

Training care givers of stroke patients: randomised controlled trial

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Abstract

Background Informal care givers support disabled stroke patients at home but receive little training for the caregiving role.

Objective To evaluate the effectiveness of training care givers in reducing burden of stroke in patients and their care givers.

Design A single, blind, randomised controlled trial.

Setting Stroke rehabilitation unit.

Subjects 300 stroke patients and their care givers.

Interventions Training care givers in basic nursing and facilitation of personal care techniques.

Main outcome measures Cost to health and social services, caregiving burden, patients' and care givers' functional status (Barthel index, Frenchay activities index), psychological state (hospital anxiety and depression score), quality of life (EuroQol visual analogue scale) and patients' institutionalisation or mortality at one year.

Results Patients were comparable for age (median 76 years; interquartile range 70-82 years), sex (53% men), and severity of stroke (median Barthel index 8; interquartile range 4-12). The costs of care over one year for patients whose care givers had received training were significantly lower (£10 133 *v* £13 794 (\$18 087 *v* \$24 619; €15 204 *v* €20 697); $P=0.001$). Trained care givers experienced less caregiving burden (care giver burden score 32 *v* 41; $P=0.0001$), anxiety (anxiety score 3 *v* 4; $P=0.0001$) or depression (depression score 2 *v* 3; $P=0.0001$) and had a higher quality of life (EuroQol score 80 *v* 70; $P=0.001$). Patients' mortality, institutionalisation, and disability were not influenced by caregiver training. However, patients reported less anxiety (3 *v* 4.5; $P<0.0001$) and depression (3 *v* 4; $P<0.0001$) and better quality of life (65 *v* 60; $P=0.009$) in the caregiver training group.

Conclusion Training care givers during patients' rehabilitation reduced costs and caregiver burden while improving psychosocial outcomes in care givers and patients at one year.

Introduction

Advances in stroke rehabilitation have successfully reduced severe disability and increased the number of disabled patients living at home supported by care givers who often feel inadequately trained, poorly informed, and dissatisfied with the support available after discharge.^{1 2}

Interventions to support stroke care givers by providing education, counselling, emotional support, or help with accessing services have shown little impact on patients and only modest improvements in psychological and social measures in care givers.³⁻⁷ Training care givers in skills essential for the day to day management of disabled stroke survivors is likely to have a role in reducing the burden of care but has not been investigated. We evaluated the effectiveness of caregiver training in reducing stroke costs and improving patient and caregiver outcomes. We describe clinical outcomes; economic analyses are described in an accompanying paper.⁸

Methods

Subjects

Patients were included if they were independent in daily living activities before the stroke, medically and neurologically stable at the time of baseline assessments, and expected to return home with residual disability (defined as the need for supervision or physical assistance for core activities of daily living). A care giver was the main person helping with activities of daily living and advocating on behalf of the patient. Care givers were required to have no notable disability (defined as a Rankin score of 0-2) and be willing and able to provide support after discharge.

Baseline assessments

Researchers undertook baseline assessments before block randomisation. Patients' assessments included demographics, stroke subtype, Barthel index,⁹ and estimations of premorbid function and quality of life; we used the Frenchay activity index⁹ and the EuroQol visual analogue scale.¹⁰ Caregiver assessments included details of demographics and accommodation, health profile, functional status, and quality of life assessments.

Interventions

All patients were managed on a stroke rehabilitation unit with established multidisciplinary practice and received conventional care in accordance with existing guidelines.

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Conventional care

- Information on stroke and its consequences, prevention, and management options
- Involvement in goal setting for rehabilitation and discharge planning
- Encouragement to attend nursing and therapy activities to learn about patients' abilities and informal instruction on facilitating transfers, mobility, and activities of daily living tasks, and
- Advice on community services, benefits, and allowances, including contact information for voluntary support services for care givers.

Caregiver training

In addition to conventional support, care givers allocated to caregiver training received

- Instruction by appropriate professionals on common stroke related problems and their prevention, management of pressure areas and prevention of bed sores, continence, nutrition, positioning, gait facilitation, and advice on benefits and local services, and
- "Hands-on" training in lifting and handling techniques, facilitation of mobility and transfers, continence, assistance with personal activities of daily living and communication, tailored to the needs of individual patients.

Training started when patients' rehabilitation needs had stabilised and discharge was contemplated. Care givers received three to five sessions depending on need, lasting 30-45 minutes, and a "follow through" session at home.

Assessment of outcome

An observer who did not participate in allocation or management of patients assessed outcome at three and 12 months after stroke onset. Most assessments were undertaken at home; patients and care givers were assessed separately wherever possible, and participants were encouraged to complete questionnaires themselves without prompts.

Outcome measures for patients included death or institutionalisation, modified Rankin scale, Barthel index and Frenchay activities index for function, hospital anxiety and depression scale for mood and EuroQol visual analogue scale for quality of life. We used the Frenchay activities index for function and social activities, hospital anxiety and depression scale and caregiver burden scale¹¹ for emotional health, and EuroQol visual analogue scale for quality of life to measure outcomes for care givers. The modified Rankin score at one year was dichotomised to good

outcome (score 0-2) and poor outcome (3-6). The Barthel index was similarly dichotomised; scores of > 18 were considered good. Patients and care givers were asked to complete a satisfaction questionnaire at 12 months.

