Original Paper

Cerebrovascular Diseases

Cerebrovasc Dis 2005;20:85–91
DOI: 10.1159/000086511

Received: December 14, 2004
Accepted: April 5, 2005
Published online: June 21, 2005

A Family Support Organiser for Stroke Patients and Their Carers: A Randomised Controlled Trial

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Key Words
Community health services · Post-stroke family support · Stroke after-care

Abstract
Background: Previous trials of interventions to support stroke survivors and their families in the community have had contradictory and inconclusive results. Using the MRC Framework for Complex Interventions we developed a family support organiser (FSO) service and refined outcome measures for evaluation. We tested the effects of the intervention in a randomised controlled trial. ***Methods:*** From 1 March 1999 to 1 April 2001 all first-in-a-lifetime strokes (n = 513) were identified and 340 (96%) of eligible strokes randomised to receive FSO or usual care. Patients and their carers were followed up at 3 months and 1 year post-stroke. Outcomes included satisfaction (main outcome) with hospital staff and outpatient services, use of social services, reintegration to normal living (RNLI) and feelings about life after the stroke. ***Results:*** The mean number of contacts with the FSO was 15 (SD = 9.8) per patient. More intervention than control patients received some social services and had increased patient and carer satisfaction in most aspects, particularly with information about recovery and feeling that someone had listened. There was little evidence at 3 or 12 months of differences in RNLI. ***Conclusions:*** A meta-analysis of trials in this area is now needed along with further trials of interventions in subgroups of the stroke population to fully identify any benefits of the FSO role.

Introduction

The long-term practical, social and emotional problems faced by stroke patients and their carers are well documented. These include depression [1] and strain [2] among carers, and depression, anxiety, pain, dementia and cognitive impairment among stroke survivors [3–5]. Emotional distress may be present in over half those caring for stroke survivors [6, 7]. Various interventions have sought to address the longer-term needs of stroke patients and their families in the community, including specialist nurse-led interventions [8], information provision [9], counselling and social work interventions [10–13]. Because of the negative or inconclusive results of these trials, the best way to support these families in the longer term still remains unclear.

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In the UK, the Stroke Association provides a family support organiser (FSO) service which may be requested and purchased by primary care trusts. The FSO service offers information, emotional support and prevention advice for families and stroke patients, and is aimed to cover the gap in support when formal treatment or therapy ends. An observational study evaluating an FSO service in inner London found that those who received the service were more likely to be satisfied with aspects of their stroke care [14]. However, only 43% of respondents had seen the FSO, with patients with higher levels of disability being more likely to have done so.

Three randomised trials of this model of family support in the UK have been published, one from Edinburgh [15], one in Oxfordshire [16] and one in Nottingham [17]. All found some evidence of improved satisfaction with aspects of care or emotional outcomes in patients and carers in the intervention arm of the trial. This was offset by evidence of poorer mental health and social adjustment [15] and less use of physio-, speech and language therapy [16] in patients in the intervention arm. One trial concluded that the intervention was ineffective [15], one that it was effective for carers but not patients [16], and one that it improved knowledge about stroke and relevant services [17]. However, there are two issues with these trials which may affect their relevance. Firstly, the interventions were imprecisely described, and therefore it is difficult to identify which aspects may be of benefit to patients/carers. Secondly, some of the outcomes assessed (e.g. mental and physical health, activities of daily living) may not have been relevant to the intervention [18].

Using the MRC Framework for Complex Interventions [19] we conducted preliminary research to define the content of the intervention and the relevant outcomes. A survey of FSOs in England recommended that FSOs should undertake a formal assessment of patients/families to assess needs and set objectives; and identified specific outcomes that an FSO intervention might affect. These included feelings of abandonment, worry, hope, adjustment to disability, knowledge about prognosis and secondary prevention [18]. A qualitative interview study conducted in Hastings sought patients' and carers' views of needs after discharge [20]. Problems were reported with getting information and on-going access to therapy and monitoring of progress. While the FSOs who were surveyed prioritised the provision of 'emotional support', interviewees thought this was best provided by family and friends. In the light of these two studies the roles of the FSO were clarified and training provided for new workers in the trial.

