention group had to use day care at least twice per week, with the control group using no day care. Participants who were discharged from day-care services or who were institutionalised were also excluded from the analysis. At baseline: 548 dyads (DC: $n = 259$; C: $n = 289$); at 3 months: 367 dyads (DC: $n = 154$; C: $n = 213$); at 12 months: 201 dyads (DC: $n = 80$; C: $n = 121$). Baseline characteristics of those included in 3-month analysis (from Table 2): carers: mean age (years): 59.8 (SD 13.7, $n = 385$), 18.6% male; Role Overload Scale: DC: 22.2 (SD 3.2, $n = 154$); C: 20.6 (SD 3.4, $n = 231$); CES-D: DC: 17.6 (SD 12.1, $n = 154$); C: 14.8 (SD 10.1, $n = 231$). Care recipients: mean age (years): 77.7 (SD 8.4, $n = 385$), 40.1% male. Behaviour problems: DC: 7.0 (SD 2.8, $n = 154$); C: 6.3 (SD 2.8, $n = 231$); ADL: DC: 7.5 (SD 2.0, $n = 154$); C: 6.9 (SD 2.2, $n = 231$). Baseline characteristics of those included in 12-month analysis (from Table 2): carers: mean age (years): 59.4 (SD 13.0, $n = 233$), 23.2% male; Role Overload Scale: DC: 21.9 (SD 3.3, $n = 80$); C: 20.5 (SD 3.5, $n = 153$); CES-D: DC: 16.1 (SD 11.8, $n = 80$); C: 13.4 (SD 10.0, $n = 153$). Care recipients: mean age (years): 76.9 (SD 8.0, $n = 233$), 36.4% male. Behaviour problems: DC: 6.9 (SD 2.6, $n = 80$); C: 5.9 (SD 2.8, $n = 153$); ADL: DC: 7.3 (SD 1.9, $n = 80$); C: 6.9 (SD 2.2, $n = 153$)
Outcome results	At 3 months (from text): carers: Role Overload Scale: DC: 20.14 (?SD, $n = 154$); C: 21.32 (?SD, $n = 231$); CES-D: unclear. At 12 months (from text): Carers: Role Overload Scale: DC: 19.96 (?SD, $n = 154$); C: 21.28 (?SD, $n = 231$); CES-D: DC: 12.77 (?SD, $n = 154$); C: 15.74 (?SD, $n = 231$)
Cost data handled appropriately	It is unclear whether the costs of carer time were adjusted when combined with productivity losses. Carers reported hours of formal support received, but use of health and social care was not assessed. Discounting was not applied as the duration of follow-up was 12 months
Uptake of intervention and control	At 3 months, the mean daily cost of adult day services was \$5.09, which implies a weekly use of approximately 1.9 days (mean daily charge: \$18.45). At 12 months, the mean daily cost of adult day services was \$6.25, which implies a weekly use of approximately 2.5 days (mean daily charge: \$17.26)
Subgroup analysis	Cost and outcome findings are reported only for a subgroup of dyads who met specified criteria for inclusion in the analysis. At 3 months, this comprised 67% of the original sample; at 12 months, the corresponding figure was 37%
Statistical analysis for patient-level stochastic data	Factors that indicated attrition at 3 months and 12 months were specified using logistic regressions. Factors associated with dropout were included in ANCOVA models to adjust for attrition bias. For both 3-month and 12-month analyses, one-way ANOVA and χ^2 tests were conducted to determine whether treatment and control conditions were similar on baseline variables. If a variable was significantly different it was included as a covariate when estimating costs and outcomes via ANCOVA. The cost necessary to alleviate one unit of carer role overload and carer depression was found by dividing mean between-group costs differences by the mean difference in outcomes

ANCOVA, analysis of covariance.

TABLE 34 *Economic evaluation data extraction form: Hedrick, 1993*

Hedrick, 1993[93,106–110,112,118]	
Study population	Frail elderly people at high risk of nursing home placement and their carers. Patients included in the study used healthcare services before the study; 82% were dependent in at least one of the basic ADL, with an average of 2.4 dependencies
Outcome results	Carers: At 12 months, there were no significant differences between carers in the DC-V group (DC-V), the usual care group (C) or the contract adult day care group (DC-C) regarding physical and psychosocial health status outcomes. However, there were some differences in satisfaction levels: compared with DC-V and DC-C, C carers were less satisfied with usual care provided in nursing homes or ambulatory care clinics, but equally satisfied with home care. DC-C carers were less satisfied with care than were DC-V carers. Care recipients: At 12 months, there were no statistically significant differences in terms of survival, SIP, psychological distress, cognitive status and health perceptions for DC-V compared with usual care (C). DC-C patients were significantly more impaired in physical function than those in DC-V or C, even after controlling for baseline differences. No other significant differences in care recipient health status were found. Satisfaction with care was significantly higher for both DC-V and DC-C than for C care recipients in nursing homes; however, care recipients in clinics or home care were as satisfied with their care as were those receiving either type of day care
Cost data handled appropriately	Cost data were handled appropriately. Discounting was not applied as the duration of follow-up was 12 months
Uptake of intervention and control	Patients assigned to DC-V attended VA day care for an average of 45.3 days over 12 months (range 0–246), with 15% having no visits. Mean days attendance for DC-C patients was 63.8 (range NR), with 8% having no visits. Usual-care (C) patients used no VA day care, but did attend non-VA day care for an average of 3.6 days annually (for DC-V and DC-C the corresponding figures were 1.6 and 1.5, respectively); between-group differences were not significant
Subgroup analysis	Subgroups for analysis were identified before the data analysis, based on findings from previously published studies. DC-V was compared with C for each outcome using the Student's *t*-test. Unmarried patients, those not hospitalised at enrolment and those very satisfied with social support had significantly better 12-month health outcomes than patients in the control group. Mean annual costs of DC-V were similar to those of usual care for: one of the four DC-V sites; the subgroup of patients at high risk of nursing home admission; and the subgroup of patients at high risk of hospital admission. Mean annual DC-V costs for the subgroup of high users of ambulatory services were lower than those for similar individuals receiving usual care (C). Mean annual costs of DC-V were higher than those of usual care for patients with higher levels of physical impairment and for those with lower levels of behavioural problems
Statistical analysis for patient-level stochastic data	Mean costs for DC-V were compared with C using *t*-tests. Cost differences were adjusted using variables found to be significantly different between the combined RCT population (DC-V + C) and the cohort population (DC-C) at baseline

