Doctor's follow-up after stroke in the south of Sweden: An observational study from the Swedish stroke register (Riksstroke)

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Abstract

Introduction: Information on follow-up practices after stroke in clinical routine are sparse. We studied the probability of doctor's follow-up within 90, 120, 180, and 365 days after hospital discharge, and how patient characteristics were associated with the probability of follow-up, in a large unselected stroke cohort.

Patients and methods: Data on patients living in southern Sweden, hospitalized with acute ischemic stroke or intracerebral hemorrhage 1 January 2008 to 31 December 2010, were obtained from the Swedish stroke register (Riksstroke) and merged with administrative data on doctor's visits during the year following stroke.

Results: Complete data were registered in 8164 patients. The cumulative probability of a doctor's follow-up was 76.3% within 90 days, 83.6% within 120 days, 88.7% within 180 days, and 93.1% within 365 days. Using Cox regression calculating hazard ratios (HR), factors associated with 90-day follow-up were: female sex HR = 1.066 (95%CI: 1.014–1.121), age: ages 65–74 HR = 0.928 (95%CI: 0.863–0.999), ages 75–84 HR = 0.943 (95%CI: 0.880–1.011), ages 85 + HR = 0.836 (95%CI: 0.774–0.904), pre-stroke dependency in activities of daily living (ADL): HR = 0.902 (95%CI = 0.819–0.994), prior stroke HR = 0.902 (95%CI: 0.764–0.872), and severe stroke HR = 0.506 (95%CI: 0.407–0.629). In patients discharged to assisted living, the following factors were associated with lower follow-up probability: living alone pre-stroke HR = 0.836 (95%CI: 0.736–0.949), and pre-stroke dependency HR = 0.887 (95%CI: 0.775–0.991).

Discussion: This study was based on hospital administrative data of post-stroke doctor's visits, but may be confounded by attendance for other conditions than stroke.

Conclusions: One in four stroke patients was not followed up within three months after hospital discharge. Vulnerable patients with high age, pre-stroke ADL dependency, and prior stroke were less likely to receive doctor's follow-up.

Keywords

Stroke, follow-up, stroke organization, cohort, transition of care

Introduction

There are approximately 34,000 new stroke events yearly in Sweden,¹ and it is estimated that at least 100,000 persons live with chronic stroke. The Swedish National Guidelines for Stroke Care recommend an early (time not defined) doctor's follow-up after stroke. The aims of follow-up are to assess tolerability and compliance to medication, and to follow-up on functional status, complications, rehabilitation, and give information and caregiver support.² Despite that, no standardized follow-up program has been implemented in clinical routine. In the Swedish national quality register for stroke care (Riksstroke), a doctor's follow-up within three months is considered an important process indicator and is prerequisite to carry out the

secondary preventive and rehabilitating measures recommended in the Swedish National Guidelines for Stroke Care.

The aim of this study was to analyze the cumulative probability of doctor's follow-up within 90, 120, 180, and 365 days after hospital discharge, as well as to analyze if patient characteristics were associated with the probability of stroke follow-up within the first 90 days.

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Methods

Materials

Data on patients living in southern Sweden (the region of Skåne with approximately 1.3 million inhabitants) who were hospitalized for acute stroke from 1 January 2008, until 31 December 2010 were obtained from the Swedish stroke register. Patients > 18 years with the ICD-10 diagnoses of ischemic stroke (I63) and primary intracerebral hemorrhage (ICH) (I61) were included in the study. Patients with stroke not defined as ischemic or hemorrhagic (I64) were excluded. For patients with more than one stroke during the three-year interval, only the first stroke event was included. Dates of doctor's visits in primary care and outpatient hospital clinics during one year following stroke were obtained from the administrative database of the Region Skåne (hospitals and primary health care) and linked to the Riksstroke data file. Mortality status and date of death were obtained by data linkage to the Swedish population register.

