The impact of stroke on informal carers: a literature review
Low J T, Payne S, Roderick P

Authors' objectives
To identify all the studies on stroke carers. Within the wider review, the authors aimed to outline the main findings and methodological criticisms of studies that examined the health service provision for informal stroke carers.

Searching
EMBASE on BIDS, MEDLINE and PsycLIT were searched from 1980 to 1997 using the following terms: 'carers', 'caregivers', 'stroke', 'quality of life', 'stroke services' and 'delivery of health care'. Only articles published in English and in peer-reviewed journals were selected.

Study selection

Study designs of evaluations included in the review
All designs of studies were to be included in the review.

Specific interventions included in the review
Stroke services provided to informal carers of stroke victims.

Participants included in the review
Informal carers of elderly (greater than 55 years) stroke victims. Voluntary workers or those in the employment of statutory services were excluded.

Outcomes assessed in the review
Coping in carers, assessed as psychological health, carer burden, physical health, social health, and miscellaneous including measure of knowledge of stroke or stroke care or additional help; educational needs; psychosocial loss; carer satisfaction; carers perceived needs.

How were decisions on the relevance of primary studies made?
The authors do not state how the papers were selected for the review, or how many of the reviewers performed the selection.

Assessment of study quality
Studies were assessed for their methodological rigour in terms of sample size, description of carer sample, design of study, and assessment tools used. The authors do not state how the papers were assessed for validity, or how many of the reviewers performed the validity assessment.

Data extraction
The authors do not state how the data were extracted for the review, or how many of the reviewers performed the data extraction.

Methods of synthesis
How were the studies combined?
A narrative synthesis was undertaken.

How were differences between studies investigated?
Studies examining the impact of stroke services on carers' quality of life were summarised separately from those examining the carers' ability to cope (not all the latter included an intervention).
Results of the review
A total of 18 studies investigated the carers ability to cope or their quality of life (n=1,430). It is unclear if all studies included an intervention. Of the included studies, 8 utilised a cross-sectional design, 5 were randomised controlled trials (RCTs) and 4 were longitudinal pilot studies; 12 studies were identified that examined the impact of stroke services on carers.

Whilst the use of positive coping strategies has some benefit, other more concrete measures such as post-discharge support, counselling, further information and practical help have been identified by carers as improving long-term health outcome, although the provision of information prior to hospital discharge was insufficient by itself. Studies examining the impact of stroke services on carers mainly concentrated on carers' perceptions of in-patient stroke services and generally explored two areas, namely, carers' perceived needs for services and their satisfaction with them. Carers were generally satisfied, but the studies highlighted the shortcomings of stroke services in meeting carers' needs, mainly in the provision of sufficient information. In particular, carers wanted information on reducing the risk of further strokes. Carers also felt inadequately supported by stroke services in tackling their emotional and personal problems. These findings come in the main part from service evaluations looking at carers' perceptions using non-standard measures. These studies have relied on the use of carers' self-reported satisfaction as their main outcome measure. This might be unreliable.

Authors' conclusions
The few studies looking at the impact of health services on carers could be divided into two areas: the effect of different deliveries of stroke rehabilitation on carers' psychological health, and the effect of different types of carer-directed interventions on their quality of life. In both these areas, there was little difference between the intervention and control groups on the carers' main outcomes.

CRD commentary
This was a very broad review of the impact of stroke on informal carers. The literature search included the main databases, but may have missed some relevant papers, particularly as only English language ones were considered. Only a small part of the review looked at the effect of any intervention on carers, and these parts were not always presented separately from the overall review. Given the broad scope of the review the very general inclusion criteria were appropriate. The quality of the studies included in the review was assessed and summarised, and although the impact of different quality studies on the findings was not discussed, they were presented in some detail. The details of the intervention were tabulated in the review, but it was not always clear what (if any) intervention had been assessed. The narrative pooling of the findings was appropriate, with the results of the review presented in terms of the nature and quality of the available studies rather than their actual findings.

Implications of the review for practice and research
Practice: The authors did not state any implications for practice.

Research: The authors state that further studies should broaden the research question in order to evaluate quality of life, using standardised measures to do this and employing either a longitudinal or randomised control design to improve the robustness of the results. More studies are also needed to evaluate the effectiveness of health services on carers' quality of life.

Funding
South and West NHS Research and Development.

Bibliographic details
PubMedID
10459884

Indexing Status
Subject indexing assigned by NLM

MeSH
Adaptation, Psychological; Caregivers /psychology; Cost of Illness; Health Services /standards; Humans; Quality of Life; Research Design /standards; Stress, Psychological /prevention & control; Stroke /psychology

AccessionNumber
12000003024

Date bibliographic record published
31/12/2001

Date abstract record published
31/12/2001

Record Status
This is a critical abstract of a systematic review that meets the criteria for inclusion on DARE. Each critical abstract contains a brief summary of the review methods, results and conclusions followed by a detailed critical assessment on the reliability of the review and the conclusions drawn.