

# Randomized Controlled Trial of a Comprehensive Stroke Education Program for Patients and Caregivers

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**Background and Purpose**—We report the findings of a randomized controlled trial to determine the effectiveness of a multidisciplinary Stroke Education Program (SEP) for patients and their informal carers.

**Methods**—Two hundred four patients admitted with acute stroke and their 176 informal carers were randomized to receive an invitation to the SEP or to receive conventional stroke unit care. The SEP consisted of one 1-hour small group educational session for inpatients followed by six 1-hour sessions after discharge. The primary outcome measure was patient- and carer-perceived health status (SF-36) at 6 months after stroke. Knowledge of stroke, satisfaction with services, emotional outcome, disability, and handicap and were secondary outcome measures.

**Results**—Only 51 of 108 (47%) surviving patients randomized to the SEP completed the program, as did 20 of 93 (22%) informal carers of surviving patients. Perceived health status (Short Form 36 [SF-36] health survey) scores were similar for SEP patients and controls. Informal carers in the control group scored better on the social functioning component of the SF-36 than the SEP group ( $P=0.04$ ). Patients and informal carers in the SEP group scored higher on the stroke knowledge scale than controls (patients,  $P=0.02$ ; carers,  $P=0.01$ ). Patients in the SEP group were more satisfied with the information that they had received about stroke ( $P=0.004$ ). There were no differences in emotional or functional outcomes between groups.

**Conclusions**—Although the SEP improved patient and informal carer knowledge about stroke and patient satisfaction with some components of stroke services, this was not associated with an improvement in their perceived health status. Indeed, the social functioning of informal carers randomized to the SEP was less than in the control group. (*Stroke*. 1999;30:2585-2591.)

**Key Words:** stroke management ■ clinical trials ■ rehabilitation

The need for better information, in addition to greater provision of support, has been voiced by stroke patients and their informal carers.<sup>1</sup> Over 10 years ago, a UK Consensus Statement on the treatment of stroke recommended that stroke patients and their informal carers were entitled to “a clear account of the nature and causes of their stroke. . . and [that] more information rather than less should be given.”<sup>2</sup> However, evidence suggests that many patients and carers continue to express a lack of understanding about stroke and its causes, secondary preventative measures, and information about both statutory and informal support.<sup>3-5</sup>

Information needs of patients and informal carers in hospital and after discharge are not being met, despite the efforts of health services and voluntary agencies.<sup>3,4,6,7</sup> It is not unusual for patients and carers to report that they have not received any information about their illness, despite having had discussions with health professionals and being given written information.

This could occur for a number of reasons: the information was not retained due to the stress of the situation, was not clear, was too complicated, was too general, or did not address the patient or carer’s own issues of concern.

A study of stroke patients’ and carers’ satisfaction with care reported that although 89% were satisfied with their overall care, 49% were dissatisfied with the information they had received while in hospital.<sup>8</sup> These results were mirrored in an audit undertaken at North Tyneside General Hospital in 1996, which found that although only 15% of stroke patients and carers felt dissatisfied with their care in general, 40% of stroke patients and 45% of their informal carers were dissatisfied with the information received about stroke before discharge. In light of these findings, a multidisciplinary group consisting of stroke unit staff, community nurses, and representatives from the Stroke Association and the local voluntary sector developed a Stroke Education Program (SEP) that

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**TABLE 1. Content of the SEP**

Session Title	Speakers	Main Themes
Inpatient session		
Introduction: the experience of stroke.	Physiotherapist, occupational therapist, speech and language therapist, nurse	Outline of SEP. The nature of stroke. Treatment and recovery. Role of therapies.
Outpatient sessions		
1. The nature of stroke.	Nurse, Stroke Association information officer	The nature of stroke. Treatment and recovery. Personal experience of stroke.
2. The role of physiotherapy and occupational therapy in stroke care.	Physiotherapist, occupational therapist	Explanations of functional recovery. Expectations of recovery. Role of physiotherapy.
3. The psychological effects of stroke.	Clinical psychologist, community nurse	Emotional and psychological effects of stroke. Role of community nursing services.
4. Caring for someone who has suffered a stroke.	Social worker	The experience of caring services and support for carers. Social services and benefits.
5. Communication and swallowing problems after stroke. Occupational therapy and stroke.	Speech and language therapist, occupational therapist	The nature of and therapy for communication and swallowing problems. Role of occupational therapy.
6. Reducing the risk of stroke. The role of the Stroke Club.	Nurse and leader of the local stroke club	Medical and lifestyle risk-factor modification. Making healthy choices and changing behavior. Role of the Stroke Club.

