

# The effectiveness of various models of primary care-based follow-up after stroke: a systematic review

Rhoda Allison<sup>1</sup>, Laura Shelling<sup>1</sup>, Rachel Dennett<sup>1</sup>, Tim Ayers<sup>1</sup>, Philip H. Evans<sup>2</sup> and John L. Campbell<sup>2</sup>

<sup>1</sup>Stroke Unit, NHS Devon, Newton Abbot Hospital, Newton Abbot, Devon, UK

<sup>2</sup>Peninsula Medical School (Primary Care), St Luke's Campus, Exeter, UK

**Aim:** To systematically review studies reporting the effectiveness of various models of follow-up in primary care on a range of outcomes (physical, psychological, social functioning, or quality of life) for survivors of stroke and their caregivers. **Background:** Stroke is a major cause of disability globally. Current UK policy calls for a primary care-based review of healthcare and social-care needs at six weeks and six months after hospital discharge and then annually. **Methods:** Trials meeting the pre-defined inclusion criteria were identified by the systematic searching of electronic databases. Data were extracted by two independent researchers. Studies were rated using the McMaster University Quality Assessment Tool. **Findings:** Nine randomised controlled trials that met the inclusion criteria were identified. These studies included interventions using stroke support workers, care coordinators or case managers. The methodological quality of the studies was variable, and models of care demonstrated inconsistent working relationships with general practitioners. Patients and caregivers receiving formal primary care-based follow-up did not show any gains in physical function, mood, or quality of life when compared with those who did not. Patients and caregivers receiving follow-up were generally more satisfied with some aspects of communication, and had a greater knowledge of stroke. **Conclusions:** The limited quality of these studies and the lack of a sound theoretical basis for the development of interventions together highlight the urgent need for high-quality research studies in this area.

**Key words:** primary care follow-up; stroke

Received 5 November 2010; accepted 6 January 2011; first published online 11 March 2011

## Introduction

The term stroke refers to a clinical syndrome, of presumed vascular origin, typified by rapidly developing signs of focal or global disturbance of cerebral function, lasting more than 24 h (World Health Organization, 1978). Stroke is the second most common cause of death in adults worldwide (Lopez and Mathers, 2006) and, with heart disease, is predicted to be the biggest global cause

of loss of disability-adjusted life years by 2025 (Murray and Lopez, 1997).

Two-thirds of patients will survive their first stroke but many are left with long-term disability (Hare *et al.*, 2006), and will have ongoing needs for rehabilitation, and healthcare and social-care services. Our earlier study described the information needs of patients and caregivers after stroke (Allison *et al.*, 2008). A number of other studies have attempted to establish the longer-term needs of patients and caregivers. Murray *et al.* (2003) identified that patients reported long-term difficulties in a number of areas including the physical, social, and emotional consequences

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Correspondence to: Rhoda Allison, NHS Devon, Stroke Unit, Newton Abbot Hospital, Newton Abbot, Devon, TQ12 2SL, UK. Email: Rhoda.allison@nhs.net

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of stroke. Hare *et al.* (2006) identified that patients and caregivers indicated the importance of using primary care as the first point of contact. The National Stroke Strategy in the United Kingdom (Department of Health, 2007) recommends that people and their caregivers should have access to a review from primary care providers of their healthcare and social-care status and secondary prevention needs at six weeks and six months after discharge, and then annually.

Who should undertake these reviews and within what model of care is uncertain as there is little guidance on the feasibility or effectiveness of different models of stroke follow-up in primary care. Mitchell *et al.* (2008) reported a systematic review of care planning involving primary care in the management of people with stroke but the majority of studies included involved coordinating the process of hospital discharge, rather than longer-term management of such people. Given this present focus of evidence on hospital-based processes, we undertook this review to investigate the evidence for the effectiveness of different models of primary care-based follow-up after stroke.

