

# Variations in care and outcome in the first year after stroke: a Western and Central European perspective

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*J Neurol Neurosurg Psychiatry* 2004;75:1702–1706. doi: 10.1136/jnnp.2004.039438

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Received 16 February 2004  
Revised 4 June 2004  
Accepted 4 June 2004

**Background:** There are significant variations in the short term patterns of care and outcome after a first stroke in Europe.

**Objective:** To estimate the variation in stroke care and outcome up to 1 year after a stroke in selected European centres.

**Methods:** Hospital based stroke registers were established in 11 hospitals in seven western and central European countries to collect demographic, clinical, and resource use data at the time of first ever stroke during 1993–4. At 3 and 12 months, details of survival, activities of daily living score, and use of services were recorded. Univariate comparisons between centres were made using the  $\chi^2$  test and stepwise regression was used to identify associations between centre, case mix, therapy provision, and outcomes.

**Results:** Of the 4048 patients registered, 23% were lost to follow up and 38% had died at 1 year. The proportions of survivors who felt they needed assistance at 12 months ranged from 35% in Italy to 77% in UK2. There were comparatively high amounts of therapy provided up to 1 year in UK3, France and Germany 1, mainly at home. At 1 year, social services were still providing support in UK1, UK5 and France, with some support in Germany 1 and family support was provided in France.

In multivariate analysis, after adjustment for case mix and receipt of rehabilitation, non-UK centres had improved activities of daily living ( $p < 0.001$ ). Older age was indicative of more need for assistance, but less likelihood of assistance from the family. Those in France were more likely to get assistance from their family than any other centre. Mainland European patients were more likely to get help from their family than those in the UK. Patients in all areas except UK2 and UK3 were more likely to be dead or dependent at 1 year than patients in UK1.

**Conclusions:** There were significant variations in the pathways of care for stroke across European centres in the mid 1990s, which were associated with variation in outcome, and remain unexplained. Family support is more prevalent in southern Europe and service support more prevalent in the UK.

Throughout Europe, the development of national and regional stroke guidelines is aimed at making care more effective and therefore presumably more standardised in approach.<sup>1,2</sup> There are documented variations in the process of stroke care in Europe and other parts of the world that indicate that there is much to be done to bring care into line with expert opinion and evidence based guidelines.

Heller and colleagues identified large variations between hospitals in 10 countries across the world, but excluding Europe, in the management of stroke.<sup>3</sup> The variation was explained by the availability of resources, even for interventions that do not necessarily depend on resource availability. Beech *et al* identified significant differences in the key processes of initial stroke care in European centres, most notably in length of stay, use of brain imaging, and receipt of rehabilitation, all of which were unexplained by case mix.<sup>4</sup> McKevitt *et al* have demonstrated considerable variation in the stroke care pathways across Europe and highlighted the need for caution in assuming that studies that control for patient characteristics thereby control for all relevant variables.<sup>5</sup> These studies were conducted in the early/mid 1990s. There is evidence from the International Stroke Trial that even in the trial setting in the late 1990s, variations in access to brain imaging and use of antiplatelet treatment varied significantly between countries after adjustment for case mix.<sup>6</sup>

We have previously shown variation in the short term outcome of care after a first stroke in European settings; after controlling for case mix there are unexplained differences in death and dependency 3 months after stroke.<sup>7</sup> Stroke is a

chronic disease that requires longer term follow up with ongoing investigation and management to improve outcome. In the first year after stroke the risk of recurrence is at its highest and the potential for improving outcome is greatest for rehabilitation.<sup>1</sup> This study follows up a cohort of first in a lifetime stroke survivors in selected centres in central and western Europe and estimates the variation in care and outcome in the first year after stroke, focusing on the period 3 months to 1 year, as we have previously reported significant variations in the first 3 months after stroke.<sup>4,7</sup> Such analyses are aimed at identifying potential gaps in service provision that European and national guidelines need to acknowledge if effective care is to be accessed equitably.

