

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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Executive summary

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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.

Publication

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