Data analysis and statistical methods

We analysed the data on an intention to treat basis. For patients who had died or were lost to follow up we used the last completed datasets in further analyses. We compared differences between the intervention and control groups. We used prospective and retrospective techniques to collect data on use of resources from health and social services over one year.⁸

We undertook sensitivity analyses to examine the effects if all the missing values for carer burden and quality of life assessments were at the lower limit and the higher limit of the interquartile range. Seventy five patients in each group received caregiver support from a family worker. We used regression analyses to assess the confounding effect of this and other baseline variables on outcome.

Results

Of the 300 patients randomised, 33 patients died before completing the study. Deaths were distributed equally between allocations. Mortality, institutionalisation, and disability data were available for all patients. Assessments according to the Frenchay activities index, hospital anxiety and depression scale, EuroQol, and caregiver burden scale were missing or incomplete in some, but not the same, patients and care givers. Reasons included communication problems in patients and perceived lack of relevance, lack of time, fatigue, or disinclination. We included in the analyses only completed assessments at each time point. (See bmj.com.)

Baseline characteristics were similar between patients randomised to caregiver training and control groups. The spouse was the main care giver in two thirds of patients; 95% of patients had additional family support. Eighty per cent of patients owned their homes, and < 5% had input from social services before stroke. The median score on the Barthel index at one week placed both groups above moderately disabled level.

We found no significant differences in mortality, institutionalisation, or functional abilities between the training and control group. Patients whose care givers had received training reported significantly improved quality of life and mood outcomes, both at three and

Outcomes for care givers allocated to training and no training groups

Outcome measure	Range (bad to good)	Training (n=151)	Missing data	No training (n=149)	Missing data	P value
Caregiver burden scale:	88-22					
3 months		43 (36-54)	0	51 (41-62)	0	0.0001
12 months		32 (27-41)	11	41 (36-50)	6	0.0001
Median Frenchay activities index at 1 year (interquartile range)	0-45	27 (23-30)	1	26 (24-30)	1	0.43
Median hospital anxiety and depression score at 1 year (interquartile range):						
Anxiety	21-0	3 (2-4)	10	4 (3-6)	6	0.0001
Depression	21-0	2 (1-3)	10	3 (2-5)	6	0.0001
Median EuroQol visual analogue score (interquartile range):						
3 months	0-100	80 (71-90)	11	70 (60-80)	7	0.0001
1 year	0-100	80 (70-90)	22	70 (60-80)	14	0.0001

at 12 months (median hospital anxiety score at one year: 3 v 4.5; $P < 0.0001$; hospital depression score at one year 3 v 4; $P < 0.0001$; and median score on EuroQoL visual analogue scale at one year 65 v 60; $P = 0.009$).

Burden of care was reduced significantly and quality of life and mood in care givers improved significantly at three and 12 months. Functional activities were not affected (table). Regression analyses showed that training care givers had a highly significant effect on caregiver burden score, EuroQoL, and hospital anxiety and depression score at 12 months, which was independent of age, stroke severity, extent of disability, and caregiver support. The difference between the training and non-training groups remained significant in the sensitivity analysis. The proportion of care givers who were satisfied with rehabilitation (45% v 58%; $P = 0.001$) and instruction in looking after the patient (75% v 36%; $p = 0.001$) was higher in those receiving training.

Caregiver training was associated with significant cost reductions over one year (£10 133 (\$18 087; €15 204) (SD £8676) v £13 794 (SD £10 510); $P = 0.001$), mainly because of lower hospital costs (£8987 (SD £7368) v £12 383 (SD £9104)). Although non-hospital costs in the 12 months after stroke (£1145 (SD £2553) v £1411 (SD £2742)) were similar, a trend towards lesser use of personal, domestic, and respite care became obvious in the training group. Detailed cost analyses have been presented in the accompanying paper.⁸

Discussion

Training care givers in basic skills of moving and handling, facilitation of activities of daily living, and simple nursing tasks reduces burden of care and improves quality of life in patients and care givers. It also reduces the costs of stroke care and a higher proportion of patients achieve independence at an earlier stage (Barthel index > 18 at 3 months 77 v 52; $P < 0.007$), contrasting with previous reports of no, or even adverse, effects on patients.^{6,7}

Several different measures have been used to assess quality of life, all with various limitations.¹² Although the practical importance of the effects of any intervention on quality of life can be difficult to interpret, the significant improvements in scores associated with caregiver training are likely to indicate an important effect that has implications for clinical practice.

Limitations of the study

We kept observer bias to a minimum by using observers not involved with allocation, interventions, or patients' care. In addition we used robust, well validated, and objective outcome measures and encouraged self completion of various subjective assessments without prompts. This may have contributed to missing data on some assessments, which is another potential source of bias. Sensitivity analyses to examine the effects of missing data showed that findings remained robust for worse or better outcome assumptions.

Generalisability of results

The study was undertaken in a largely middle class suburban area, and an interaction between the accept-

What is already known on this topic

Interventions to support stroke care givers by using information packages, specialist nurses, or family support workers have little impact on patients and modest psychological or social benefits for care givers

What this study adds

Caregiver training in basic nursing, moving, and handling and facilitation of activities of daily living is feasible during stroke rehabilitation

Caregiver training significantly reduces caregiver burden, anxiety, and depression and improves quality of life and satisfaction with care among care givers at three and 12 months

Patients whose care givers received training reported better quality of life and psychological outcomes at three and 12 months

Patients' mortality, institutionalisation, and disability were not influenced by caregiver training

ability of interventions and education, affluence, living accommodation, informal support, and cultural beliefs is possible. Patients and care givers who chose to participate were likely to be fit and motivated. The generalisability of these interventions to other settings needs to be established.

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