The intervention to be tested in the trial comprised the employment of an FSO employed by the Stroke Association Charity. The aim of the FSO is to offer information, emotional support and prevention advice to families and patients. This support was aimed at assisting patients and families in the transition from hospital to home and could include facilitating access to local statutory and voluntary services; providing advice about ongoing physiotherapy. Support provided was decided following an initial assessment and the frequency and duration of the interactions was at the discretion of the FSO. We carried out a single-blind randomised controlled trial to compare the effect of a (Stroke Association) FSO to usual care on emotional outcomes, reintegration to normal life, and use of and satisfaction with services among stroke patients and their carers in Hastings (UK).

Methods

Ethics approval was obtained from Hastings Local Research Ethics Committee. Eligible patients were residents of Hastings with a first-in-lifetime stroke between 1 March 1999 and 1 April 2001. Patients admitted to hospital and those cared for in the community were included. Each eligible patient was visited by the fieldworker who explained the study and sought consent for randomisation. Where the patient was incapable of giving consent, assent was sought from the next of kin or from the manager or professional caring for the patients in a nursing home.

Intervention

Patients in the intervention arm and their families and carers received support from the FSO service. The Stroke Association and project team provided FSOs with training in physiotherapy and secondary prevention, health promotion, a clinical update on stroke, time management, provision of emotional support, and the social services and benefits system. The assistance provided by the FSO is in addition to any similar advice that may be provided by any healthcare professional who manages stroke patients and their families. For the first part of the study, two FSOs participated in the study. One FSO left in November 2000 and was not replaced. The two FSOs allocated patients between them, depending on workload and geographical location. Each FSO recorded every visit/interaction made, including the time, duration and outcome of the visit.

Those in the control group received usual outpatient care and information.

Follow-Up

Patients and their carers were followed up at 3 months and 1 year after randomisation. Postal questionnaires were used except where patients preferred a home visit, when they were visited by the fieldworker. Where no response to a postal questionnaire was received, a reminder was sent, followed by a telephone reminder.

The main outcome measure was patient satisfaction with services and the sample size was based on this. The other outcome

measures were considered important to assess as they were potentially important measures reflecting the aims of the intervention: reintegration into society, anxiety and depression. The Barthel Score was used for comparison with other trials. We assessed patient depression using the Hospital Anxiety and Depression scales [21], and the impact of the stroke on the patient's everyday life using a modified version of the Reintegration to Normal Living Index (RNLI) [22]. The modified RNLI asks patients to agree/disagree with 11 statements, such as 'I get around my house as I need to', given an 11-point scale. We also asked patients about adaptations made to the home and use of social services, and assessed their satisfaction with stroke care using the Pound Satisfaction Scale [23]. We assessed activities of daily living for patients using the Barthel Index [24].

Outcome scales used for carers included the Caregiver Strain Index and the Hospital Anxiety and Depression scales [21]. We also asked about aspects of social life and life after the stroke, and assessed satisfaction with stroke care using the carer version of the Pound Satisfaction Scale [23].

Sample Size Calculation

A total of 336 patients (168 in each arm of the trial) would give 80% power to detect a 15% difference between the two arms of the trial in the proportion of patients satisfied with an aspect of stroke care.

Statistical Analysis

We analysed the data by group of allocation. For all continuous outcomes, a t test was used to assess the difference between the intervention and control groups. Where the continuous outcome was non-normal, robust standard errors were used. For binary outcomes, the z test for proportions was used to assess the difference between the intervention and control groups.

Analysis of FSO Forms

To identify what support was provided in this intervention, we analysed records kept by FSOs, detailing for each patient/family contact: needs identified, objectives and outcomes. We randomly selected 100 out of 2,410 records and carried out content analysis of these records.

Assignment

The unit of randomisation was the patient. Randomisation was by computer-generated random numbers, in blocks of ten. As the fieldworker enrolled each patient, patient details were sent to the central administrator (in the Department of Public Health Sciences, King's College London), who performed the randomisation. For each patient randomised to the intervention arm, the central administrator then sent the patient details on to the FSO. The fieldworker was thus blind to the randomisation of each patient, as were all those involved in patient care.