## Methods

We conducted a systematic review of published research articles of interventions in primary care follow-up after stroke. We defined these as interventions involving both a healthcare and social-care element, which would be suitable to meet the requirements of the post-discharge and annual review of the stroke strategy. We interpreted this as interventions that included a review of medications and an assessment of longer-term disability and caregiver needs, as well as the provision of information and signposting to other services. We did not include studies that considered secondary prevention in isolation or that evaluated ongoing community-based rehabilitation. The review excluded studies in which follow-up interventions were provided by secondary care alone, but included interventions involving reaching out into primary care. The review primarily focused on how and by whom the models of follow-up care were coordinated. Articles were included if they were written in English, had targeted a population of people over the age of 18 years in primary care with a diagnosis of stroke,

and where any of the following outcomes were evaluated: patient satisfaction, patient health outcome, levels of depression, patient behaviour, levels of function, quality of life, caregiver burden scales, and readmissions to hospital.

## Search strategy

Multiple search strategies including electronic online database searches and hand searching of individual journals were used. The following electronic databases were searched: MEDLINE (1950–May 2008), EMBASE (1980–May 2008), CINAHL (1982–May 2008), AMED (1985–May 2008), and the Cochrane Library (1980–May 2008). The following key words were used in combinations: stroke, cerebrovascular, long-term care, chronic disease, primary health care, family practice, and community health services. Relevant papers were also identified by citation tracking, using reference lists from journals.

One investigator (RA) conducted the search. All titles or abstracts retrieved were then screened by at least two of the other investigators (RA, TA, LS, or RD) to decide whether the study was suitable for inclusion. Disagreements about eligibility were resolved by consensus or adjudication by a third investigator.

## Data extraction and analysis

Key data were extracted from the identified papers using a structured form, which included the following components: general study information (title, author, and country of study), details of the intervention, study characteristics (population data, intervention, comparator, and outcomes), and findings including length of follow-up. The theoretical basis of the intervention was also extracted (if reported).

All relevant studies were independently rated by at least two of the investigators (RA, TA, LS, or RD) using the Quality Assessment Tool for quantitative studies developed by the Effective Public Health Practice Project at McMaster's University in Canada (Effective Public Health Practice Project, 2008). This tool rates a number of components for risk of bias including sample selection, study design, identification of confounding factors, blinding of assessors, reliability and validity of data collection methods, recording of withdrawals, and intervention integrity and

analysis. The tool produces an overall rating of strong, moderate, or weak. It has been shown to have good content and construct validity, in addition to good reliability, and has been used in at least 20 systematic reviews (Thomas *et al.*, 2004). In this review,  $\kappa$ -statistics were used to analyse inter-observer reliability of the overall quality rating. Any discrepancy in data extraction or quality rating was resolved through discussion.

## Results

Over 20 000 references were initially identified, although the majority of these did not evaluate models of care. A total of 128 abstracts were retrieved, but 119 were excluded because they focused only on secondary prevention of stroke or on ongoing community-based rehabilitation. In total, nine studies were suitable for quality assessment. All of the studies referred to were randomised controlled trials. The articles by Claiborne (2006a; 2006b) and Mant *et al.* (2000; 2005) presented data from the same study, but because different outcome measures were reported in the former and different time scales in the latter, they were included separately in this systematic review.

## Interventions

The studies that were of sufficient quality for inclusion evaluated interventions provided by stroke support workers, care coordinators, case managers, or a care management model linked with systems of recall and clinical guidelines in primary care. All the studies identified patients before hospital discharge but did not report how long this was after the stroke. They all evaluated interventions that were provided for periods of three months up to nine months, with final follow-up usually at the end of the intervention period. Five studies were from the United Kingdom and four from North America.

In seven of the studies (Dennis *et al.*, 1997; Mant *et al.*, 2000; 2005; Lincoln *et al.*, 2003; Tilling *et al.*, 2005; Claiborne 2006a; 2006b), there did not appear to be a formal established relationship between the intervention worker and other primary care services. In the remaining two studies, there was evidence of a relationship linking the intervention with the patient's general practitioner

(GP), although in one of the studies the nature of this link was only loosely described (Mayo *et al.*, 2008), and in the other (Allen *et al.*, 2002), although the protocol detailed joint working, the detail of that relationship was not recorded.