TABLE 35 *Outcomes reported in included studies or economic evaluations*

Outcome measure	No. of studies reporting measure	Carer outcome measures reported	Care recipient outcome measures reported
Quality of life (carer/care recipient)	4	Cuestionario de Calidad de Vida (scale and content NR) (Ruiz *et al*., 1993)[a] Life Satisfaction Questionnaire (28 items, scored 0–84)[a] Quality of Life Questionnaire (20 dichotomous questions) Subjective well-being reported as profile of various measures covering physical health, psychological health, burden and carer attitudes	Life Satisfaction Questionnaire (28 items, scored 0–84)
Physical health (carer/care recipient)	14	Blood pressure and pulse monitoring; repeated sampling for catchecholamines (noradrenaline and adrenaline). GHQ (Goldberg, 1978; 30 items) Health Assessment Scale (25 items) Philadelphia Geriatric Center Assessment Instrument (self-rated health subindex) (Lawton *et al*., 1982; four items; scored 4–13) Self-rated health (five-point scale: perfect to 'not good at all') Other self-reported assessment (details not provided)[a]	Adaptive Behaviour Scale (Nihira, 1974; four subscales: independent functioning; physical and perceptual skills; communication; occupation) Crichton Royal Behavioural Rating Scale (eight dimensions, scored 0–31, higher denotes lower ability)[a] Functional capacity (ECA: Ritchie scale)[a] Global health (1 = perfect to 5 = not good at all) Mortality rate[a] Non-cognitive severity (scored 17–65; assessed at baseline only) Self-rated health (five-point: perfect to 'not good at all') SIP (physical functioning; 45 items, scored 0–100, higher scores indicate greater impairment; Bergner *et al*., 1981)[a] Survival rate[a] Verbal fluency Vision/hearing

continued

TABLE 35 *Outcomes reported in included studies or economic evaluations (cont'd)*

Outcome measure	**No. of studies reporting measure**	**Carer outcome measures reported**	**Care recipient outcome measures reported**
Mental/psychological health (carer/care recipient)	14	Brief Symptom Inventory (four-point scale) Coping Strategy Inventory-Revised (39 items) Delusions–Symptoms–States Inventory for anxiety and depression (DDSI/sAD) Depression: CESD (Radloff, 1977; 20 items; scored 23–80)[a] Geriatric Center Morale Scale (nine items) Geriatric Depression Scale (Yesavage *et al*., 1983; 30 items) Global Severity Index (derived from the Brief Symptom Inventory) Grief Scale (six items; four-point scale; scoring range NR) Guilt Scale (three items; four-point scale; scoring range NR) Loneliness: UCLA Loneliness Scale (Russel *et al*., 1980; 20 items) Memory and Behaviour Problems Checklist Mood disturbance (tension/anxiety, depression/dejection, anger/hostility, vigour/activity, fatigue/inertia, confusion/bewilderment) Morale (24 items) (Montgomery, 1985) Positive and negative affect: Affect Balance Scale (Bradburn, 1969; ten items each for positive and negative affects; each scored 5–10) Profile of Mood States (POMS) (McNair *et al*., 1983; 65 items; scale NR) Psychological Distress Scale (24 items: scored 24–144, higher scores indicate greater impairment)[a] Relative's Stress Scale (Greene *et al*., 1982; 21 items; scored 0–60) Role Overload Scale (seven items; Zarit, 1998)[a] Self Esteem (six items; scored 0–18) Social support adequacy: Personal Resource Questionnaire II (PRQ-II) used to assess quality and perceived adequacy of received support (Brandt and Weinert, 1981; 25 items, Likert scale) Structured Interview Guide for the Hamilton Depression and Anxiety Scales	Abbreviated Mental Test score (Qureshi, 1974) Alzheimer's Disease Assessment Scale (scoring method unclear; Reisburg *et al*., 1987) Behaviour Problems Checklist (Gilleard, 1984; items rated on three-point scale; scoring range NR) Behavioural symptoms (BEHAVE-AD)[a] CES-D (Radloff, 1977; 20 items; scored 0–60)[a] Cognitive severity (scored 6–30) Delayed memory (composite of two tests) Dementia Rating Scale (DRS) Escala Comportamental y de Adaptacion (ECA) (Ritchie *et al*., 1991)[a] Immediate memory (composite of three tests) Minexamen Cognoscitivo (Lobo *et al*., 1979)[a] MMSE (Folstein, 1975; 11 items; scored 0–30)[a] MMSE (Folstein, 1985; modified; max.: 32)[a] Nuremberg Aging Inventory (Oswald, 1982; scoring method NR) Philadelphia Geriatric Morale scale (Lawton, 1975; 17 items; scored 0–17) Problem solving (composite of two tests) Psychological Distress Scale (24 items; scored 24–144, higher scores indicate greater impairment; Veit *et al*., 1983)[a] Self Esteem (six items; scored 0–18) STAI (Spielberger, 1983; 20 items; scored 20–100)[a]

continued

TABLE 35 *Outcomes reported in included studies or economic evaluations (cont'd)*