was available to stroke patients admitted to North Tyneside General Hospital and their main informal carer.

The aim of the present study was to determine the effectiveness of the Stroke Education Program for improving patients' and carers' perceived health status through enhancement of their knowledge of the causes and consequences of stroke and the availability of community support.

### Subjects and Methods

The study was a pragmatic randomized controlled trial and was approved by the local ethical committee.

#### Study Participants

North Tyneside General Hospital has an organized stroke service that cares for all patients admitted with acute stroke. All such patients admitted between January 1, 1997, and December 1, 1998, and their informal carer (next of kin or the person providing most day-to-day support), were approached between 5 and 9 days after stroke. Patients who were too unwell at that time were reassessed once medically stable. Patients were excluded if they were discharged within 24 hours, lived outside of the study area, or were admitted from a residential or nursing home. Zelen's 2-stage method of consent was used.<sup>9</sup> The initial assessment comprised a structured interview that covered demographic details, age at which patient ended full-time education, comorbidity, a screening test for cognitive impairment,<sup>10</sup> prestroke function,<sup>11</sup> support and services, and stroke subtype.<sup>12</sup> When it was not possible to obtain information from the patient (for example, because of dysphasia or cognitive impairment), the information was sought from their informal carer and supplemented when appropriate from medical notes. Patients who were unable to complete the interview and had no carer were excluded from the study. The Barthel Activities of Daily Living (ADL) Index at 7 days after stroke was recorded.<sup>13</sup> For informal carers, the initial assessment consisted of demographic details, background, and prior experience as a carer.

#### Randomization

Stroke patients and their informal carer were randomized through a central telephone service to receive either an invitation to attend the SEP or conventional stroke unit care. Randomization was comput-

erized, and the patient and informal carer (when present) were randomized as a pair. Patients were initially randomized in blocks of 8 and were stratified by continence of urine at 24 hours after stroke as a proxy marker for stroke severity<sup>14</sup> and by presence of an informal carer. Due to low initial compliance with the SEP, the randomization process changed in the seventh month of the study. Patients were then randomized in a ratio of 2 SEP to 1 conventional care. Randomization was then done in blocks of 9.

#### Stroke Education Program

The SEP consisted of a rolling program of one 1-hour small-group educational sessions for inpatients and their informal carer followed by six 1-hour educational sessions after discharge from hospital. The SEP aimed to improve knowledge of the nature of stroke and of the rationale for treatment and therapeutic interventions; increase awareness of services available while in hospital or after discharge; give advice and information about the prevention of stroke; and provide an opportunity for patients and carers to ask questions and gain support within an informal group setting. An outline of the content of the SEP is given in Table 1. Each session was led by a member of the multidisciplinary team, and the SEP included input from nursing, physiotherapy, occupational therapy, speech and language therapy, clinical psychology, social work, district nursing, the local carers center, and the stroke club. Group sessions were held 1 morning per week in the day hospital situated at the main hospital site. Transport was provided for those who required it. We defined attendance at the SEP as those who attended  $\geq 3$  outpatient group sessions. Those randomized to the SEP were sent a questionnaire by mail after either completion of the SEP or nonattendance. The questionnaire sought their views about the program or reasons for nonattendance. Nonresponders were sent a postcard reminder at 2 weeks followed by another copy of the questionnaire after an additional 2 weeks.

