Systematic review of respite care in the frail elderly

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Executive summary

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Executive summary

Objectives

The aim was to provide a systematic literature review of the effectiveness and cost-effectiveness of breaks in care in improving the well-being of informal carers of frail and disabled older people living in the community. The review also aimed to identify carer needs and barriers to uptake of respite services from a synthesis of qualitative studies.

Methods

Data sources

Electronic searches were carried out in MEDLINE, EMBASE, PsychInfo, AMED, ASSIA, IBSS, CINAHL, Econlit, Social Care Online, Sociological Abstracts, Web of Science, Cochrane databases of reviews and trials (CDSR, CMR, CENTRAL, DARE), PubMed Cancer Citations, Scopus and databases of ongoing research (NRR, CRISP). Searches were run from the earliest possible date to December 2005, with an update to April 2008 using MEDLINE, CINAHL and PsychInfo.

Study selection

Studies were included in the quantitative review if:

- they assessed an intervention designed to provide the carer with a break from caring, and they assessed carer outcomes
- the care recipient population was aged 65 years or over (or included subsample analysis of participants over 65 years)
- the respite intervention was compared with no respite or another intervention.

Studies were excluded if:

- they assessed only care recipient outcomes
- the intervention was designed to change the state of the care recipient (e.g. stroke rehabilitation).

All types of study design were included [randomised and non-randomised controlled trials (RCTs), longitudinal before-and-after studies, and observational studies using cross-sectional or longitudinal methods]. Studies were not excluded on the basis of language or year of publication.

Studies were included in the qualitative review if:

- they employed qualitative methods (face-to-face semistructured/in-depth interviews; focus groups; open questions in questionnaires)
- they reported the views of carers and/or recipients
- the care recipient population was aged 65 years or over, the mean age was 65 years or over, or analysis identified those over the age of 65 years when reporting findings

and either:

- they reported views of respite care or reported respite as a theme in relation to other types of care, e.g. care aimed to change the state of the care recipient

or:

- views of respite included:
  - respite care service provision/satisfaction with services
  - impact of respite on the carer and/or care recipient
  - unmet needs/perceived needs for respite care
  - reasons for utilising or not utilising respite care.

Data extraction

Studies for inclusion were identified by title, abstract or full paper by two reviewers. Data extraction was a two-stage process: data on study methods were entered into summary tables, followed by extraction of numerical data for meta-analysis of quantitative studies and extraction of text for thematic analysis of qualitative studies.

Data synthesis

Meta-analyses were carried out for each carer outcome separately, both on follow-up data only and on change scores, estimating change standard

deviations when necessary based on correlations between baseline and follow-up of 0.6. Narrative synthesis is presented for studies not appropriate for meta-analysis.

Thematic analysis was carried out on qualitative data exploring the similarities and differences in the findings of qualitative studies. A coding frame was developed to deconstruct the data, following which an explanatory model of barriers to uptake of respite services was developed by examining the relationships between the various codes.

Results

Quantitative synthesis

In total, 104 papers were identified for inclusion, 16 of which were appropriate for meta-analysis.

- Carer burden was reduced at 2–6 months' follow-up in single-sample studies but not in RCTs and quasi-experimental studies.
- Depression was reduced in RCTs in the short term and for home care but not for day care. These effects, however, were not significant in random-effects models. There was a trend for longer interventions to have more positive effects than shorter interventions.
- There was no effect of respite on anxiety, but it had positive effects on morale and anger and hostility. Single-group studies suggested that quality of life was worse after respite use.
- There were increased rates of institutionalisation after respite use; however, this does not establish a causal relationship as it may be a result of respite being provided late in the caregiving career.

Qualitative synthesis

A total of 70 papers were identified for inclusion. Uptake of respite care was influenced by:

- carer attitudes to caring and respite provision
- the caregiving relationship
- knowledge of, and availability of, services
- the acceptability to, and impact of respite care on, care recipients
- hassles resulting from the use of respite care
- quality of respite care
- the appropriateness and flexibility of service provision.

Respite needs to provide a mental break and not just a physical break. Carers expressed needs for active information provision about services, support offered early in the caregiving career, access to a variety of services with flexible provision, reliable transport services, continuity of care, good-quality care, appropriate environments, care that provides benefits for care recipients (socialisation and stimulation), and appropriate activities for care recipients' levels of abilities and interests.