Outcome measure	No. of studies reporting measure	Carer outcome measures reported	Care recipient outcome measures reported
Satisfaction (carer/care recipient)	15	% Satisfied or very satisfied with intervention Carer opinion (four-point scale: very satisfied to dissatisfied) Caregiving impact (negative satisfaction; seven items; scored 7–35) Caregiving uplifts (positive satisfaction; eight items; scored 13–45) Carer (experimental group only): eight-item scale, each item scored on four-point scale from poor to excellent Degree of relief from any type of formal/informal respite received (scored 1 = no relief to 5 = very great relief) Life Satisfaction Scale (Andrews *et al*., 1976, as modified by Michalos, 1980, 1985; scored 0–7, higher scores indicate more satisfied) Marital Satisfaction Scale (24 items) Overall satisfaction with all types of formal/informal respite received (1 = dissatisfied to 4 = very satisfied) Perception of day centre's effects Satisfaction questionnaire (scored 8–40) Satisfaction with 'help' (information/support) received Satisfaction with caregiving process (Client/patient General Satisfaction Scale; Attkisson, 1979) Semi-structured questions on positive or negative effects of day care Unstructured comments on intervention	ADHC Long Term Care Patient Satisfaction Questionnaire (Hedrick *et al*., 1991)[a] ADHC Patient Satisfaction Questionnaire (Hedrick *et al*., 1991)[a] Perception of day centre's effect[a] Satisfaction questionnaire (scored 8–40) Unstructured comments on intervention Cuestionario de Satisfaccion del Cliente (Larsen, 1979)[a]

continued

TABLE 35 *Outcomes reported in included studies or economic evaluations (cont'd)*

Outcome measure	No. of studies reporting measure	Carer outcome measures reported	Care recipient outcome measures reported
Carer burden	13	Caregiver Impact Questionnaire (CIQ) ((Montgomery and Borgatta, 1985; 12-items; five-point scale; scored 12–60)[a] Caregiver strain index (Robinson, 1983; 13 items, scored 0–13) Carer Burden Inventory (Novak and Guest, 1989; 24 items; scored 0–96)[a] Carer burden (12 items; five-point scale): time for self, others, work, leisure; adequate finances; stress in relationship; nervousness/depression in relationship; privacy; manipulation; appreciation; vacation; excessive demands Financial strain (three items; three-point scale) Length of time spent caring (used as proxy for burden) Modified burden index (nine items; five-point scale; Montgomery *et al*., 1985). Includes subjective burden (perceptions of stress, manipulation, excessive demands, depression); objective burden (time for self, recreation, vacation, own work, own social life) Objective burden (Montgomery, 1989; six items) Overload (seven items; four-point scale; scored 7–28) Perceived seriousness of behaviour problems[a] Role captivity (three items, three-point scale, scored 3–12) Subjective burden (emotional stress): modified Zarit burden index (four items) Subjective caregiving burden (13 items; scored 14–69) Worry and Strain (eight items; five-point scale, scored 8–32) Zarit Caregiver Burden Interview (Zarit, 1983; 22 items; scored 0–88)[a]	

continued

TABLE 35 *Outcomes reported in included studies or economic evaluations (cont'd)*

Outcome measure	No. of studies reporting measure	Carer outcome measures reported	Care recipient outcome measures reported
Utilisation of any health and social services (carer/care recipient)	14	Use of community health and social services; use of study services[a] Use of day care and support groups[a] Use of day care, day hospital, home care services, hospital care, long-term care, outpatient professional services, physician care, transportation[a] Use of direct healthcare services assessed by inventory by Browne (1990) Use of institutional care (nursing home, hospital); ambulatory care; day care; laboratory tests; outpatient pharmacy; special supplies/devices; prosthetics; home care; transportation; home living costs[a] Use of intervention[a] Use of meal delivery, homemaker, home health or transportation services[a] Use of non-study services[a] Use of respite (in-home; day care; nursing home); homemaker visits, meals on wheels, personal care visits; nurse, physician or other clinician visits; acute and psychiatric hospital days; transportation, shopping trips[a] Use of respite, day care, home help and other nursing aid[a]	Use of day care, day hospital, home care services, hospital care, long-term care, outpatient professional services, physician care, transportation[a] Use of direct healthcare services assessed by inventory by Browne (1990) Use of home-based community care[a] Use of intervention[a] Use of nurse visits[a] Use of social, health and private sector services[a] Use of respite (in-home; day care; nursing home); homemaker visits, meals on wheels, personal care visits; nurse, physician or other clinician visits; acute and psychiatric hospital days; transportation, shopping trips[a]
Utilisation of informal or voluntary support services (carer/care recipient)	8	Number of weekly contacts Perceived Social Support (Fydrich, 1987; 15 items, scored 0–45) (Pearlin *et al*., 1981) Social Support Questionnaire (Schaefer, 1981; scoring method NR, but includes degree of reliable help, emotion, caring, perceived trust, informational support) Social Support Scale (importance of individuals in network; size; satisfaction with help received; degree of upset/helpfulness; number of confidants)[a] Use of informal assistance with ADL (hours per year) Use of informal respite (hours per year) Use of voluntary services[a]	Number of weekly contacts Perceived Social Support (Fydrich, 1987; 15 items; scored 0–45) Social Support Scale Use of informal assistance with ADL (hours per year) Use of informal respite (hours per year) Use of voluntary day-care services[a]

continued

TABLE 35 *Outcomes reported in included studies or economic evaluations (cont'd)*

