

# Training care givers of stroke patients: economic evaluation

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## Abstract

**Background** Training care givers reduces their burden and improves psychosocial outcomes in care givers and patients at one year. However, the cost effectiveness of this approach has not been investigated.

**Objective** To evaluate the cost effectiveness of caregiver training by examining health and social care costs, informal care costs, and quality adjusted life years in care givers.

**Design** A single, blind, randomised controlled trial.

**Setting** Stroke rehabilitation unit.

**Subjects** 300 stroke patients and their care givers.

**Interventions** Caregiver training in basic nursing and facilitation of personal care techniques compared with no caregiver training.

**Main outcome measures** Health and social care costs, informal care costs, and quality adjusted life years in care givers over one year after stroke.

**Results** Total health and social care costs over one year for patients whose care givers received training were significantly lower (mean difference – £4043 (\$7249; €6072), 95% confidence interval – £6544 to – £1595). Inclusion of informal care costs, which were similar between the two groups, did not alter this conclusion. The cost difference was largely due to differences in length of hospital stay. The EQ-5D did not detect changes in quality adjusted life years in care givers.

**Conclusion** Compared with no training, caregiver training during rehabilitation of patients reduced costs of care while improving overall quality of life in care givers at one year.

## Introduction

Informal care givers make an important contribution to supporting disabled stroke survivors at home, often at a great personal cost.<sup>1-3</sup> The United Kingdom health and community care reforms seem to have done little to provide support for care givers<sup>6</sup> but may have increased the burden of care.<sup>7</sup> Studies on caregiver interventions show limited benefits; their cost effectiveness has not been evaluated.<sup>8</sup> This study reports an economic evaluation of an intervention that entailed training care givers, carried out within a randomised controlled trial.<sup>9</sup>

## Methods

Full details of the study have been given previously<sup>9</sup>; 300 patients and their care givers were randomised to receive caregiver training, in addition to conventional care on a stroke rehabilitation unit. Training consisted of instruction in basic skills of moving and handling, facilitation of activities of daily living, and simple nursing tasks.

## Assessment of caregiver quality of life

We used the EuroQol five-dimensional questionnaire (EQ-5D)<sup>10</sup> at baseline, and at 4, 12, 26, and 52 weeks after stroke to carry out assessments. We imputed missing values for care givers with partially missing EQ-5D data by carrying forward the last value. We applied utility weights from a UK general population survey to EQ-5D health states to calculate quality adjusted life years (QALYs). We examined QALY outcomes in terms of change between baseline and week 52 (see [bmj.com](http://bmj.com))

## Use of resources

We adopted a societal perspective, including health services, other formal care agencies, and informal carers for the economic evaluation. We collected data on use of health and social care services over one year after onset of stroke and on use of hospital resources for a three month period before stroke. Therapists recorded data on hospital use and therapy input after stroke. We used a specially adapted version of the client service receipt inventory to collect data on use of services after discharge from hospital retrospectively, at 12, 26, and 52 weeks during patients' assessment interviews.<sup>11</sup>

## Costs

To obtain a cost per patient we multiplied resource volumes by unit costs. We used the opportunity cost method to estimate the cost of informal care. We used the United Kingdom minimum wage (then £4.10 per hour) as a proxy valuation of care givers' time. We standardised all costs to 2001-2 prices. See [bmj.com](http://bmj.com) for details.

## Data analysis and statistical methods

The primary outcome measure for the study was health and social care costs during the first year after onset of stroke. We analysed the data on an intention to treat basis. Data were incomplete for those patients who died before the end of the study and their care givers, and for some survivors and their care givers. We included all available data in the analyses. We used Student's *t* test to compare differences between groups and non-parametric bootstrap methods, with 5000 repetitions, to obtain 95% confidence intervals.

## Results

We found no significant difference between the groups for the number of patients who died, or the number of days that they were alive ( $P = 0.88$ ). It was therefore not necessary to adjust cost data for differential survival time.



The health economics checklist is on [bmj.com](http://bmj.com)



This is the short version of the paper; the long version is on [bmj.com](http://bmj.com)

### Quality adjusted life years

Mean QALY values for trained and untrained care givers were comparable at baseline (0.94 (SD 0.10) *v* 0.94 (SD 0.14)) and at one year (0.91 (SD 0.11) *v* 0.90 (SD 0.14)). We found no significant difference between groups in QALY losses between baseline and one year. Given that the visual analogue scale detected changes over time and a difference between the groups,<sup>9</sup> it is likely that the EQ-5D was insensitive to change in caregiver health related quality of life, rather than that there were no effects on QALYs.

### Resource use and costs

The two groups used resources to a similar extent at baseline. Patients in the training group stayed in hospital less long (mean difference -12.4 days, 95% confidence interval -19.5 to -5.6) and had less physiotherapy (-30.2 units, -51.8 to -8.9) and occupational therapy (-3.2 units, -4.8 to -1.6) than patients in the no training group. Use of speech and language therapy was similar between the two groups. About a third of patients in both groups received help from social services with personal care, and 14-17% received domestic help. Although a trend towards lesser use of personal and domestic care services became obvious in the training group, the difference was significant only for use of day care (-2.8 visits, -5.1 to -0.5).