## METHODS

The detailed methods of case ascertainment, documentation of the acute stroke episode, and the 3 month assessment are detailed elsewhere.<sup>5,7</sup> Briefly, the project involved 11 centres in seven European countries: England, France, Germany, Hungary, Italy, Portugal, and Spain. The hospitals are not necessarily typical of care in their country, but the vast majority provides general acute care and some are also teaching hospitals. Only centres with 1 year outcome assessments were included, hence UK centre 4 and one of the centres in Spain were not included in this analysis but are reported in the baseline study.<sup>7</sup>

**Abbreviations:** ADL, activities of daily living; OT, occupational therapy; PT, physiotherapy; SLT, speech and language therapy

Baseline information used for these analyses included: demographic factors (age, sex, prestroke Rankin Handicap Score, living conditions prior to stroke); clinical state, including case mix, at the time of maximum impairment (level of consciousness, site of paralysis/weakness, speech or swallowing problems as a result of stroke, incontinence), type of stroke (cerebral infarction or haemorrhage, subarachnoid haemorrhage), and use of hospital resources (length of stay in hospital, use of diagnostic tests). At 3 and 12 months, surviving patients were reassessed by face to face interview, except in Italy where follow up was by telephone. These data were supplemented with information from case notes, other routine hospital sources, and carers. Living conditions were noted (alone, with companion, institutionalised), clinical state was reassessed, and the use of further diagnostic tests, rehabilitation (receipt of any rehabilitation yes/no), and visits to the physician/family doctor was documented. Outcome was assessed in terms of survival and dependence (activities of daily living (ADL); Barthel and Rankin scales).<sup>5,7</sup>

### Statistical analysis

Analyses were based on centres with follow up rates of 75% or more (excluding Portugal and Hungary) or with more than 70 patients (excluding Spain).

Analysis included univariate comparisons between centres for initial demography, case mix, and use of resources. The univariate association between centres and categorical variables was examined using the  $\chi^2$  test. One way analysis of variance was used to investigate the univariate association between centre and continuous variables. Outcome at 12 months was defined as dead, alive with a Barthel <20 (dependent), alive with a Barthel of 20 (independent), or unknown (including those known to be alive but with unknown Barthel, and those whose vital status was not known).<sup>7</sup>

Logistic regression models were developed to look at the relationship between centre and each outcome (receipt of assistance from family; Barthel score = 20, indicating independence; and death or dependency by Barthel score (<20)), adjusting for case mix and use of rehabilitation (initial, 3 and 12 month variables). The case mix variables considered were age (years), sex, pre-stroke Rankin score, level of consciousness (coma/non-coma), swallowing problems, incontinence at time of maximum impairment, and limb deficit at time of maximum impairment (none, deficit, paralysis).<sup>7</sup> The initial model included all potential confounding variables plus centre. The variable with the largest p value ( $p>0.2$ ) was then removed and the model re-fitted. This procedure was repeated until all variables in the model had p values smaller than 0.2. Each model therefore adjusts for all the case mix variables listed in the appropriate table, and for those case mix variables not listed, there was no strong evidence of a relationship with the outcome ( $p>0.2$ ).

## RESULTS

For the centres with 1 year follow up data, a total of 4048 first in a lifetime strokes were registered. The proportions that were lost to follow up are detailed in table 1. There was variation in follow up rates, from 0% in France and Italy to 57% in Portugal, with seven centres having follow up loss rates <20%. Table 1 also shows the proportions that had died (38%) by 1 year and the proportions of the survivors who were independent using both Rankin scores (49%) and Barthel Index (45%). There was variation between centres in the proportion living at home alone 1 year following stroke, ranging from 6% in Italy to 54% in France.

As reported in detail previously there were significant differences between centres for all case mix and resource use variables ( $p<0.001$ )<sup>7</sup> (data not reported in detail again here).

There was a wide variation in the proportion of patients who had initial urinary incontinence (24% in France to 64% in UK3), initial swallowing problems (11% in Germany1 to 55% in UK3), and initial speech problems (46% in France to 72% in Portugal). The proportion initially in coma ranged from 7% in Germany1 to 20% in UK2.

There were variations between the centres in the use of diagnostic tests after the acute hospitalisation with a high use of brain imaging (82%), carotid Doppler (20%), and echocardiography (33%) at 3 months. From 3 months to 1 year, high use of brain imaging (21%), carotid Doppler (38%), and echocardiography (33%) was observed in Germany1. There were differences in therapy use between the centres at 3 months, with fairly high amounts of rehabilitation in UK1 (47% physiotherapy (PT), 35% occupational therapy (OT) and 38% speech and language therapy (SLT)] and Germany 2 (55% PT, 22% OT and 46% SLT). At 1 year the proportion receiving any therapy was <10% in two centres, and was 23% in UK 1, 22% in France, and 30% in Germany1, with an average of 22%.