Outcome measure	No. of studies reporting measure	Carer outcome measures reported	Care recipient outcome measures reported
Time to institutionalisation	8		% Institutionalised[a] % Living in congregate care facilities Institutionalisation rate Mean number of days alive in the community[a] Number (%) admitted to nursing home[a]
Time spent on caring tasks	9	Hours in previous week spent on personal care tasks, household tasks and financial tasks Hours of direct caring/day Hours spent with relatives Time spent caring (hours per week) Time spent in care-giving (hours per day) for PADL and IADL Time spent on caring tasks[a] Transportation, banking, feeding, dressing, grooming, toilet use, ambulation, bathing, medications	
ADL	6	ADL scale adapted from Katz scale (five items; scored 0–5) IADL (seven items; scored 0–28) Effects of caring on carers (adverse effects on health, job, hobbies, having visitors, 'normal' life, other)[a] Opportunity cost of caring (alternatives to caring; enjoyment of retirement, holidays, social life, looking after family; Donaldson *et al*., 1989)[a]	ADL (Multidimensional Functional Assessment, plus OARS 1978, plus Katz IADL; Katz *et al*., 1963; 12 items; 36 points)[a] ADL disability adapted from Lawton and Brody (1969) scale to combine physical (PADL) and instrumental (IADL) dimensions (scored 0–10) Barthel index (Mahoney, 1965; ten items, scored 1–100; reported by carer) IADL (Katz, 1963; 12 items; 36 points) Nuremberg Aging Observation Scale (Oswald, 1982; 15 items; scored 0–30) OARS (Pfeiffer, 1975) PADL (five items; scored 0–5)
Other service benefits	1	Day care: freedom/relaxation for carer (Donaldson *et al*., 1989)[a] Respite care: gives carer a break[a] Voluntary help: i.e. carers' support groups, day care, home visitor, freedom to go out, support when needed[a]	Day care: good for confused person[a] Dependant behaves normally for day
Financial costs of caring	1	Costs incurred: loss of income, extra heating, domestic help, repair/replacement, travel, laundry, clothing, additional help/care, diet, other[a]	

[a] Reported in an economic evaluation.
IADL, instrumental activities of daily living; PADL, physical activities of daily living.

Appendix 5

Quality assessment

Quality assessment of controlled studies and economic evaluations

TABLE 36 *Effectiveness review: quality assessment of controlled studies (n = 17)*

Study characteristics	**Artaso Irigoyen, 2002[95]**	**Baumgarten, 2002[35]**	**Burch, 2001[89]**	**Conlin, 1992[94]**	**Donaldson, 1989[104]**	**Grant, 2003[97]**	**Hedrick, 1993[93]**	**Kosloski, 1993[76]**	**Lawton, 1989[106]**	**Montgomery, 1985[124]**	**Montgomery, 1989[117]**	**Niebuhr, 1989[96]**	**Quayhagen, 2000[101]**	**Wells, 1987[34]**	**Wishart, 2000[79]**	**Zank, 2002[103]**	**Zarit, 1998[102]**
Type of respite	*DC*	*DC*	*DC*	*RP*	*DC*	*INR*	*DC*	*RP*	*RP*	*IHR*	*RP*	*IHR*	*DC*	*IR*	*INR*	*DC*	*DC*
1. Was the method used to assign participants to the treatment groups really random or, if the study used a cross-over design, was the sequence of treatments really random?	×	✓	✓	×	×	U	✓	×	✓	U	U	×	U	U	✓	×	×
2. Was the allocation of treatment concealed?	NA	A	B	C	NA	B	A	NA	B	B	B	NA	B	B	B	NA	NA
3. If possible, were the outcome assessors blinded to treatment?	U	U	✓	U	U	U	U	U	U	U	U	U	✓	U	U	×	U
4. Were the eligibility criteria specified?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
5. Were the participants appropriate to the study question?	✓	✓	✓	✓	✓	✓	✓	✓	✓	U	U	✓	✓	✓	✓	✓	✓
6. Did the authors report that ITT was used?	×	✓	✓	×	×	×	✓	×	×	×	×	×	×	×	×	×	×
7. Is there a complete description of withdrawals to allow ITT analysis?	×	×	✓	×	×	×	×	×	×	×	×	×	×	×	×	×	×
8. Was the statistical analysis appropriate?	U	✓	✓	✓	U	✓	U	U	×	U	U	U	U	U	U	U	U
9. Were any co-interventions identified that may influence the outcomes for each group?	✓	✓	×	✓	✓	×	✓	×	✓	✓	✓	×	✓	✓	✓	✓	×
10. Was an association with a sponsor reported by the authors?	✓	✓	×	✓	✓	✓	✓	✓	✓	✓	✓	×	✓	×	✓	✓	✓

Type of respite: DC: day care; INR: in-home respite; IR: institutional respite; RP: respite package.
✓, Yes; ×, no; NA, not applicable; U, unclear.
Concealment of treatment allocation: A, adequate; B, unclear; C, inadequate; NA, not applicable.