#### Information Received by the Control Group About Stroke and Services

In addition to routine communication with nurses, doctors, and therapy staff members throughout their inpatient stay, all patients admitted to the stroke unit and their informal carer received an information leaflet about the stroke service on admission. Patients and informal carers were invited to take Stroke Association leaflets on a number of topics, which were clearly displayed in the ward. The Stroke Care Pathway, a multidisciplinary record, was used for all

inpatients,<sup>15</sup> and it was readily available to patients, carers, and staff members. The record provided and recorded information given to patients and informal carers about aspects of stroke. Before discharge, patients and informal carers were given details of a telephone "hotline" run by the stroke unit that they could contact.

### Outcome Measures

Patients and their informal carers were interviewed in their own homes at 6 months after stroke by a researcher who was blinded to the randomization group. The primary outcome measure was patient's and informal carer's perceived health status, as assessed by the Short Form 36 healthy survey questionnaire (SF-36).<sup>16</sup> Knowledge of stroke, satisfaction with services, emotional outcome (patients, Hospital Anxiety and Depression Scale<sup>17</sup>; carers, General Health Questionnaire 30),<sup>18</sup> disability, and handicap (Nottingham E-ADL<sup>11</sup> and Oxford Handicap Scale)<sup>19</sup> were secondary outcome measures. The knowledge of stroke scale consisted of 26 items selected from other instruments<sup>4</sup> and the content of the SEP.<sup>20,21</sup> The reliability and validity of this instrument has not been formally tested. Patient and informal carer satisfaction was measured by use of instruments from previous studies.<sup>22-24</sup> The informal carers of patients who died during the course of the study were not contacted further. Proxy measures of perceived health status or emotional outcome were not obtained. When a patient was unable to complete disability or handicap scales, this information was obtained by proxy from the informal carer.

### Analysis

From audit data, we estimated that 30% of patients would not be able to participate in the SEP as a result of dysphasia or cognitive impairment and that 15% of stroke patients would have no carer. Using a 1-tailed test for independent samples with a power of 80% and a significance level of 5%, we estimated that 80 patients and 108 carers in each randomization group would enable us to detect differences ranging from 5 to 10 points in the subscales of the SF-36 at 6 months. Data were analyzed on an intention-to-treat basis with nonparametric techniques to allow for nonnormative data distribution. The main comparative analyses were made with the Mann-Whitney *U* test. For ordered categorical variables, the  $\chi^2$  test was used to detect differences in proportions; a 2-sided 5% significance level was used throughout. Odds ratios and 95% confidence intervals were used to analyze responses to questions about satisfaction.

### Results

Three hundred ninety-eight patients were admitted with acute stroke during the study period. Two hundred four patients and 176 informal carers agreed to participate. Figure 1 shows the trial profile. Table 2 shows the baseline characteristics of study subjects. Groups were well matched. More total anterior circulation stroke patients were randomized to SEP, but this was not statistically significant. No statistically significant differences occurred in stroke severity as measured by the Barthel ADL Index at 7 days after stroke, length of stay, or discharge destination.

SEP attendance was low: 51 stroke patients and 20 informal carers attended  $\geq 3$  outpatient sessions, of whom 55 (77%) returned the evaluation questionnaire. Forty-four (80%) felt that the SEP was beneficial and overall feedback from attendees was positive. Forty-seven (85%) felt that it had been helpful to talk to other people who had had a stroke and their relatives. Thirty-nine (71%) felt that they had been able to use the information gained from the SEP in their everyday life.

Patients who attended the SEP did not differ from nonattenders with regard to age, sex, age at which full-time education was ended, and stroke severity, but they had a