This corresponds to the findings of Mitchell *et al.* (2008) who found that few studies looking at multidisciplinary care planning described the actual role provided by GPs.

## Theoretical basis

The theoretical basis of the organisational model was difficult to establish in the majority of the reports because most studies presented only an introduction and a review of the methods. Four of the studies (Dennis *et al.*, 1997; Mant *et al.*, 2000; 2005; Lincoln *et al.*, 2003) evaluated existing components of care. The study of stroke support workers conducted by Tilling *et al.* (2005) was preceded by two postal surveys, one of stroke support workers and one of patients, both suggesting what the intervention should include. The remaining studies used theoretical models of case management (Mayo *et al.*, 2008), chronic disease management (Allen *et al.*, 2002), and care coordination (Claiborne 2006a; 2006b), but did not formally examine the *a priori* evidence for these models.

## Methodological quality

The methodological details reported in the papers were of variable quality. All of the studies described selection criteria and gave a full account of patients who withdrew from the study. Using the McMaster Tool, three studies were found to be of high quality, five were of moderate quality, and two were rated weak. The quality of studies is presented in Table 1. The most common shortcomings related to lack of sample size calculations and inadequate assessor blinding. The inter-rater agreement for judging the quality of the studies was moderate ( $\kappa$ -coefficient 0.59).

## Participants

The participants in the studies are shown in Table 1. A total of 1425 patients and 267 caregivers participated in the studies included in the review. Broadly, the studies included a representative sample of people after stroke, although most studies excluded people who had previously

lived in nursing homes, and two of the studies only included people with caregivers (Mant *et al.*, 2000; 2005).

## Outcomes

Most studies did not identify a single primary outcome measure but reported instead on a range of outcomes including physical functioning, mood, quality of life, hospital readmissions, and health service utilisation. In one of the studies (Allen *et al.*, 2002), traditional measures were subsumed within composite measures, which meant that identifying the effect on individual outcomes was impossible. The heterogeneity of the interventions meant that it was not possible to meta-analyse the data. A summary of the findings is given in Table 1.

### Physical functioning

Six of the nine studies included physical functioning as an outcome measure. The well-established Barthel Index was used as a measure in five of the studies. In addition, one study (Mayo *et al.*, 2008) evaluated the impact of the intervention on gait speed and Timed up and Go test, two studies reported the use of the Rivermead Mobility Index (Mant *et al.*, 2000; 2005), three studies examined the use of the Frenchay Activities Index (Dennis *et al.*, 1997; Mant *et al.*, 2000; 2005), and one used the Nottingham Extended Activities of Daily Living Scale (Lincoln *et al.*, 2003). None of these studies showed any significant differences between the intervention and control groups in physical functioning.

### Mood

Eight of the studies included an outcome measure of mood. Four studies used the Hospital Anxiety and Depression Scale (HADS; Dennis *et al.*, 1997; Mant *et al.*, 2000; 2005; Tilling *et al.*, 2005), and the remainder used the Centre for Epidemiological Studies Depression Scale (Allen *et al.*, 2002), the General Health Questionnaire (Lincoln *et al.*, 2003), and the Geriatric Depression Scale (Claiborne, 2006b; Mayo *et al.*, 2008). Claiborne (2006b) showed that patients receiving the care coordinator intervention were significantly less depressed than those in the control group. This study was the smallest with only 28 participants in total and was rated 'weak' with the

McMaster Tool. In all of the other studies, no difference was demonstrated between the intervention and control groups.

### Quality of life

Six of the studies measured quality of life, using SF-36 (Mant *et al.*, 2000; 2005; Mayo *et al.*, 2008), Dartmouth Co-op charts (Mant *et al.*, 2000; 2005), Euroquol EQ-5D (Mayo *et al.*, 2008), Reintegration to Normal Living Index (Tilling *et al.*, 2005), and Stroke-Adapted Sickness Impact Profile (Allen *et al.*, 2002), respectively. One study (Claiborne, 2006b) indicated a significant improvement in the mental health component of SF-36, but this was a small study of overall weak quality. No other studies showed any significant difference on measures of quality of life.