TABLE 37 *Economic evaluations: quality assessment checklist*

Study question	**Artaso Irigoyen, 2002**[156]	**Baumgarten, 2002**[35]	**Donaldson, 1989**[104]	**Gaugler, 2003**[114]	**Hedrick, 1993**[93]
Were costs and effects examined?	✓	✓	✓	✓	✓
Alternatives compared?	✓	✓	✓	✓	✓
Viewpoint(s) clearly stated?	✓	✓	✓	×	✓
Selection of alternatives					
All relevant alternatives compared (including do nothing if applicable)?	✓	✓	✓	✓	✓
All relevant alternatives clearly described (who did what, to whom, where and how often)?	×	✓	✓	×	✓
Rationale for choosing the alternative programmes compared is stated	P	✓	✓	✓	✓
Form of evaluation					
Choice of form of economic evaluation is justified in relation to questions addressed?	×	✓	✓	✓	✓
If a cost-minimisation analysis is chosen, have equivalent outcomes been adequately demonstrated?	NA	NA	NA	NA	NA
Effectiveness data					
The source of effectiveness estimates used are stated (e.g. single study, selection of studies, systematic review, expert opinion)	✓	✓	✓	✓	✓
Effectiveness data from RCT or review of RCTs	×	✓	×	×	P
Potential biases identified (especially if data not from RCTs)	✓	✓	✓	✓	✓
Details of method of synthesis or meta-analysis of estimates are given (if based on an overview of a number of effectiveness studies)	NA	NA	NA	NA	NA
Costs					
All the important and relevant resource use included	✓	✓	✓	×	✓
All the important and relevant resource use measured accurately	P	✓	P	✓	×
Appropriate unit costs reported separately from resource-use data (with methodology)	✓	✓	✓	✓	✓
Unit cost reported separately from resource use	×	✓	✓	×	✓
Productivity costs treated separately from other costs	✓	NA	NA	✓	NA
The year and country to which unit costs apply is stated, with appropriate adjustments for inflation and/or currency conversion	✓	✓	✓	✓	×
Benefit measurement and valuation					
The primary outcome measure for the economic evaluation is clearly stated	×	✓	×	✓	✓
Methods to value health states and other benefits are stated	NA	✓	✓	✓	✓
Details of the individuals from whom valuations were obtained are given	NA	✓	✓	✓	✓
Decision modelling					
Details of any model used are given	NU	NU	NU	NU	NU
The choice of model used and the key input parameters on which it is based are adequately detailed and justified	×	×	×	×	×
All model outputs described adequately	×	×	×	×	×

continued

TABLE 37 *Economic evaluations: quality assessment checklist (cont'd)*

Study question	**Artaso Irigoyen, 2002**[156]	**Baumgarten, 2002**[35]	**Donaldson, 1989**[104]	**Gaugler, 2003**[114]	**Hedrick, 1993**[93]
Discounting					
Discount rate used for both costs and benefits	NA	NA	NA	NA	NA
Do discount rates accord with NHS guidance?	NA	NA	NA	NA	NA
Allowance for uncertainty					
Stochastic analysis of patient-level data					
Details of statistical tests and confidence intervals are given for stochastic data	P	P	P	✓	✓
Uncertainty around cost-effectiveness estimates expressed (e.g. confidence interval around incremental cost-effectiveness ratio, cost-effectiveness acceptability curves)	×	✓	×	×	✓[a]
Sensitivity analysis used to assess uncertainty in no-stochastic variables (e.g. unit costs, discount rates) and analytical decisions (e.g. methods to handle missing data)	×	×	×	×	×
Stochastic analysis of decision models					
Are all appropriate input parameters included with uncertainty?	×	×	×	×	×
Is second order uncertainty (uncertainty in means) included rather than first order (uncertainty between patients)	×	×	×	×	×
Are the probability distributions adequately described and appropriate?	×	×	×	×	×
Sensitivity analysis used to assess uncertainty in non-stochastic variables (e.g. unit costs, discount rates) and analytical decisions (e.g. methods to handle missing data)	×	×	×	×	×
Deterministic analysis	×	×	×	×	×
The approach to sensitivity analysis is given (e.g. univariate, threshold analysis)	×	×	×	×	×
The choice of variables for sensitivity analysis is justified	×	×	×	×	×
The ranges over which the variables are varied are stated	×	×	×	×	×
Presentation of results					
Incremental analysis is reported using appropriate decision rules	NA	✓	✓	✓	✓
Major outcomes are presented in a disaggregated as well as an aggregated form	NA	×	×	✓	NA
Applicable to the NHS setting	U	U	✓	U	U

[a] Costs only.

NU, not undertaken; P, partial; U, uncertain.

Quality assessment of uncontrolled studies

Host family respite

***Robertson, 2002*[91]**

The qualitative cohort study by Robertson[91] aims to evaluate an innovative respite service model (providing joint family-based short breaks) by gaining an understanding of the experiences of people with dementia and their carers who access the service. The study is located within an existing knowledge base and highlights the importance of evaluating whether new approaches to respite care successfully enhance quality of life in dementia care.

The researcher has given consideration to ethical issues, gaining access to participants and issues of consent. Participants who accessed the family-based short-break service were recruited via project workers. However, there is no detail of sampling procedure (e.g. purposive) to ensure that those selected were most appropriate to inform the study.

Semi-structured interviews were carried out at one time-point with ten people using the family-based short-break service. Participants included three couples currently having a short break together, and one couple and two carers who had previously received a break. Details are provided for location of the interviews (either the place providing the short break or the participants' own home), choice of interview style (as a couple or individually), use of a topic guide to address specific questions but provide flexibility for participants to focus on issues of their own importance, and duration of interview (range 25–40 minutes). Data were tape-recorded and transcribed before emergent thematic analysis, then related to research questions and existing research.