Sixty per cent of total annual costs in each group were accounted for by bed days during the initial admission, which rose to 80% after including therapy costs (table 1). These costs were significantly lower in the training group and were due to the shorter initial stay in hospital rather than reduced costs in the 12 months after stroke.

The number of care givers providing assistance to patients in various informal care activities increased in both groups compared with baseline. We found no significant differences in the average number of care hours provided per day, the number of days that such care was provided, or the total average annual number of care hours. Informal care, costed at minimum wage, amounted to an average of £884 (\$1585; €1328) (SD £1482) in the training and £933 (SD £1283) in the no training group. The addition of these to total annual costs did not alter the finding that the training group had lower total costs.

### Sensitivity analyses

We carried out sensitivity analyses on two aspects of the evaluation to assess the robustness of the findings. First, we used the replacement cost method to estimate the costs of informal care. This did not affect comparisons of total costs. Secondly we examined the effect of increasing the length of stay of patients in the training group by 10%, 15%, and 20%. Differences between the groups in hospitalisation costs remained, with an up to 15% increase in the training group's length of stay and in total annual costs for health and social care with up to a 20% increase in length of stay (see [bmj.com](http://bmj.com))

### Discussion

Improving the skills of consenting informal care givers during the rehabilitation of inpatients reduces costs for stroke care and improves their quality of life without increasing the burden of care to families or transferring costs to the community.

Training care givers did not substantially reduce use or costs of resources in the community after discharge from hospital. The possibility exists that the trends towards lower personal and domestic care costs may have reached significance in a larger sample.

### Potential biases

Cost advantages seem to be a result of earlier discharge from hospital in the training group. This unexpected finding has several potential explanations. The most likely reason is that training and some input into care before discharge may have increased the confidence and competence of care givers. It is also possible that patients' and care givers' awareness that they were receiving extra interventions or these families being viewed as "special" by the multidisciplinary team may have expedited discharge, although there was no evidence that they received more therapy input, or more community support after discharge. Finally, the possibility of bias due to unblinding was considered to be small because length of hospital stay was not a pre-defined outcome measure, the team deciding discharge was different to the research team, and sensitivity analyses showed that findings remained valid even when the length of stay was increased by 20% in these patients.

Mean costs in £, at 2001-2 prices, in the first year after onset of stroke

	Training (n=151)		No training (n=149)		Training <i>v</i> no training	
	No of patients using service or resource	Mean (SD)	No of patients using service or resource	Mean (SD)	Mean difference (BS, 95% CI)	P value
<b>Initial admission for stroke</b>						
Stroke unit	151	7 189 (6177)	149	10 079 (7 851)	-2890 (-4515 to -1301)	<0.001
Therapy	151	1 365 (1087)	149	1 650 (1 043)	-285 (-525 to -37)	0.021
Total	151	8 554 (6939)	149	11 729 (8 506)	-3176 (-4980 to -1409)	<0.001
<b>12 month follow up period</b>						
Secondary care	134	434 (1399)	125	555 (2 317)	-120 (-633 to 303)	0.611
Social services	151	1 235 (2708)	149	1 471 (2 898)	-236 (-881 to 402)	0.466
Other community based care	134	221 (501)	125	258 (491)	-38 (-159 to 86)	0.544
Informal care	134	884 (1482)	125	933 (1 283)	-49 (-392 to 303)	0.777
Total excluding informal care	134	1 953 (3400)	125	2 494 (4 060)	-541 (-1479 to 353)	0.244
Total including informal care	134	2 837 (4182)	125	3 427 (4 409)	-590 (-1634 to 469)	0.270
<b>Total annual costs</b>						
Total excluding informal care	134	10 544 (9278)	125	14 587 (10 844)	-4043 (-6544 to -1595)	0.001
Total including informal care	134	11 429 (9825)	125	15 520 (11 106)	-4091 (-6675 to -1578)	0.002

SD=standard deviation, BS=bootstrap, CI=confidence interval

### What is already known on this topic

In England care givers are increasingly being recognised as one of the building blocks of community care

Little is known, however, about the costs of assisting care givers effectively

### What this study adds

Training care givers reduces health and social care costs in the first year after stroke compared with not training them

Costs of informal care are similar between trained and untrained care givers, and therefore no shift in the burden of care from statutory services towards carers is becoming apparent

Caregiver training is associated with smaller losses of quality of life among care givers; this effect is apparent soon after the patient's stroke

The EQ-5D questionnaire did not detect changes in care givers' quality adjusted life years

### Weaknesses of the study

Assessment of costs did not include the initial investment into developing the training intervention. The ongoing costs of training care givers were also embedded within the activity returned by the therapists and difficult to dissect from overall costs of therapy. The costs suggested by the protocol are likely to be an

underestimate that does not reflect true service costs. The inclusion of these costs would equalise costs of therapy but not affect comparisons between groups.