### Health service utilisation

Two of the studies examined health service utilisation. Mayo *et al.* (2008) showed that there were no differences in health service utilisation between groups receiving care from a stroke coordinator and those receiving standard care. Claiborne (2006a) showed that patients receiving case management from a social worker attended significantly more outpatient appointments but had less emergency attendances than those in a control group. However, the sample size was small ( $n = 28$ ) and there was large variation in each individual's use of services.

### Patient behaviour

Only one study (Claiborne, 2006b) reported the effects of the intervention on patient behaviour. Claiborne measured behaviour through an index of self-care that included concordance with medication regimes and attendance at hospital appointments. Although the study showed a significant improvement in adherence to self-care in favour of intervention, it is unclear how this was measured on the index or how the validity of the measure was established.

### Satisfaction

Five studies reported patient and caregiver satisfaction with services. Four of these studies (Dennis *et al.*, 1997; Mant *et al.*, 2000; 2005; Tilling *et al.*, 2005) used a formally developed satisfaction questionnaire, and the other (Lincoln *et al.*, 2003) used a questionnaire designed by the study team.

**Table 1** Review of included studies

Authors and Journal	Theoretical framework	Intervention	Number of participants	Quality rating	Follow-up point	Outcome measures	Impact on outcomes
Allen <i>et al.</i> (2002), <i>Journal of Stroke and Cerebrovascular Disease</i>	Chronic care model	Care manager, clinical information systems, self-management	93 patients	Moderate	3 months	Barthel, stroke knowledge, CES-D, readmissions, BP control, SA-SIP30	Patients in intervention group had greater stroke knowledge, and less hospital readmission No differences in other measures
Claiborne (2006a), <i>Research on Social Work Practice</i>	Care coordination	Social work care coordination	28 patients	Weak	3 months	Health service utilisation	Patients in intervention group attended significantly more outpatient appointments and significantly less emergency attendances than controls
Claiborne (2006b), <i>Health and Social Work</i>	Care coordination	Social work care coordination	28 patients	Weak	3 months	SF-36, GDS, 'adherence' assessment	Patients in intervention group were significantly less depressed and more likely to adhere to self care practice
Dennis <i>et al.</i> (1997), <i>British Medical Journal</i>	Evaluation of existing component of care	Stroke support worker	417 patients	Strong	6 months	Barthel, Oxford Handicap score, FAI, GHQ, HADS	Higher satisfaction with information but higher incidence of depression for patients in intervention group Higher satisfaction with information for caregivers in intervention group No other differences
Lincoln <i>et al.</i> (2003), <i>Stroke</i>	Evaluation of existing component	Stroke FSO	187 patients	Moderate	9 months	GHQ, Not EADL, Barthel, perceived knowledge	Intervention group had improved levels of stroke knowledge No other differences
Mant <i>et al.</i> (2000), <i>The Lancet</i>	Evaluation of existing component of care	Stroke FSO	323 patients 267 caregivers	Strong	6 months	FAI, SF-36, knowledge, Barthel, RMI, LHS, HADS, GHQ, Dartmouth co-op charts	Caregivers in intervention group had greater social activities and quality of life There were no significant differences for patients
Mant <i>et al.</i> (2005), <i>Journal of Neurology, Neurosurgery, and Psychiatry</i>	Evaluation of existing component of care	Stroke FSO	294 patients 112 caregivers	Moderate	12 months	As previous	No significant difference for patients or caregivers
Mayo <i>et al.</i> (2008), <i>Age and Ageing</i>	Case management	Nurse case manager linking with personal physician	190 patients	Moderate	6 months	Health service utilisation, physical component SF-36, Barthel, gait speed, TUG, GDS	Fewer specialist visits in intervention group in post intervention period No other differences

**Table 1** Continued

Tilling <i>et al.</i> (2005), Evaluation of existing component of care based on survey of patient's needs	Stroke FSO	298 patients	Strong	12 months	Patient satisfaction, HADS, reintegration to Normal Living Index, Caregiver Strain Index	Patients in intervention group had higher satisfaction with information about recovery and stroke prevention Caregivers in intervention group were less satisfied with information on benefits and services No other differences
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BP = blood pressure; SA-SIP30 = Stroke-Adapted 30-item Sickness Impact Profile version; GDS = Geriatric depression scale; FAI = Frenchay Activities Index; GHQ = General Health Questionnaire; HADS = Hospital Anxiety and Depression Scale; FSO = Family Support Organiser; Not EADL = Nottingham extended activities of daily living; RMI = Rivermead Mobility Index; LHS = London Handicap scale; TUG = Timed Up and Go.