The findings are clearly presented and data are provided to support themes and are discussed in relation to the existing literature. The findings are largely positive. This raises two concerns for credibility: first, the relationship of the researcher to the new service development; and secondly, the timing and location of the interviews. The relationship between researcher and participants is not clear; for example, whether the researcher was involved in the development of the family-based short-break initiative. This could introduce bias in data collection and analysis and therefore it is difficult to judge the credibility of the findings. In addition, the varying locations and time-points for the participants may have influenced the findings. The majority of participants were interviewed while on a break and these participants may be experiencing an immediate feeling of benefit. It is possible that these interviews generated very different experiences from interviews carried out with people after the break, who had had time to reflect on the experience and settle back into routine life in their own home. No consideration was given to these important factors in the analysis.

The study provides support for the positive impact of family-based short breaks on people with dementia and their carers. However, it is difficult to establish the relevance of the findings to other settings and populations owing to the lack of detail on content of the service and characteristics of the participants, such as age, gender or cognitive impairment. In addition, the study is small scale and evaluates a new type of respite service provision located in one geographical location.

***Holm and Ziguras, 2003*[90]**

The qualitative study by Holm and Ziguras[90] uses observations and interviews to gather the perspectives and experiences of carers and care recipients with dementia using a host-home respite programme. It is unclear who the participants in this study are. Minimal data are presented in terms of age, gender, country of birth and caring relationship. The care-recipient sample was comprised of those currently attending the programme, but it is not clear how carers were sampled and how representative they are of carers of the care-recipient population.

The processes of data collection are unclear. No detail is given of questions asked in the telephone interviews with carers and no details are provided of how the care recipients were observed or their views gathered. The form on which data were collected is also unclear; it is difficult to determine whether the quotes used to support findings are verbatim (recorded and transcribed) or derived from researchers' notes and possibly not an accurate record of participants' words. In addition, there is no indication of how data were analysed and it appears that anecdotes to support the programme were selected.

This study was carried out by researchers employed by the same organisation that was being evaluated (Brotherhood of St Laurence). No consideration is given to how this might have influenced the design and conduct of the study and analysis of the data collected. The study presents positive findings, but interpretation of these should be treated with caution. Participants may have been reluctant to express any negative perspectives or experiences, particularly where the care recipient may be continuing to attend the programme. In addition, no consideration is given to ethical issues and ethics committee approval is not reported. This lack of consideration is significant, especially since care recipients with dementia were observed and interviewed.

The design and methods used in this study are largely unclear. The quality of the study therefore means that the findings should be cautiously interpreted with regard to any transferability to other host-home programmes.

Multidimensional respite packages

Clark and colleagues, 2000[84]

The descriptive study by Clark and colleagues[84] uses a range of data sources (both qualitative and quantitative) to establish the structure and organisation of seven geographically dispersed pilot Macmillan carer schemes, the service activities, user satisfaction with the scheme and the impact of the scheme on other services. The paper presents findings on some of these aims: service activities and user satisfaction. The study had ethical approval.

All user referrals to the Macmillan carer service were monitored and so sampling issues are not addressed. Descriptive statistics are presented on reasons for referrals, source of referrals, services offered, number of visits and total input, and tasks undertaken by Macmillan carers. The views of service users were gathered using a postal structured questionnaire; five questions (focusing on timing, tasks, carer choice and standards) with a four-point Likert scale response (always, mostly, sometimes and never). There was space for respondents to write in free text.

There was a response rate of 56% to the questionnaire. These were returned by bereaved and non-bereaved carers, the majority were returned from women (65%) and over half (58%) were aged over 60 years. The authors indicate that there were no differences in response patterns between bereaved and non-bereaved carers, but do not address whether there were differences by age or gender. Findings are presented for all respondents in one table.

The responses to the questionnaire indicated that carers were satisfied with the Macmillan carer scheme. The authors address the limitations of user satisfaction measures and that they tend to produce favourable viewpoints. Indeed, they point out that missing data is highest (12%) for the question asking whether the informal carer was able to choose tasks undertaken by the Macmillan carer. The authors speculate that this might be because respondents who were critical of the scheme might be more inclined to leave the question blank than to reply negatively. The paper presents some free text responses that are positive about the service, even though they state that there were two adverse comments about the manner of Macmillan carers. No further details are presented on negative comments. The lack of response to the questionnaire by 44% of users should be noted and findings of this part of the study interpreted with caution. Future studies of such schemes may seek to carry out a more in-depth study of users' perspectives from a representative sample of users.

The study provides descriptive data of the service activities of pilot Macmillan carer schemes and user satisfaction. As such, the study provides useful information for further developmental work. The geographical dispersion of the pilot sites implies that this scheme is transferable and of interest to providers of respite care for cancer patients and their informal carers.

In-home respite

Johnson and colleagues, 1988[85]

The descriptive study by Johnson and colleagues[85] reports on a hospice-based relative support scheme for relatives of dying patients.

The paper is not explicit about methods: these are stated in the results section, but no detail is provided. Descriptive data are provided on patient age, condition, carer age and relationship to patient, source of referral, number of visits, deaths and discharges. A postal questionnaire was used to elicit relatives' opinions of the service. Seventy-seven per cent of relatives responded. No details are provided about the content of the questionnaire and how it was designed. The authors do not address the limitations of structured postal questionnaires and interpretation of response rates. There is no differentiation of the responses between relatives where patients had died or been discharged, or any indication of who responded to the questionnaire and whether there were differences depending on relationship (e.g. spouse compared with child). There is no indication that there was space for relatives to add free text; no data of this sort are presented.