Masking

The patients (and their families and carers) were not blind to which arm of the trial they were in. The fieldworker enrolling the patients and assessing their outcome was completely separated from the randomisation process, and was blind to which arm of the trial each patient was in.

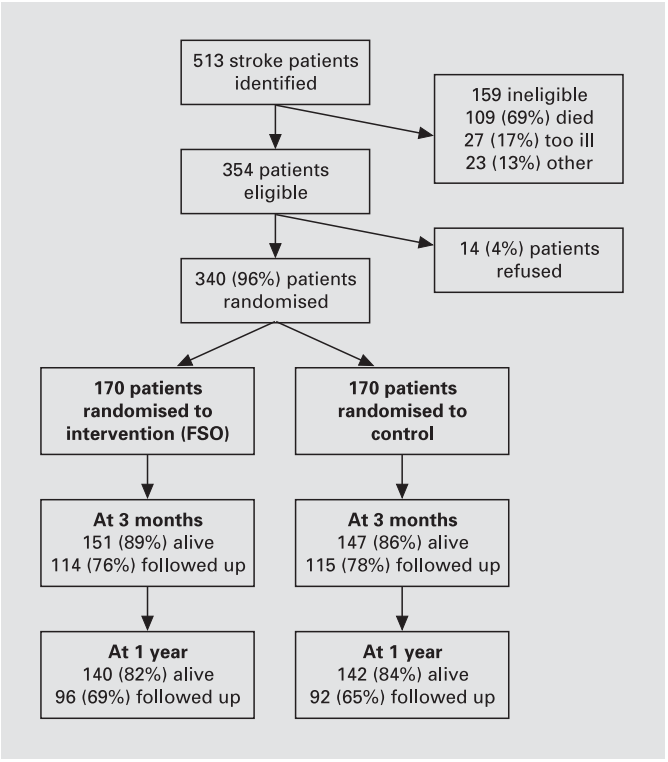

Fig. 1. CONSORT diagram showing the flow of patients through the trial.

Results

Participant Flow and Follow-Up

A total of 513 patients with first stroke were identified over the study period, of whom 159 were ineligible. Of these, 109 (69%) died before being seen by the researcher, 27 (17%) were unable to consent because they were too ill/cognitively impaired, 4 (3%) moved out of the area, 9 (6%) could not be contacted by the researcher, 10 (6%) had no or 'other' reasons recorded. Of the 354 eligible patients, 340 (96%) consented to randomisation, 170 patients were randomised to each group. Figure 1 shows a CONSORT diagram of the flow of patients through the trial.

Table 1 shows the characteristics of patients at baseline. There was no evidence of differences between the two groups in any of these characteristics.

There were between 1 and 60 FSO contacts for each patient in the FSO group (including telephone or face-to-face contacts with the patient, the patient's carer, or both), with a mean of 15 (SD = 9.8) per patient. These included both telephone contacts and face-to-face contacts.

Table 1. Baseline characteristics

Characteristic	Control (n = 170)	Intervention (n = 170)
Male	74 (44%)	67 (39%)
Age, years (mean ± SD)	77 (10.6)	78 (11.6)
Non-manual professionals	103 (63%)	98 (64%)
Pre-stroke Barthel = 20	91 (54%)	91 (54%)
Not admitted to hospital	6 (4%)	6 (4%)
Medical ward	58 (36%)	44 (27%)
No motor deficit	20 (13%)	15 (9%)
Swallowing difficulty	82 (49%)	83 (49%)
Dysarthria	104 (62%)	107 (63%)
Dysphasia	101 (59%)	86 (51%)
Incontinent	80 (47%)	88 (52%)
7-Day Barthel (mean ± SD)	11 (6.2)	11 (6.4)
GCS of 15 at 7 days	141 (83%)	128 (75%)
LOS, days (mean ± SD)	48 (49.6)	50 (41.5)
Cerebral infarct	109 (66%)	118 (71%)
Intracerebral haemorrhage	16 (10%)	8 (5%)
SAH	4 (2%)	2 (1%)
Unclassified	35 (21%)	38 (22%)

GCS = Glasgow Coma Scale; LOS = length of stay.