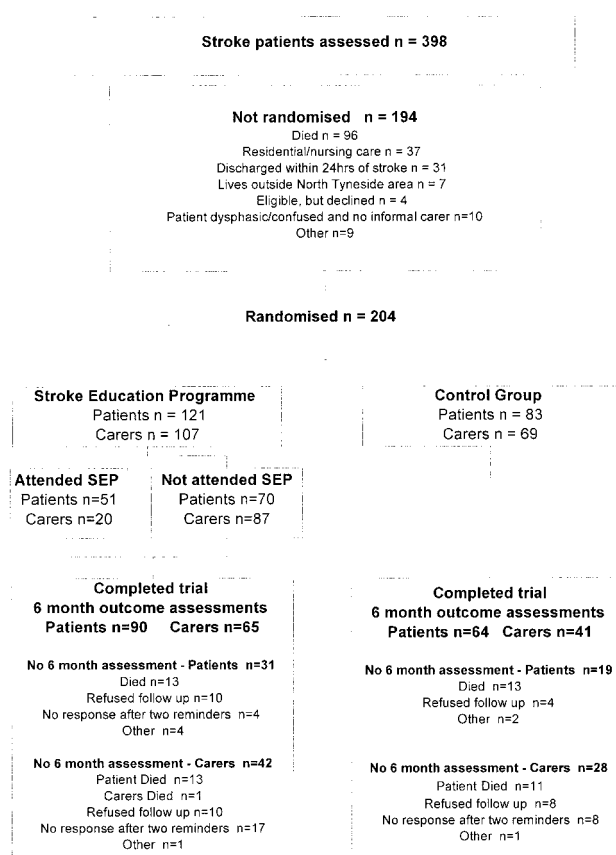


Figure 1. Trial profile.

higher level of activity before stroke (median Nottingham E-ADL, 17 versus 16;  $P=0.05$ ). Prestroke Oxford Handicap Scores did not differ. No demographic differences existed between carers who did and did not attend.

The response rate to the questionnaire by SEP nonattenders was low: only 18 patients and 33 carers who did not attend returned questionnaires, which gave a response rate of 33%. Reasons given for nonattendance by patients included poor health, lack of interest, and difficulty getting to the hospital. Informal carers stated that they were unable to attend because of their own poor health, work commitments, or lack of interest.

### Primary Outcome

Table 3 shows patient and carer SF-36 scores at 6 months after stroke. Thirty-seven of 154 (24%) patients who agreed to a 6-month outcome interview did not complete the SF-36, mainly as a result of dysphasia or cognitive impairment. No differences in SF-36 scores were seen when patient and informal carer scores were analyzed together. However, separate analyses of patient and informal carer scores found that informal carers randomized to the SEP had lower social-functioning subscale scores compared with controls ( $P=0.04$ ).

### Secondary Outcomes

Table 4 shows knowledge about stroke and emotional and functional outcomes at 6 months after stroke. Both patients and informal carers randomized to the SEP program had

**TABLE 2. Characteristics of Study Participants**

	SEP	Control
Patients, n	121	83
Age, y (range)	74 (36–94)	76 (36–95)
Female, n (%)	62 (51)	45 (54)
Previous stroke/TIA, n (%)	48 (40)	29 (35)
Prestroke Nottingham E-ADL <sup>11</sup> , n (range)	16 (2–21)	16 (1–22)
Barthel ADL Index at 7 days <sup>13</sup> (range)	11 (0–20)	9 (0–20)
Length of stay, d (range)	26 (1–115)	31 (1–127)
Discharged to original address, n	88 (73)	62 (75)
Stroke classification, <sup>12</sup> n (%)		
TACS	26 (22)	11 (13)
PACS	53 (44)	39 (47)
LACS	27 (22)	18 (22)
POCS	15 (12)	15 (18)
Age at which full-time education ended, n (%)		
12–14	77 (64)	51 (62)
15–18	33 (27)	25 (30)
19–23	5 (4)	2 (2)
Not known	6 (5)	5 (6)
Informal carers, n	107	69
Age, y (range)	58 (14–84)	60 (30–81)
Female, n (%)	75 (70)	46 (67)
Spouse/partner, n (%)	47 (44)	30 (43)
Age at which full-time education ended, n (%)		
12–14	35 (32)	18 (26)
15–18	62 (58)	48 (70)
19–23	6 (6)	2 (3)
Still at school	1 (1)	0 (0)
Not known	3 (3)	1 (1)

Values are medians unless otherwise indicated. TIA indicates transient ischemic attack; E-ADL, extended activities of daily living scale; TACS, total anterior circulation stroke; PACS, partial anterior circulation stroke; LACS, lacunar stroke; POCS, posterior circulation stroke. No statistically significant differences occurred between SEP and control groups.

higher scores on the knowledge of stroke scale than controls ( $P=0.02$  and  $P=0.01$ ). Both groups of patients had high scores on the Hospital Anxiety and Depression (HAD) Scale but did not differ. Informal carers also did not differ in General Health Questionnaire 30 (GHQ-30) scores, which showed high levels of stress. No differences occurred between intervention and control groups in patients' functional outcomes.