Interpretation and relevance of these findings to other settings are questionable owing to the lack of transparency of methods and findings. The findings are not well presented and do not go beyond description. The study focuses on one relative support scheme. The authors do not address any limitations of the study.

Video respite

Lund and colleagues, 1995[92]

The study by Lund and colleagues[92] aims to contribute to the understanding of the potential use and benefits of video respite (VR) by examining for whom and when it may be most and least effective, the content of tapes that are most and least effective, and benefits and limits to impaired viewers, family and professional caregivers. The study uses varied methods including videotapes to record observational data of viewers' attention to the video respite, trained coders subjectively to rate viewers' interest and enjoyment, and pre- and post-intervention interviews with caregivers to determine use of VR and their experiences of use. No further details are provided about the methods, such as how coders were trained and any structures for subjective ratings, or whether an interview schedule (topic guide) was used for interviews with caregivers. Ethical issues and concerns are not addressed. This is unusual given the vulnerability of participants, people with dementia, the majority of whom were "moderately to severely cognitively impaired" (p. 685).[92]

The methods of sampling and recruitment are unclear. Description of the participants appears to represent a range of impaired elders and their carers in terms of gender, age, relationship and cognitive impairment. However, there are no details of non-participants and so it is not possible to judge why some people chose not to participate.

The paper reports interim study findings and trends: percentages of people remaining seated during the VR tapes, ratings of viewers' interests in the VR tapes, frequency of use of VR tapes by caregivers, and two quotes of the experience of use by caregivers. Methods of data analysis are not described. The presented findings are descriptive and only support the VR intervention, raising concerns of rigour in data analysis because no contradictory data are presented. It could be expected that the intervention would be more amenable to people in early stages of dementia, whereas people in later stages may experience difficulties watching a video. These issues are not addressed in the paper. These concerns are exacerbated by a lack of reflexivity: the authors are involved in the development of VR material and yet do not address their role and influence on data collection and analysis. The limited reporting means that it is not possible to judge the credibility of the findings.

The VR intervention has some similarities with reminiscence therapy, which involves the discussion of past events, activities and experiences. However, there is limited evidence of the effectiveness of reminiscence therapy for older people with dementia and their carers.[196] The claims made in this paper about the potential benefits of VR should be cautiously interpreted. It is not possible to judge the transferability of these interim findings to other populations. However, the paper provides useful process information relating to the development of VR material and details of ongoing studies in the area of VR.

Appendix 6

Studies excluded from the literature review

TABLE 38 *Respite studies excluded from the effectiveness review (n = 29)*

Study	**Respite care**	**Comparison group**	**Frail elderly**	**Carer outcomes assessed**	**Controlled trial**	**Reason for exclusion**
Brodaty, 1989[136]	Carer education plus patient residential memory programme, providing respite for carers	(1) Residential memory programme (2) No treatment	✓	✓	✓	Multidimensional package, impact of respite element unclear
Burdz, 1988[197]	2-week nursing home respite	Waiting-list control (ongoing in-home care)	✓	✓	U	Comparison waiting-list group assessed 1 year later than intervention group; findings cannot be controlled for exogenous factors
Chang, 1992[151]	Inpatient respite care	(1) Acute care patients (2) Community-based patients receiving home care	✓	×	✓	No carer outcomes reported. Focus is on patient health
Colvez, 2002[198]	Five European carer support programmes; two provided respite	Five European programmes compared	✓	✓	×	Cross-sectional study with non-comparable groups; interventions do not allow impact of respite to be determined
Droes, 2000[199]	Day centre with family support	Day centre	✓	✓	✓	At least 18% of intervention group aged <65 years, but subgroup analysis by age not reported. Study assesses additive effect of family support
Droes, 2004[200]	Day care plus support group	Day care only	✓	✓	✓	Study assesses additive effect of support group
Droes, 2004[201]	Psychogeriatric day care	Integrated family support programme	✓	✓	✓	Study assesses additive effect of support group plus education
Eloniemi-Sulkava, 2001[137]	Coordinated support programme including respite	Usual care	✓	✓	✓	Multidimensional package, impact of respite element unclear
Feinberg, 1998[202]	Consumer-directed and professionally managed respite	None	×	×	×	Effects of respite not reported. Includes patients aged <65 years, but subgroup analysis by age not reported
Hinchliffe, 1995[138]	Tailored package of respite, medication, psychological techniques, environmental adaptations, support group (16 weeks) followed by no intervention (16 weeks)	No intervention (waiting list) (16 weeks) followed by intervention (16 weeks)				Multidimensional package, impact of respite element unclear
MacDonald, 1998[203]	Massage	None	U	✓	×	No other study of massage as a respite intervention identified, but age of hospice patients not reported

continued

TABLE 38 *Respite studies excluded from the effectiveness review (n = 29) (cont'd)*