Of the initial 340 patients, 23 (14%) control and 19 (11%) intervention patients died before 3 months. Of the remainder, 115 (78%) control and 114 (75%) intervention patients, and the carers of 81 (55%) control and 70 (46%) intervention patients were followed up at 3 months. There was no evidence of a difference between the two groups in death rate, or patient or carer follow-up rates ($p = 0.51$, $p = 0.58$ and $p = 0.13$, respectively). At 1 year there was no evidence of differences between the groups in death rate, or patient or carer follow-up rates ($p = 0.77$, $p = 0.5$ and $p = 0.38$, respectively).

Three-month patient outcome data: mean total RNLI score was lower in the intervention [6 (SD = 3.1)] than control group [7 (SD = 3.1); 95% CI –1.7, +0.01; $p = 0.05$], indicating poorer outcome in the intervention group. A higher proportion of intervention [56 (52%)] than control [80 (75%)] patients thought that the stroke still had a negative effect on their life (95% CI +10, +35; $p < 0.001$). There was little evidence of differences between the two groups in patient satisfaction at 3 months, except that a lower proportion of patients in the intervention group were satisfied with community services [45 (76%) control, 32 (55%) intervention; $p = 0.02$] and a higher proportion of patients in the intervention group were satisfied with information about recovery [53 (49%) control, 76 (71%) intervention; $p = 0.001$] and advice about prevention [46 (42%) control, 58 (54%) intervention; $p = 0.09$]. A higher proportion of patients in the intervention group were satisfied with the item of care for 7/10 items in the Patient Satisfaction Scale, but the overall differences in satisfaction score were not significantly different [7.4 (SD = 0.5) control, 7.6 (SD = 0.6) intervention; $p = 0.8$].

At 3 months, more carers in the intervention group (control 12 (16%) vs. intervention 18 (28%); $p = 0.08$) felt that some good had come out of the stroke, fewer intervention patients were satisfied with equipment they had at home and more were satisfied with information about recovery [control 48 (61%) vs. intervention 53 (75%); $p = 0.07$], advice about prevention [control 31 (39%) vs. intervention 43 (61%); $p = 0.007$], knowing who to contact and feeling that someone had listened to them [control 42 (54%) vs. intervention 49 (70%); $p = 0.04$]. A higher proportion of carers in the intervention group were satisfied with the item of care for 6/10 items in the Carer Satisfaction Scale, although overall there was no significant difference between arms [6.9 (SD = 0.7) control vs. 7.5 (SD 0.64) intervention; $p = 0.54$].

Table 2 shows the 1-year outcome data for patients. More patients in the intervention group had seen their GP, and fewer had been seen in hospital for stroke. There was no overall difference between the two groups in the proportion having contact with either a GP or hospital. There was weak evidence of lower mean RNLI in the intervention than control group. A higher proportion of intervention patients thought that the stroke still had a negative effect on their life. There was little evidence of differences between the two groups in patient satisfaction at 1 year, except that a higher proportion of patients in the intervention group were satisfied with the information they had been given about recovery, and felt that someone had listened to them. A higher proportion of patients in the intervention group were satisfied with the item of care for 6/10 items in the Patient Satisfaction Scale.

Table 3 shows the 1-year outcome data for carers. Fewer carers in the intervention group were satisfied with the information they received about benefits and social services or the help they received applying for services, but more felt that someone had listened to them. A higher proportion of carers in the intervention group were satisfied with the item of care for 6/10 items in the Carer Satisfaction Scale.

Content analysis of the 100 randomly selected FSO forms suggested that needs were identified through discussion with staff, patient and family members but there was little evidence of targeting the intervention to need.