Information on whether the stroke survivors felt they needed assistance and who provided social support for them was also collected at 3 months and 1 year (year 1 data shown in table 2). There were wide variations between the centres in the proportions of survivors who felt they needed assistance at 3 months, ranging from 38% in Germany1 to 85% in UK3, and 1 year, ranging from 35% in Italy to 77% in UK2. At both time points, of those who required assistance, most people received assistance from their family. At 3 months, friends were providing support in France and UK3 but by 1 year, this was only in the case in France. Social services were providing support in all UK centres, except UK2, and in France at 3 months. At 1 year, social services were still providing support in UK1, UK5, and France.

### Stepwise regression modelling

Table 3 shows receipt of assistance of families for everyday activities at 1 year (for those who reported that they needed assistance) and is adjusted for all case mix variables, including age. Men who needed assistance were more likely than women to get help from family. Older age was associated with less likelihood of assistance from family. Patients with speech problems or incontinence were less likely to receive assistance from their family. Those in France were more likely to get assistance from their family than any other centre, and generally, mainland European patients were more likely to get help from their family than those in the UK. UK1 had the best family support of the UK centres.

Modelling the effect of centre, age, sex, pre-stroke Rankin score, swallowing problems, limb weakness/paralysis, incontinence, and coma on independence at 1 year (Barthel = 20) showed significant centre variation ( $p<0.001$ ) with better outcomes in non-UK centres (table 4). There were also independent adverse effects of age, pre-stroke Rankin score and case mix variables on independence (all  $p<0.001$ ) (table 4).

Table 5 shows the effect of centre, case mix, and rehabilitation input on death and dependence at 1 year. The inclusion of therapy input into this model was used to estimate the effect of therapy on outcome. Patients in all areas except UK2 and UK3 were less likely to be dead or dependent at 1 year than patients in UK1. Older, female patients with pre-stroke handicap, speech or swallowing problems, incontinence, coma, and limb deficit (all at baseline) were more likely to be dead or dependent at 1 year.

## DISCUSSION

This large European study provides striking evidence of significant inequity in stroke service provision that appears to

**Table 1** Survival and outcome at 1 year

Centre	Registered at baseline		Lost to follow up		Dead at 1 year		% of survivors			
							Rankin score = 0, 1, 2 (independent)		Barthel score = 20 (independent)	
	n		n	%	n	%	n	%	n	%
UK1	214		39	18	76	43	45	45	61	62
UK2	160		37	23	63	51	26	43	8	13
UK3	220		23	10	98	50	34	34	14	14
UK5	256		40	16	140	65	34	45	25	33
France	213		0	0	60	28	99	65	84	55
Portugal	657		378	57	146	52	61	45	73	54
Hungary	160		62	39	30	31	55	81	38	56
Spain	77		3	4	35	47	22	56	21	54
Germany1	1152		277	24	232	27	386	60	334	52
Germany2	302		52	17	87	35	90	55	108	66
Italy	635		0	0	232	37	94	23	115	29
					76	43				
Total	4048		911	23	1199	38	946	49	881	45

impact on longer term outcomes. There were wide variations in the way services were provided at a time when there little evidence of effectiveness for much of the care that was being provided. The differences in outcome could not be explained by conventional case mix adjustment. The results build upon our previous reports of variations in acute hospital stroke care to 3 months across European centres. For the first time, we estimate the use of health and social support for a cohort of people with stroke during the first year. This time period is of relevance as it is then that both the risk of recurrence of stroke and the potential for benefit from rehabilitation is highest.<sup>1</sup>

The study has the advantage of including over 4000 patients who were followed up for 1 year in 11 centres in seven countries. Previous and subsequent studies have followed up patients only during the initial stages after stroke, and the findings here help to map out the patchy nature of longer term stroke care,<sup>5,7</sup> although the study did not follow up patients for recurrent stroke. The centres were self selected and contained physicians and researchers with an interest in stroke. Because there is often only one centre per country, the centres are not necessarily representative of their country, yet they do probably reflect the range of care practised in the 1990s.

There are problems with this and other studies using cross centre comparisons. Control for confounding factors such as socioeconomic status was not undertaken, partly because assessing this in the elderly stroke population is problematic. Control for case mix used acceptable variables from previous studies, yet more recently a set of variables has been identified from systematic review of the literature on predictors of stroke outcome, which could be used in future

studies.<sup>8</sup> Additionally, although the study was able to adjust for case mix, we were unable to control for selection biases that may have varied between centres, particularly with respect to variations in the categorisation of coma, incontinence, and paralysis.