Study	Respite care	Comparison group	Frail elderly	Carer outcomes assessed	Controlled trial	Reason for exclusion
Kosloski, 1995[194]	Respite package	None	✓	✓	×	Uncontrolled study: examination of one arm of trial[117]
Leitsch, 2001[204]	Medical adult day service	Social adult day service	✓	✓	×	Analysis of one arm of a quasi-experimental study[102]
Lorensini, 1997[205]	Day-centre care	No day care and non-caregivers	✓	✓	×	Cross-sectional observational study examining carer outcomes for self-selecting groups
Marks, 1987[206]	In-home respite	Waiting list (no in-home respite)	✓	✓	U	Cross-sectional study, no longitudinal data
Mohide, 1990[78,139]	Caregiver support programme: carer-focused healthcare, education about dementia and caring, assistance with problem solving, regular in-home respite, self-help family caregiver support group	Conventional community nursing care	✓	✓	✓	Multidimensional package, impact of respite element unclear
Newcomer, 1999[141–144]	Two case management models with different staffing ratios and service waivers: home care, homemaker/chore services, personal care services, companion services, day care	Usual care	✓	✓	✓	Multidimensional package, impact of respite element unclear
O'Connor, 1991[145]	Financial benefits, physical aids, home help, respite admissions, day care, night-sitter service, practical advice, psychiatric assessments, support group	Matched controls receiving usual care	✓	✓	✓	Multidimensional package, impact of respite element unclear
Oktay, 1990[83]	Post-Hospital Support Program: assessment, case management, nursing, counselling, referrals, respite, education, support group, medical back-up, on-call help	Usual care	✓	✓	✓	Multidimensional package, impact of respite element unclear
Pattie, 1991[146]	Community-based services, including day care, domiciliary support, continuing care, respite care, relaxation class, meals on wheels	Usual care	✓	✓	✓	Multidimensional package, impact of respite element unclear

continued

TABLE 38 *Respite studies excluded from the effectiveness review (n = 29) (cont'd)*

Study	Respite care	Comparison group	Frail elderly	Carer outcomes assessed	Controlled trial	Reason for exclusion
Reever, 2004[207]	Adult day services and care management	Adult day services	✓	✓	✕	Study assesses additive effect of case management
Schulz, 2003[147–150]	Resources for Enhancing Alzheimer's Caregiver Health (REACH): six sites offering variety of multicomponent interventions, two sites included respite elements	Control varied by site, comprising 'usual care' or 'minimal support conditions'	✓	✓	✓	Multidimensional package, impact of respite element unclear
Seltzer, 1988[208]	In-hospital respite care	None	✓	✓	✕	Uncontrolled study
Skelly, 1993[209]	In-hospital respite care (28 days per year)	No in-hospital respite	✓	✓	✕	Cross-sectional observational study comparing those using and not using in-home respite
Strain, 1987[152]	Adult day care	No day care and use of home care services (control group 1) No day care and no home care services (control group 2)	U	✕	✓	Phase II reports no carer outcomes. Age of care recipients unclear (23% of original sample aged <60 years). Frailty of care recipients unclear
Treloar, 2001[210]	Overnight respite (new attenders)	Overnight respite (regular attenders)	✓	✓	✕	Control appears inadequate. Inadequate reporting of findings
Warren, 2003[211]	Adult day programmes	None	✓	✓	✕	Uncontrolled study
Weissert, 1980[153,154]	Adult day care	Homemaker services; combined group with adult day care plus homemaker services	✓	✕	✓	No carer outcomes reported
Wells, 1990[212,213]	Special dementia day care	Those about to start using special day care	✓	✓	✕	Uncontrolled study
Wimo, 1993[155]	Dementia day care	Waiting list (no day care)	✓	✕	U	No carer outcomes reported

✓, yes; ✕, no; U, unclear.

TABLE 39 *Economic evaluations excluded from the literature review (n = 23)*

Study	**Is respite care evaluated?**	**Were care recipients primarily frail elderly people?**	**Were at least two services compared?**	**Were costs assessed?**	**Were benefits assessed?**	**Comments**
Abt-Zegelin, 2004[171]	✓	✓	×	×	×	Descriptive study
Allen, 1991[160]	✓	✓	×	✓	×	No comparator or evaluation of benefits
Axelsson, 1998[162]	×	✓	✓	✓	✓	Programme aimed to improve palliation and extend time at home. Not respite
Bea van Beveren, 1995[98]	✓	✓	×	×	×	Think piece
Bonato, 2001[169]	✓	×	×	✓	✓	Methodological study
Chiu, 1999[164]	✓	U	×	×	✓	Elicited willingness to-pay-values in terms of respite care
Cox, 1994[172]	✓	✓	×	P	×	Descriptive study
Drummond, 1991[140]	✓	✓	✓	✓	✓	Multidimensional support package
Elliott, 2001[165]	✓	U	✓	×	×	Summarised a conference paper
Gramain, 2004[175]	✓	✓	✓	×	✓	Costs not assessed
Hayes, 1999[176]	✓	✓	✓	×	×	Descriptive study
Kirwin, 1993[177]	✓	✓	✓	✓	×	No assessment of benefits
Kobelt, 2000[170]	✓	×	×	✓	✓	Descriptive study
Mehnert, 1989[173]	✓	✓	×	✓	×	Descriptive study
Montgomery, 1984[119]	✓	✓	✓	×	✓	No costs
Pattie, 1991[146]	✓	✓	✓	✓	✓	Multidimensional support package
Reifler, 1999[166]	✓	U	×	P	×	Descriptive study
Sansom, 1993[174]	✓	✓	×	×	×	Descriptive study
Schulz, 1991[163]	×	×	×	✓	✓	Not respite. Assesses the impact of radiotherapy
Shantz, 1995[167]	✓	U	✓	×	✓	No costs
Shulman, 1993[178]	✓	✓	✓	✓	✓	Multidimensional support package
Stalker, 1996[168]	✓	U	×	×	×	Descriptive study
Wimo, 1994[180]	✓	✓	✓	✓	✓	Benefits for carers not included

✓, yes; ×, no; P, partial; U, unclear.

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We look forward to hearing from you.

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