Table 2. One-year patient outcomes (mean ± SD) unless stated otherwise

Outcome	Control (n = 92)	Intervention (n = 96)	95% CI for difference (intervention: carer)[a]	p value
Adaptations to home	26 (29%)	36 (38%)	–5, 22	0.21
Special equipment	47 (55%)	45 (49%)	–20, 9	0.44
Social Services				
Home help	9 (10%)	22 (23%)	3, 24	0.01
Day hospital	10 (11%)	8 (8%)	–11, 6	0.57
District nurse	19 (21%)	20 (21%)	–11, 12	0.95
Number of services	1.59 (0.15)	1.66 (0.17)	–0.38, 0.53	0.74
Seen GP	72 (80%)	83 (89%)	–1, 20	0.08
Seen in hospital for stroke	35 (38%)	20 (21%)	–30, –4	0.009
Barthel	14 (0.62)	14.1 (0.60)	–1.64, 1.76	0.94
Anxiety	7.2 (0.48)	7.4 (0.56)	–1.28, 1.63[b]	0.81
Depression	7.3 (0.53)	8.2 (0.52)	–0.59, 2.35[b]	0.24
RNLI	7.2 (0.34)	6.5 (0.38)	–1.70, 0.31	0.18
Life after stroke				
Manage stroke all right now	55 (64%)	52 (58%)	–20, 9	0.45
Come to terms with stroke	59 (69%)	59 (65%)	–18, 10	0.60
Stroke still has a negative effect on life	45 (53%)	59 (66%)	–1, 28[b]	0.07
Some good has come out of stroke	14 (17%)	20 (23%)	–6, 18	0.32
Patient satisfaction				
Stroke information	61 (70%)	70 (76%)	–7, 19	0.37
DSS information	48 (72%)	50 (68%)	–19, 11	0.60
Applying for services	53 (80%)	56 (74%)	–20, 7	0.35
Community services	35 (74%)	39 (75%)	–17, 18	0.95
Equipment at home	49 (86%)	58 (84%)	–14, 11	0.77
Recovery information	48 (56%)	62 (68%)	–3, 26	0.11
Prevention advice	45 (54%)	54 (59%)	–9, 20	0.44
Know who to contact	63 (73%)	71 (77%)	–9, 17	0.55
Someone has listened	53 (62%)	70 (76%)	1, 28	0.04
Felt abandoned	18 (21%)	28 (30%)	–3, 22	0.15
Total satisfaction score	8.0 (0.64)	7.8 (0.63)	–2.04, 1.58	0.80

[a] Positive values indicate better outcome in intervention than control group.
[b] Positive values indicate poorer outcome in intervention than control group.

Information was provided about stroke, secondary prevention, medication use, and social service entitlements. Secondary prevention information was also provided. Most services provided were offered by other professionals but FSOs emphasised their on-going availability. FSOs acted as a go-between between clients and other service providers (including GPs) and voluntary sector groups. In this process they appeared to provide a further level of service delivery, raising questions about why patients and families needed assistance accessing existing services.

Discussion

Family support appears to benefit stroke patients and their carers in several aspects of life after stroke at both 3 months and 1 year. There were consistent patterns between the two time points, with more intervention than control patients reporting receipt of some social services and being seen by their GP. There were also consistent patterns in patient/carer satisfaction, with increased satisfaction in most aspects, particularly with information about recovery and feeling that someone had listened. There was some evidence of a lower RNLI score for in-