### Follow up

Follow up included both death and dependency, which are similar outcomes to those assessed in clinical trials of stroke care.<sup>6</sup> The follow up rate was poor in two centres and the numbers small in a third; consequently these centres were excluded from any regression analysis to reduce bias. We have previously reported that in four of the six centres where follow up to 3 months was low, the probability of being followed up was associated with one or more case mix variables and there was evidence that loss to follow up was not random.<sup>7</sup>

### Comparisons between centres

As previously reported, the differences in initial case severity may reflect differing hospital admission policies and hence the need for case mix adjustment.<sup>7</sup> The estimates of the proportions of patients receiving specific diagnostic tests or management (type of bed and therapy) varies considerably, with some of that variation being explained by case mix. In the mid 1990s, evidence was only just becoming available that stroke unit care improved outcome.<sup>1</sup>

The use of further diagnostic tests after the acute phase is relatively low, yet in one German centre, one in five patients have a brain scan or carotid Doppler between 3 months and 1 year. Some of this variation may be explained by case mix, but it appears that either resources are more readily available

**Table 2** Social support at 1 year

Centre	Requires assistance		Support from family		Support from friends		Receipt of social services		Other services	
	n	%	n	%	n	%	n	%	n	%
UK1	72	73	52	72	9	13	28	39	9	13
UK2	46	77	27	52	5	11	5	11	11	24
UK3	74	75	24	32	0	0	0	0	0	0
UK5	42	55	17	40	0	0	13	31	21	50
France	64	42	65	94	42	59	44	63	29	42
Germany1	352	55	253	72	33	9	87	25	67	19
Germany2	82	50	62	76	2	2	3	4	17	21
Italy	141	35	102	72	2	1	4	3	23	16

**Table 3** Stepwise regression analysis of the need for assistance from family for everyday activities at 1 year, among those patients saying they need assistance

Variable	Odds ratio	95% CI	p value
Centre			
UK1	1.00		
UK2	0.61	0.39 to 0.94	<0.001
UK3	0.57	0.25 to 1.31	
UK5	0.20	0.09 to 0.44	
France	6.33	2.16 to 18.51	
Germany 1	1.06	0.58 to 1.93	
Germany 2	1.51	0.67 to 3.38	
Italy	1.24	0.63 to 2.45	
Dependent in BI	1.00		
Independent in BI	0.61	0.39 to 0.94	0.024
Age (per 1 year increase)	0.97	0.95 to 0.98	<0.001
Female	1.00		
Male	1.49	1.07 to 2.08	0.020
No speech problem	1.00		
Speech problem	0.70	0.50 to 0.98	0.036
Continent	1.00		
Incontinence	0.68	0.48 to 0.96	0.030

\*Stepwise regression including centre, age, sex, pre-stroke Rankin score, swallow, limb weakness/paralysis, incontinence, speech problems, and coma (all at baseline).

in some centres to further investigate risk factors or the culture is such that physicians repeatedly investigate patients. In the absence of guidelines and audit of practice, it was not possible to assess the appropriateness of these investigations.

The finding that a sizeable proportion of patients with impairments does not receive any therapy, even during the initial hospital episode, may reflect a financing constraint in certain countries where therapy services are not well developed. Overall, use of physiotherapy at 3 months was achieved by at most a third of those that needed it, and regression analysis indicated that those most severely impaired received it, yet their functional outcome remained poor. The evidence of effectiveness for physiotherapy is limited to the first 6 months after a stroke, but there is some evidence suggesting that possible benefits may be achieved longer term.<sup>1</sup> Up to 30% of survivors in one German centre were still providing therapy at 1 year at home, whereas 30% of survivors who required therapy in Portugal obtained it privately.

As with other chronic diseases, the family appears to be the cornerstone for longer term social support, particularly in mainland Europe. The use of statutory social services is the mainstay in the UK, although coverage appeared patchy, but was higher in France.