With regard to patient satisfaction, none of the studies showed a significant difference in overall satisfaction, although some of the studies identified differences in response to individual aspects of satisfaction. For example, in Dennis *et al.* (1997), patients in the intervention group felt someone had listened to their needs. Tilling *et al.* (2005) showed small non-significant effects with higher satisfaction with information about stroke prevention but lower satisfaction with community services, and Lincoln *et al.* (2003) found that patients in the intervention group were more satisfied with information about community services and about emotional support.

For caregivers, two studies (Mant *et al.*, 2000; Tilling *et al.*, 2005) showed no differences in caregiver satisfaction. Lincoln *et al.* (2003) showed a statistically higher level of satisfaction for caregivers in the questions concerning provision of information on emotional support and practical help, but this did not translate into a difference in overall satisfaction. Dennis *et al.* (1997) found that caregivers receiving follow-up were significantly more likely to feel that someone had listened and were less likely to feel neglected.

*Perceived knowledge*

Three of the studies examined the perceived knowledge of both patients and caregivers (Mant *et al.*, 2000; 2005; Lincoln *et al.*, 2003), and one looked at patients alone (Allen *et al.*, 2002). All of these studies used questionnaires designed by each study team, usually to assess knowledge of whom to call in the event of another stroke, how to access information, and secondary prevention. None of the studies described how these questionnaires had been validated and the findings were inconsistent. Lincoln *et al.* (2003) showed that both patients and caregivers in the intervention group had a higher perceived knowledge of stroke, risk factors, and resources available. Allen *et al.* (2002) also showed a positive benefit for patients. However, Mant *et al.* (2000; 2005) established no differences for either patients or caregivers in respect of knowledge regarding stroke.

*Caregiver strain*

Five of the studies measured caregiver burden: four used the Carer Strain Index (Mant *et al.*, 2000; 2005; Lincoln *et al.*, 2003; Tilling *et al.*, 2005)

and one used the Care Giving Hassles Scale (Dennis *et al.*, 1997). Although the trend in one study was for less strain in caregivers in the intervention group (Dennis *et al.*, 1997), there were no significant differences observed in favour of the intervention group in any of the studies. Four of the studies also looked at care-giver mood and socialisation. Although two studies showed no impact on caregiver mood using HADS (Tilling *et al.*, 2005) or General Health Questionnaire (Lincoln *et al.*, 2003), Mant *et al.* (2000) showed that caregivers in the intervention group reported less depression on the HADS and were involved in significantly more social activities. These positive effects were continued at follow-up at one year.

#### *Adverse events*

Adverse events or side effects of the interventions were not reported in any of the studies.

In summary, patients and caregivers receiving formal primary care follow-up delivered using a range of models did not show any gains in physical function, mood, or quality of life. Some patients and caregivers receiving follow-up were more satisfied with some aspects of communication, and had a higher perceived knowledge of stroke, but these were not consistently shown. In two of the studies, patients receiving follow-up had fewer emergency attendances when compared with patients not receiving follow-up.

## **Discussion**

The aim of this systematic review was to evaluate the effectiveness of models of primary care-based follow-up after stroke. The studies identified compared groups of patients and caregivers who received contact with stroke support workers, care coordinators, and case managers with those who received standard care. From the evidence reviewed, there is insufficient evidence to support or refute the value of these models of follow-up after stroke.