Table 3. One-year carer outcomes (mean ± SD) unless stated otherwise

Outcome	Control (n = 58)	Intervention (n = 50)	95% CI for difference (intervention: carer)[a]	p value
Caregiver strain	4.5 (0.51)	4.4 (0.60)	–1.65, 1.46[b]	0.91
Anxiety	7.5 (0.59)	7.0 (0.72)	–2.42, 1.24[b]	0.52
Depression	6.3 (0.63)	5.7 (0.72)	–2.51, 1.27[b]	0.51
Life after stroke				
Manage stroke all right now	50 (89%)	40 (87%)	–15, 10	0.72
Come to terms with stroke	45 (85%)	44 (90%)	–8, 18	0.46
Stroke still has a negative effect on life	31 (61%)	26 (55%)	–25, 14[b]	0.58
Some good has come out of stroke	12 (23%)	13 (28%)	–13, 22	0.60
Social life				
Has someone to help	53 (91%)	44 (88%)	–15, 8	0.56
Attends support group	4 (8%)	2 (5%)	–13, 7	0.59
Has had a break from caring	17 (41%)	13 (45%)	–20, 27	0.78
Attends respite care	12 (29%)	4 (14%)	–33, 4	0.14
Carer satisfaction				
Stroke information	41 (72%)	38 (76%)	–13, 21	0.63
DSS information	34 (74%)	23 (58%)	–36, 3	0.11
Applying for services	31 (79%)	21 (57%)	–43, –2	0.03
Community services	23 (79%)	14 (64%)	–41, 9	0.21
Equipment at home	34 (85%)	30 (91%)	–9, 21	0.45
Recovery information	37 (64%)	37 (76%)	–6, 29	0.19
Prevention advice	28 (49%)	27 (55%)	–13, 25	0.54
Know who to contact	45 (76%)	31 (66%)	–29, 6	0.19
Someone has listened	29 (51%)	32 (68%)	–1, 36	0.08
Felt abandoned	21 (36%)	11 (24%)	–30, 5[b]	0.18
Total satisfaction score	8.6 (0.81)	7.8 (0.70)	–2.98, 1.38	0.46

[a] Positive values indicate better outcome in intervention than control group.
[b] Positive values indicate poorer outcome in intervention than control group.

tervention patients at both time points. The intervention did not appear to affect ADL, anxiety or depression but was not powered to detect such differences.

One major strength of our study was that we used evidence from FSOs, patients and carers to develop the intervention and identify relevant outcomes. However, content analysis of the FSO diaries revealed that in practice the FSOs did not always target the intervention they provided according to need. The FSOs also placed an emphasis on emotional support and providing a 'listening ear', which our earlier work had shown to be less relevant to the patients and their families. Further training of FSOs may result in greater effects on patient and carer outcomes than those shown here. The negative effects of the FSOs in respect to patient reintegration need further investigation, as there may be potential for strengthening the communication with the patients as well as families.

Our trial included all people identified with strokes in this area, including patients in nursing homes, and those not admitted to hospital for stroke (approximately 4% of the sample, compared to approximately 16% of patients in a population-based stroke register) [25]. Our patients were older than those recruited by the Edinburgh or Oxford trials, reflecting the demographics of the Hastings area. A randomised trial of a nurse-led support intervention found evidence of an effect of the intervention only in patients with mild disability (Barthel 15–19) at randomisation [8]. At 7 days after stroke the mean Barthel Index in our trial was 11 (SD = 0.34), indicating that many of our patients were still severely disabled at this stage. The FSO intervention might show more of an im-

pact if analysis was restricted to patients not in nursing homes, or who had mild to moderate levels of disability after the stroke [18]. Caregiver characteristics can also influence how much they benefit from such interventions [26]. The impact of the FSO intervention in relation to patient and carer characteristics needs further investigation.

Here we have added to the body of evidence on the effectiveness of the FSO service by conducting a randomised controlled trial in the entire first-time stroke population in an area with no stroke unit. Previous trials have suffered from imprecisely defined interventions or inappropriate outcomes. Here, preliminary research defined the role of the FSO and the needs of patients, and these were incorporated into the trial design. Even so, there were few differences in outcome between the FSO and control groups. A meta-analysis of trials in this area is now needed to fully identify any benefits of the FSO role along with further trials, informed by the perceived needs of patients and their families, of different groups of patients. Defining a more effective role for family and carer support will require more detailed understanding of their perceived needs at various time points after stroke and this will vary between countries and cultures. Future trials should stratify by disability level and discharge destination to identify the groups that will benefit most. The positive elements of the role include: the ability of the FSO to direct people to relevant services such as social services and primary care and the provision of information. More focus on the patient would appear to be warranted given that the RNLI scores were poorer in patients in the intervention group.