The EQ-5D seemed insensitive to changes in care givers' QALYs. Although it has been used successfully with care givers,<sup>12</sup> others have shown it to be less sensitive.<sup>13 14</sup>

### Strength of the study

We examined costs as well as changes in health outcomes. In addition, the study takes into consideration the possibility of shifting costs from statutory services to informal care and shows that caregiver training can reduce costs of formal care without shifting costs on to care givers, while improving clinical outcomes in care givers and patients.<sup>9</sup>

### Conclusion

Despite care givers being recognised as one of the building blocks of community care, little is known about how care givers can be assisted effectively. Improving the skills of consenting informal care givers during inpatient rehabilitation reduces stroke care costs and improves their quality of life without increasing the burden of care to families or transferring costs to the community.

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### Corrections and clarifications

#### *Every breath you take*

In this news article about environmental pollution in South Asia by Sanjay Kumar (3 April, p 787), some words were omitted that explain further why poor people may be more likely to be exposed to indoor pollution than more affluent people. In the ninth paragraph, the first part of the quote from Jai Prakash Narain (coordinator for HIV/AIDS and tuberculosis for the World Health Organization in Delhi) should have read: "Exposure to indoor pollution may also lead to a higher risk for tuberculosis, especially among the poor, who live in overcrowded and poorly ventilated environments."

#### *Correction: Interactive case report: Treatment of nausea and vomiting during pregnancy*

The use of "primiparous" in an interactive case report (31 January, p 276) seems to have caused confusion. A subsequent rapid response advising that we had wrongly used the word primiparous in the report prompted us to publish a correction (27 March, p 762). It now seems that perhaps primiparous was correct after all. *Dorland's Illustrated Medical Dictionary* (30th edition) defines primiparous as "bearing or having borne but one child" (as was the case in our article) and "primipara" as "a woman who has had one pregnancy that resulted in a fetus that attained a weight of 500 g or a gestational age of 20 weeks, regardless of whether the infant was living at birth."

#### *Clustering of common risk factors does not explain risk of CHD*

We inadvertently omitted some vital words from the title of the summary paragraph in This Week in the BMJ for the paper by Shah Ebrahim and colleagues ("Clustering of risk factors and social class in childhood and adulthood in British women's heart and health study: cross sectional analysis," 10 April, pp 861-4). The summary should have been titled: "Clustering of common risk factors does not explain social inequalities in the risk of CHD."

- 1 Wilkinson PR, Wolfe CDA, Warburton FG, Rudd AG, Howard RS, Ross-Russell RW, et al. A long-term follow-up of stroke patients. *Stroke* 1997;28:507-12.
- 2 Claesson L, Gosman-Hedstrom G, Johannesson M, Fagerberg B, Blomstrand C. Resource utilization and costs of stroke unit care integrated in a care continuum: a 1-year controlled, prospective, randomized study in elderly patients: the Goteborg 70+ stroke study. *Stroke* 2000;31:2569-77.
- 3 Dewey HM, Thrift AG, Mihalopoulos C, Carter R, Macdonell RA, McNeil JJ, Donnan GA. Informal care for stroke survivors: results from the north east Melbourne stroke incidence study (NEMESIS). *Stroke* 2002;33:1028-33.
- 4 Anderson CS, Linto J, Stewart-Wynne EG. A population-based assessment of the impact of caregiving for long-term stroke survivors. *Stroke* 1995;26:843-9.
- 5 Bugge C, Alexander H, Hagen S. Stroke patients' informal caregivers. Patient, caregiver, and service factors that affect caregiver strain. *Stroke* 1999;30:1517-23.
- 6 Parker G, Clarke H. Making ends meet: do carers and disabled people have a common agenda? *Policy Politics* 2002;30:347-59.
- 7 Bauld L, Chesterman J, Davies B, Judge K, Mangalore R. *Caring for older people: an assessment of community care in the 1990s*. Aldershot: Ashgate, 2000.
- 8 Forster A, Smith J, Young J, Knapp P, House A, Wright J. Information provision for stroke patients and their caregivers. *Cochrane Database Syst Rev* 2001;(3):CD001919.
- 9 Kalra L, Evans A, Perez I, Melbourn A, Patel A, Knapp M, et al. Training care givers of stroke patients: randomised controlled trial. *BMJ* 2004;328:1099-101.
- 10 The EuroQol Group. EuroQol: a new facility for the measurement of health related quality of life. *Health Policy* 1990;16:199-208.
- 11 Beecham J, Knapp M. Costing psychiatric interventions. In: Thornicroft G, Brewin C, Wing J, eds. *Measuring mental health needs*. London: Gaskell, 1992.
- 12 Gunnell D, Coast J, Richards SH, Peters TJ, Pounsford JC, Darlow M-A. How great a burden does early discharge to hospital-at-home impose on carers? A randomized controlled trial. *Age Ageing* 2000;29:137-42.
- 13 Longworth L, Bryan S. An empirical comparison of EQ-5D and SF-36 in liver transplant patients. *Health Econ* (in press).
- 14 Donaldson C, Atkinson A, Bond J. Should QALYs be programme-specific? *J Health Econ* 1988;7:239-57. (Accepted 5 March 2004)