Conclusions

There was some evidence to support respite having a positive effect on carers but the evidence was limited and weak. There was a lack of good-quality larger trials and respite interventions were varied, often with poor descriptions of the characteristics of interventions and limited provision and uptake. There was also a lack of economic analysis.

Implications for health care

Because of the variety of interventions identified and the uncertainty in the evidence, this review could not determine the effectiveness or otherwise of different models of respite care provision. It is difficult, therefore, to make recommendations as to the most appropriate form of delivery of respite, apart from the suggestion that a range of services is probably most appropriate, to provide flexibility of respite provision and responsiveness to carer and care recipient characteristics and needs and also changes in those needs over time. The qualitative review identified a need for information, respite early in the caregiving career, better training of formal carers (particularly in relation to dementia care), continuity of care, better transport services and good-quality service provision that provides stimulation to care recipients.

Recommendations for research (numbered in priority order)

1. There is a need for high-quality trials utilising randomisation and/or appropriate comparison groups but, before this, developmental work is needed to quantify carer needs and preferences to define the characteristics of an appropriate intervention, define and validate care recipient outcomes based on carer expectations and on the aims and processes of the intervention, and develop appropriate process measures.

2. Trials should include good-quality economic evaluations and consider short- and long-term outcomes, taking account of mortality, carer and care recipient characteristics, intervention characteristics, adequate provision of respite, uptake of respite and use of other services. In addition, they should utilise mixed-methods approaches to identify process outcomes and the quality of the interventions and their responsiveness to needs.
3. Studies are needed to address the optimum time point for provision of respite to provide carer relief from burden and to evaluate interventions to break down barriers to respite use.
4. Studies need to address the appropriateness of both carer and care recipient outcome measures. Studies should consider including carer outcomes such as depression, anger and hostility, morale, quality of life and institutionalisation as well as carer burden.
5. Studies should include ethnic minority groups and assess how needs may differ.
6. Qualitative research is needed to explore the meaning of a 'mental break' and how interventions may be developed to help carers achieve this.
7. Research into how to improve communication of service availability to carers is needed.

Publication

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The Health Technology Assessment (HTA) programme, part of the National Institute for Health Research (NIHR), was set up in 1993. It produces high-quality research information on the effectiveness, costs and broader impact of health technologies for those who use, manage and provide care in the NHS. 'Health technologies' are broadly defined as all interventions used to promote health, prevent and treat disease, and improve rehabilitation and long-term care.

The research findings from the HTA programme directly influence decision-making bodies such as the National Institute for Health and Clinical Excellence (NICE) and the National Screening Committee (NSC). HTA findings also help to improve the quality of clinical practice in the NHS indirectly in that they form a key component of the 'National Knowledge Service'.

The HTA programme is needs led in that it fills gaps in the evidence needed by the NHS. There are three routes to the start of projects.

First is the commissioned route. Suggestions for research are actively sought from people working in the NHS, from the public and consumer groups and from professional bodies such as royal colleges and NHS trusts. These suggestions are carefully prioritised by panels of independent experts (including NHS service users). The HTA programme then commissions the research by competitive tender.

Second, the HTA programme provides grants for clinical trials for researchers who identify research questions. These are assessed for importance to patients and the NHS, and scientific rigour.

Third, through its Technology Assessment Report (TAR) call-off contract, the HTA programme commissions bespoke reports, principally for NICE, but also for other policy-makers. TARs bring together evidence on the value of specific technologies.

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Reviews in *Health Technology Assessment* are termed 'systematic' when the account of the search, appraisal and synthesis methods (to minimise biases and random errors) would, in theory, permit the replication of the review by others.

The research reported in this issue of the journal was commissioned by the HTA programme as project number 04/07/06. The contractual start date was in June 2005. The draft report began editorial review in January 2007 and was accepted for publication in June 2008. As the funder, by devising a commissioning brief, the HTA programme specified the research question and study design. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HTA editors and publisher have tried to ensure the accuracy of the authors' report and would like to thank the referees for their constructive comments on the draft document. However, they do not accept liability for damages or losses arising from material published in this report.

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