Figures 2 and 3 show patient and informal carer satisfaction with services. Patients but not carers who were randomized to SEP were more satisfied with the information they received about stroke than were controls.

The sensitivity of researcher to correctly identify the randomization group after the 6-month assessment interview was 0.40 and specificity, 0.98.

## Discussion

Although the SEP improved patient and informal carer knowledge about stroke and increased some aspects of

**TABLE 3. SF-36 Scores at 6 Months After Stroke**

	SEP	Control	<i>P</i>
Patients, n	66*	51*	
Physical functioning	17.5 (0–100)	20 (0–90)	0.76
Role physical	0 (0–100)	0 (0–100)	0.45
Bodily pain	57.5 (0–100)	51 (0–100)	0.56
General health	43.5 (15–100)	47.5 (10–97)	0.71
Vitality	30 (0–90)	45 (5–90)	0.07
Social functioning	37.5 (0–100)	50 (0–100)	0.71
Role emotional	0 (0–100)	0 (0–100)	0.94
Mental health	64 (12–100)	60 (16–100)	0.96
Informal carers, n	65	41	
Physical functioning	85 (0–100)	80 (0–100)	0.49
Role physical	50 (0–100)	75 (0–100)	0.42
Bodily pain	72 (0–100)	84 (0–100)	0.11
General health	67 (10–100)	65 (5–100)	0.89
Vitality	50 (5–100)	50 (0–95)	0.65
Social functioning	62.5 (13–100)	100 (0–100)	0.04
Role emotional	66.7 (0–100)	100 (0–100)	0.13
Mental health	68 (12–100)	78 (0–100)	0.24
All, n	131	92	
Physical functioning	55 (0–100)	47.5 (0–100)	0.62
Role physical	0 (0–100)	0 (0–100)	1.00
Bodily pain	62 (0–100)	68 (0–100)	0.67
General health	52 (10–100)	57 (5–100)	0.92
Vitality	40 (0–100)	45 (0–95)	0.19
Social functioning	50 (0–100)	62.5 (0–100)	0.51
Role emotional	33.3 (0–100)	66.7 (0–100)	0.33
Mental health	68 (12–100)	66 (0–100)	0.61

Values are median (range) unless otherwise indicated.

\*24 patients randomized to SEP and 13 patients in the control group were unable to complete the SF-36 due to dysphasia or cognitive problems.

satisfaction with services, this was not associated with an improvement in their perceived health status. Providing patients with information and education has been shown to improve outcome in several other chronic conditions.<sup>25–28</sup>

Social functioning, as measured by the SF-36, of informal carers randomized to the SEP was lower than in the control group. Several explanations could explain this finding: the SEP may have increased carers' awareness of the nature and consequences of stroke and as a result, they may have reduced their social activities to spend more time with the patient or attending the SEP may have resulted in reduced social activities, particularly for those who needed to ask a friend or relative to stay with the stroke patient while they left the house. Although the SEP gave carers a better understanding of stroke and its consequences and may have provided them with professional and peer group support, it was not always possible to provide them with a positive solution to their problems. Alternatively, this could be a chance finding, given that the study did not show consistently adverse carer outcomes in the SEP group.