References

1 Han B, Haley WE: Family caregiving for patients with stroke. Review and analysis. Stroke 1999;30:1478–1485.
2 Bugge C, Alexander H, Hagen S: Stroke patients' informal caregivers. Patient, caregiver, and service factors that affect caregiver strain. Stroke 1999;30:1517–1523.
3 Madureira S, Guerreiro M, Ferro JM: Dementia and cognitive impairment three months after stroke. Eur J Neurol. 2001;8:621–627.
4 Kong KH, Woon VC, Yang SY: Prevalence of chronic pain and its impact on health-related quality of life in stroke survivors. Arch Phys Med Rehabil 2004;85:35–40.
5 Wolfe CDA, Rudd AG, Beech R: Stroke Services and Research: An Overview with Recommendations for Future Research. London, The Stroke Association, 1996.
6 Dennis M, O'Rourke S, Lewis S, Sharpe M, Warlow C: A quantitative study of the emotional outcome of people caring for stroke survivors. Stroke 1998;29:1867–1872.
7 Anderson CS, Linto J, Stewart-Wynne EG: A population-based assessment of the impact and burden of caregiving for long-term stroke survivors. Stroke 1995;26:843–849.
8 Forster A, Young J: Specialist nurse support for patients with stroke in the community: a randomised controlled trial. BMJ 1996;312:1642–1646.
9 Rodgers H, Atkinson C, Bond S, Suddes M, Dobson R, Curless R: Randomized controlled trial of a comprehensive stroke education program for patients and caregivers. Stroke 1999;30:2585–2591.
10 Logan PA, Ahern J, Gladman JR, Lincoln NB: A randomized controlled trial of enhanced Social Service occupational therapy for stroke patients. Clin Rehabil 1997;11:107–113.
11 Friedland JF, McColl M: Social support intervention after stroke: results of a randomized trial. Arch Phys Med Rehabil 1992;73:573–581.
12 Towle D, Lincoln NB, Mayfield LM: Service provision and functional independence in depressed stroke patients and the effect of social work intervention on these. J Neurol Neurosurg Psychiatry 1989;52:519–522.
13 Christie D, Weigall D: Social work effectiveness in two-year stroke survivors: a randomised controlled trial. Community Health Stud 1984;8:26–32.
14 Richardson E, Warburton F, Wolfe CD, Rudd AG: Family support services for stroke patients. Prof Nurse 1996;12:92–96, 99.
15 Dennis M, O'Rourke S, Slattery J, Staniforth T, Warlow C: Evaluation of a stroke family care worker: results of a randomised controlled trial. BMJ 1997;314:1071–1076.
16 Mant J, Carter J, Wade DT, Winner S: Family support for stroke: a randomised controlled trial. Lancet 2000;356:808–813.
17 Lincoln NB, Francis VM, Lilley SA, Sharma JC, Summerfield M: Evaluation of a stroke family support organiser: a randomized controlled trial. Stroke 2003;34:116–121.
18 Pound P, Wolfe CD: Stroke in the community: the role of the family support organiser. Br J Ther Rehabil 1998;5:482–488.
19 Medical Research Council: A framework for development and evaluation of RCTs for complex interventions to improve health. 2000. http://www.mrc.ac.uk/pdf-mrc_cpr.pdf.
20 McKevitt C, Wolfe CD: Community support after stroke: patient and carer views. Br J Ther Rehabil 2000;7:6–10.
21 Zigmond AS, Snaith RP: The hospital anxiety and depression scale. Acta Psychiatr Scand 1983;67:361–370.
22 Daneski K, Coshall C, Tilling K, Wolfe CDA: Reliability and validity of a postal version of the Reintegration to Normal Living Index, modified for use with stroke patients. Clin Rehabil 2003;17:835–839.
23 Pound P, Gompertz P, Ebrahim S: Development and results of a questionnaire to measure carer satisfaction after stroke. J Epidemiol Community Health 1993;47:500–505.
24 Mahoney FI, Barthel DW: Functional evaluation: the Barthel Index. Md State Med J 1965;14:61–65.
25 Stewart JA, Dundas R, Howard RS, Rudd AG, Wolfe CD: Ethnic differences in incidence of stroke: prospective study with stroke register. BMJ 1999;318:967–971.
26 van den Heuvel ETP, de Witte LP, Stewart RE, Schure LM, Sanderman R, Meyboom-de Jong B: Long-term effects of a group support program and an individual support program for informal caregivers of stroke patients: which caregivers benefit the most? Patient Educ Couns 2002;47:291–299.