Most of the studies included in this review provided an inadequate description of their methods to allow a full assessment of their methodological quality. Where detailed methods were described, most studies were found to be of only moderate quality. Given the relatively small sample size of

most of these trials, a lack of statistically significant differences between groups may simply reflect a lack of statistical power rather than the absence of a real effect. The heterogeneity of the interventions meant that it was not possible to meta-analyse the data.

The choice of outcomes may also have affected the ability to demonstrate an effect. First, it is unclear whether the outcomes selected would be sensitive to change. For example, models of follow-up based on general support and information transfer are unlikely to directly affect physical function, and since the models did not include a formal intervention to manage depression, such as a psychological therapy, they may be unlikely to affect mood. Only two of the studies identified primary outcome measures (Tilling *et al.*, 2005; Mayo *et al.*, 2008). Most of the studies measured a wide range of outcomes and it was often unclear exactly which outcome the intervention was targeting. It is also possible that the choice of outcomes was not ideal, as some may have shown ceiling effects. The Barthel Index, for example, focuses on basic physical function, and in three of the studies, most participants had achieved the maximum scores at the time of the final measure.

The majority of studies did not report a sound theoretical basis for the development of the intervention given. It is essential that a 'complex intervention', such as a model of healthcare and social-care follow-up, has a theoretical basis (Medical Research Council, 2008). Theoretical models of chronic disease management (Wagner, 1998) have been used to improve approaches to care in other conditions, such as diabetes (Wagner *et al.*, 2001) and chronic pulmonary disease (Adams *et al.*, 2007), and consideration should be given to the value of these models for stroke.

Finally, although the interventions provided took place in the community, there appeared to be little attention paid to the extent and quality of communication between intervention staff and the patient's GP. There is significant evidence to show how poor communication between primary care and secondary care clinicians, or other community services may have a negative impact on patient care (White and Marriot, 2004; Farquhar *et al.*, 2005). We would, therefore, suggest that future studies of follow-up give consideration to the mechanisms of communication and interface with primary care staff.

The National Stroke Strategy (Department of Health, 2007) recommends that stroke survivors and their caregivers are provided with a health-care and social-care review by primary care professionals at key points following their discharge from hospital, and that patients and caregivers have identified the importance of primary care as a first point of contact (Hare *et al.*, 2006). Currently, there is very little evidence on which to base models for providing these reviews. Further research is underway to evaluate a comprehensive assessment approach to post-acute stroke care (Murray *et al.*, 2006), but attention may still need to be given on how assessment roles link with GPs. Further research is needed to inform future practice, and examples of chronic disease management, such as those increasingly used in the United States, may be useful in developing models of follow-up after stroke.

## Conclusions

Overall, the findings do not support the use of stroke support workers, care coordinators, or case managers working in the ways described in these studies to deliver the primary care-based health-care and social-care review after stroke. The lack of a theoretical model on which to base the worker's intervention, and the lack of a defined relationship or route of communication with the stroke survivor's GP may be potential reasons for the lack of positive effect.

The lack of a sound theoretical basis for the development of primary care-based follow-up after stroke highlights the need for urgent work to develop this. The Complex Interventions Framework (Medical Research Council, 2008) provides some guidance on how this could be developed. The limited quality of the studies considered in this review highlights the need for high-quality trials of primary care-based interventions aimed at following up patients who have sustained a stroke.

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## Appendix 1: Search Strategy

MEDLINE, CINAHL, EMBASE, AMED, BNI

1. Stroke
2. Cerebrovascular
3. CVA
4. CVE
5. Vascular accident
6. Long-term care
7. Chronic disease
8. Primary health care
9. Family practice
10. Community health services
11. Follow-up
12. 1, 2, 3, 4, or 5
13. 6, 7, 8, 9, 10, or 11
14. 12 and 13

Cochrane Stroke Group Trials Register, Cochrane Central Register of Controlled Trials (CENTRAL), Cochrane Effective Practice, and Organisation of Care Group (EPOC)

1. Stroke
2. Long-term care
3. Chronic disease
4. Primary health care
5. Family practice
6. Community health services
7. Follow-up
8. 2 or 3 or 4 or 5 or 6 or 7
9. 1 and 8

Department of Health data, Kings Fund