**TABLE 4. Patient and Informal Carer Knowledge About Stroke; Emotional and Functional Outcomes at 6 Months After Stroke**

	SEP	Control	P
Patients, n	90	64	
HAD scale, n (%)	66	51	
Anxiety cases (+11)	36 (55)	29 (61)	0.47
Depression cases (+11)	30 (46)	23 (46)	0.93
Nottingham Extended ADL Scale, median n (range)	84	61	
Mobility	1 (0–6)	1.5 (0–6)	0.395
Kitchen	3 (0–5)	4 (0–5)	0.469
Domestic	0 (0–5)	1 (0–5)	0.581
Leisure	2 (0–6)	2 (0–6)	0.983
Total	7 (0–22)	8 (0–21)	0.689
Oxford Handicap Scale, n (%)	89	64	
0–2	29 (33)	14 (22)	
3	29 (33)	27 (42)	0.291
4–5	31 (35)	23 (36)	
Knowledge about stroke, n	66	51	
Score	17/26	15/26	0.02
Informal carers, n	65	41	
GHQ-30: Possible psychiatric disorder (5+), n (%)	34 (52)	18 (44)	0.29
Knowledge about stroke: Score, n	18/26	15/26	0.01

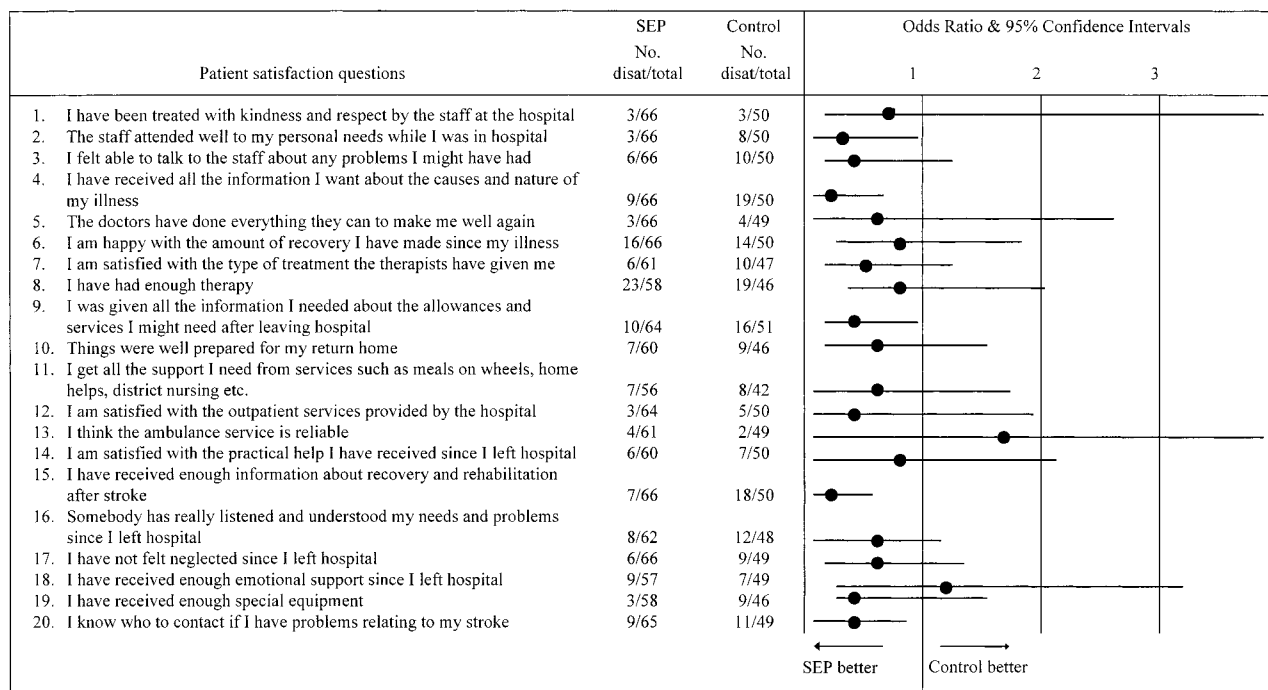
The finding of lower social functioning in carers randomized to the SEP should be treated with caution, given that we have seen a statistically significant difference in only 1 of the 7 subscales of the SF-36, particularly because the social

functioning subscale contains only 2 items, which are similar. The internal consistency of the social functioning subscale is the lowest of all of the subscales (Cronbach’s  $\alpha=0.76$ ).<sup>29,30</sup> Ideally, this value should exceed 0.8.<sup>31</sup> The internal reliability and coefficient of reliability of this subscale are also lower than for other subscales but are considered to be within acceptable limits.<sup>30</sup>