Documentation of variations in the process of care in itself often raises more questions than it answers. Assessing the effect of such variation in care on outcome is central to the delivery of good quality care, yet as can be seen in the first year after stroke, the potential interventions are legion and the effect on outcome complex to interpret. The impression from this and other studies is that stroke care is suboptimal. In the largest clinical trial in stroke, the International Stroke Trial, Weir and colleagues observed significant variations in outcome across countries.<sup>6</sup> Adjustment for case mix explained only some of the variation in outcomes between countries in a trial setting. They argued that the residual differences in outcome at 6 months were too large to be explained by variations in care; however, they only looked at several indicators of care, rather than a broader range of indicators as in this study. Difference in baseline characteristics between countries was thought to be central to explaining these differences, and our study has also

**Table 4** Stepwise regression analysis of the effect of variables on independence in activities of daily living (Barthel score = 20) at 1 year\*

Variable	Odds ratio	95% CI	p value
Centre			
UK1	1.00		
UK2	0.45	0.17 to 1.17	<0.001
UK3	0.44	0.19 to 1.02	
UK5	1.66	0.73 to 3.75	
France	2.75	1.42 to 5.30	
Germany 1	1.92	1.12 to 3.30	
Germany 2	5.84	2.58 to 13.18	
Italy	1.67	0.93 to 3.00	
Age (per 1 increase)	0.93	0.92 to 0.95	<0.001
Female	1.00	1.06 to 1.88	0.019
Male	1.41		
No pre-stroke handicap	1.00	0.05 to 0.30	<0.001
Pre-stroke handicap	0.12		
No swallowing problems initially	1.00	0.29 to 0.77	0.003
Swallowing problems	0.47		
No physiotherapy at 3 months	1.00	0.49 to 0.97	0.031
Physiotherapy at 3 months	0.69		
No physiotherapy at 1 year	1.00	0.12 to 0.79	0.015
Physiotherapy at 1 year	0.31		
Continent initially	1.00	0.19 to 0.47	<0.001
Incontinent	0.30		
No limb weakness/paralysis initially	1.00	0.38 to 0.75	<0.001
Weakness/paralysis	0.53		

\*Stepwise regression including centre, age, sex, pre-stroke Rankin score, swallow, limb weakness/paralysis, incontinence, speech problems, coma (all at baseline).

identified gaps in baseline management.<sup>4 5</sup> Considering this is a common chronic disease, it is disappointing that we do not have at our disposal routine measures of sociodemography, case mix, and patient centred outcome that can be used in international comparisons. We and others have argued that outcome in the UK may be poorer, as there is less focus on acute stroke support and this notion is reinforced by

**Table 5** Stepwise regression analysis of death and dependency (Barthel <20)

Variable	Odds ratio	95% CI	p value
Centre			
UK1	1.00		
UK2	3.38	1.35 to 8.47	<0.001
UK3	2.02	0.93 to 4.39	
UK5	0.99	0.50 to 1.97	
France	0.36	0.21 to 0.63	
Germany 1	0.72	0.45 to 1.16	
Germany 2	0.25	0.13 to 0.47	
Italy	0.90	0.54 to 1.49	
Age (per 1 year increase)	1.06	1.05 to 1.07	<0.001
Female	1.00	0.58 to 0.92	0.008
Male	0.73		
No speech problems initially	1.00	0.94 to 1.50	0.156
Speech problems initially	1.18		
Not in coma initially	1.00	2.11 to 11.45	<0.001
In coma initially	4.92		
No pre-stroke handicap	1.00	4.84 to 21.49	<0.001
Pre-stroke handicap	10.20		
No swallowing problems	1.00	1.62 to 3.70	0.001
Swallowing problems	2.45		
Continent initially	1.00	3.16 to 6.37	<0.001
Incontinent initially	4.49		
No weakness/paralysis initially	1.00	1.72 to 2.92	<0.001
Weakness/paralysis initially	2.24		

\*Stepwise regression including centre, age, sex, pre-stroke Rankin, swallow, limb weakness/paralysis, incontinence, speech problems, coma (all at baseline), and rehabilitation at baseline, 3 months, and 1 year.

observational data from a subsequent European study.<sup>9</sup> Bhalla *et al* studied the acute management of physiology after stroke in four centres and identified significant variation in acute physiological support which remained unexplained by case mix.<sup>10</sup> The link between acute physiological support and outcome requires more formal evaluation to identify those interventions that are most effective. There is also some evidence that acute stroke unit care, which focuses more on physiological support, improves outcome.<sup>11</sup>

This study has identified unexplained differences in the process and outcome of care across a range of acute and community based interventions aimed at improving the outcome after stroke. The methods currently available to adjust for potential confounding in such comparisons are not sensitive enough to allow robust comparisons. The outcomes of care appear better in some settings, and we need to identify those processes that impact on outcome so that efficient audit tools can be put in place.

## ACKNOWLEDGEMENTS

This study was supported by the European BIOMED 1 Programme.

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Competing interests: none declared.

## APPENDIX

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