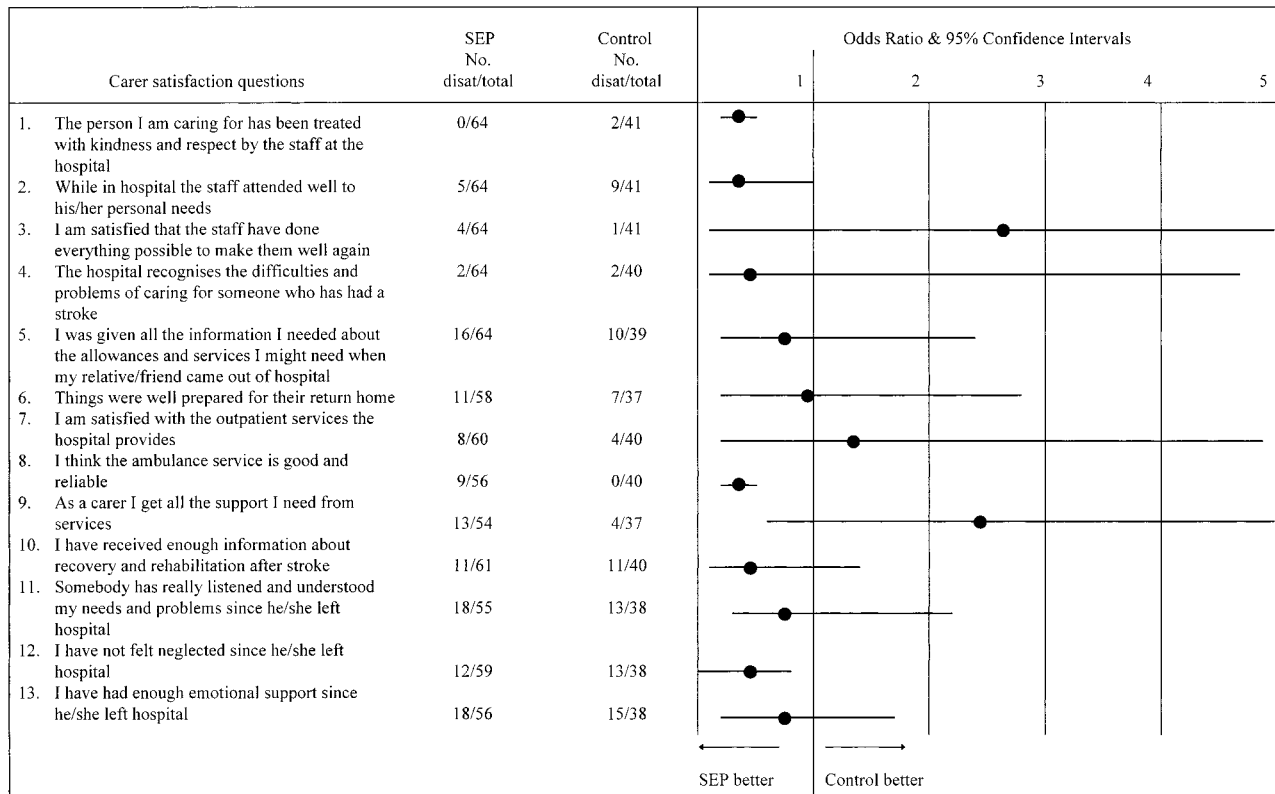
The SF-36 was selected as the primary outcome measure because it is one of the most widely used generic measures of health status and has been used with stroke patients previously.<sup>32–34</sup> However, concerns are emerging about both the response rates and individual item relevance to older people.<sup>35–37</sup> To improve completeness, questionnaires were initially sent by mail and checked for completeness at the interviewer visit. It would have been valuable to have had a measure that could have been used by proxy, given the proportion of patients (24%) who were unable to complete the SF-36 due to language or cognitive problems. There is a need to use a stroke-specific measure of health status as well as a generic measure in studies of this kind, but we are not aware of any measure whose validity and reliability has yet been adequately tested.

The study was prone to a type II error. Although the numbers of patients recruited was as anticipated, we overestimated the proportion of patients who were able to complete the SF-36 at 6 months after stroke. Thus, patient SF-36 scores were only available for 117 of 154 (76%) 6-month survivors, which represents 73% of patients of the requirements defined in the original power calculation (117 of 160).

At recruitment, informal carers were identified for only 176 of 204 (86%) of patients. Available carer outcome SF-36 scores at 6 months after stroke were available for 106 of 176 (60%) of recruited carers. This was considerably less than originally estimated in the power calculation, 106 of 216 (49%).



**Figure 2.** Patient satisfaction with services. Disat indicates dissatisfied.



**Figure 3.** Informal carer satisfaction with services.

Attendance at the SEP was disappointingly low, which would have diluted any treatment effect. Nevertheless, the SEP was well received and valued by those who attended, and we have demonstrated a clear benefit of the SEP in improving patient and carer knowledge of stroke and satisfaction with services.

This study suggests that improved knowledge about stroke may not be associated with improved health status and psychological outcomes. This raises issues about the content, timing, delivery, and duration of the program, which provides information for stroke patients and carers. However, it also raises questions about the potential adverse effects of increasing knowledge.

Information needs vary over time and circumstances and may continue for several years after stroke.<sup>7</sup> Discharge from hospital is very stressful for patients and informal carers; some feel abandoned by services once they have returned home, and they are uncertain who to turn to for information and practical help.<sup>38</sup> At this time, a lack of knowledge about stroke, the longer-term consequences, and the support available are associated with increased anxiety and worry and may contribute to patients' failure to realize their maximal potential after discharge.

Psychological morbidity is high after stroke and poorly addressed, given the current emphasis upon physical recovery within rehabilitation.<sup>39,40</sup> Despite our awareness of this issue and attempts to address psychosocial support issues within the SEP, patient anxiety levels were high but not different in both randomization groups.

Research of other chronic conditions suggests that personalized information can lead to better quality of life.<sup>25,41</sup> In stroke, small randomized controlled trials of written information have found that although there was increased knowledge<sup>20,42,43</sup> and satisfaction with information in those who received written information,<sup>20,42</sup> no differences existed in patients' quality of life.<sup>20,43</sup> Improved carer mental health was found in 1 study.<sup>43</sup>

The SEP also aimed to provide support within an informal group. Other studies have evaluated services that provide individual support or counseling in addition to information.<sup>24,44-47</sup> Although education was found to improve some aspects of family functioning, the addition of counseling was associated with better outcomes.<sup>45</sup> Provision of a structured, personalized information program to patients and carers by a specialist nurse in their own home in the 12 months after discharge resulted in no differences in outcome between intervention and control groups.<sup>46</sup> However, the qualitative component of this study found that patients and carers visited by a specialist nurse felt that they had received personalized support and information, but the control group felt that they lacked personally relevant information that would have helped them practically and emotionally.<sup>47</sup> Although visits by a stroke family care worker improved patient and carer satisfaction with services, they had no measurable effect on physical, psychological, or social outcomes of patients and carers.<sup>24</sup>

Providing patients and carers with information about stroke may be insufficient to improve health status. It is important to realize that services developed by caring enthusiastic health

professionals to meet the expressed need for information by stroke patients and their informal carers may not be necessarily beneficial. Further work is needed to investigate the relationship between knowledge of stroke, how such knowledge is provided, and perceived health status. Before beginning an additional randomized controlled trial of an educational intervention, we intend to undertake further development work that involves patients, carers, and experts in health education to more clearly identify optimal ways of meeting patient and carer information needs and improving problemsolving skills.

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