The Riksstroke variables

Riksstroke is a hospital-based national quality register of stroke care since 1994, with a coverage rate close to 90%.³ Validation have shown > 90% accuracy for most of the information from medical records and data entered into Riksstroke.⁴ At the hospital stay, data on pre-stroke functional status, vascular risk factors, medication, and living conditions were registered, as well as medical care, secondary prevention, discharge location, and planned rehabilitation. Vascular risk factors registered in Riksstroke are hypertension, diabetes, atrial fibrillation, and smoking. Level of consciousness on admission was registered using the Reaction Level Scale RLS-85 with categories of alert, drowsy, and comatose. A previous study found level of consciousness to be equal to National Institute of Health Stroke Scale (NIHSS) score in predicting mortality.⁵ Dependency in activities of daily living (ADL) pre-stroke was defined as dependency in dressing and/or toileting and/or indoor mobility.

At discharge, some patients were transferred to an inpatient rehabilitation unit. The time from discharge to follow-up was calculated from the date of discharge from either hospital or inpatient rehabilitation.

The Region Skåne administrative data on doctor's visits

Dates of all-cause doctor's visits in primary care, hospital-based outpatient clinics, and in care institutions (for patients with assisted living) were obtained from the administrative database of the Region Skåne for the

365 days following hospital or inpatient rehabilitation discharge in all individuals. Consultant visits registered during hospitalization were excluded. Only information on the dates, and not the types of unit visited was available. Hospitalizations were not registered.

Statistical methods

All analyses were performed in SPSS 23.0. Simple frequency tables were used to calculate proportions and Chi square test was used to compare proportions. Independent samples *T*-test was used to compare means. Kaplan-Meier was used for 1-survival curves and Cox regression was used for multivariate analysis using backwards elimination to find the best fitted model. In the multivariate models we introduced all variables with a *p* value of 0.2 or less in a univariate analysis.

Study's main outcome variable

The main outcome variable used was the cumulative probability of receiving a doctor's visit in primary care or hospital outpatient clinic within 90, 120, 180, and 365 days from hospital or inpatient rehabilitation discharge.

Ethical considerations

The study was approved by the local ethics committee (2012/453).

Results

Patient baseline characteristics

Patient baseline characteristics are shown in Table 1. The number of patients with acute ischemic stroke or ICH was 8164. We excluded 211 patients with stroke not characterized as ischemic or hemorrhagic (I64 diagnosis).

A total of 1026 (12.6%) patients died during hospital stay. Among the 6963 patients who survived hospital stay, 4665 (67%) patients were discharged to own home with or without home rehabilitation, 1501 (21.6%) were discharged to assisted living in a care institution, 554 (8%) were discharged to in-hospital rehabilitation, and 237 (3.4%) to other hospital wards.

Doctor's follow-up within 90, 120, 180, and 365 days

The cumulative probability of a doctor's follow-up within 90 days was 76.3%. At 120 days the cumulative probability of follow-up was 83.6%, at 180 days 88.7%,

Table 1. Baseline characteristics in 8164 patients with acute stroke.^a

Variable	Observations N (%)	
	M	W
No. of men and women	4151 (50.8%)	4013 (49.2%)
Mean age men and women (SD)	72.6 (SD = 12.1)	77.9 (SD = 12.1)
Living conditions		
Living alone	4003 (49.3)	
Co-living	4123 (50.5)	
Living in own home	7423 (90.9)	
Assisted living	642 (7.9)	
Other	52 (0.6)	
Functional status		
ADL dependent	786 (9.8)	
Risk factors		
Hypertension	4759 (58.6)	
Diabetes	1554 (19.1)	
Current smoker	1216 (16.2)	
Atrial fibrillation	2179 (26.8)	
Prior stroke	1593 (19.6)	
Stroke subtype		
Ischemic stroke	7100 (87)	
Intracerebral hemorrhage	1064 (13)	
Level of consciousness on admission		
Fully awake	6769 (83.4)	
Somnolent	906 (11.2)	
Comatose	441 (5.4)	

^aMissing data in <2%, except for smoking 8.3%.

and at 365 days 93.1%. At 30 days the cumulative follow-up probability was 44.9% and at 60 days 65.4%.

Associations between baseline patient characteristics and the probability of follow-up within 90 days in an unadjusted model

Significantly lower proportions of patients with high age, pre-stroke disability and severe stroke, received follow-up within 90 days (Table 2). There were no differences between men and women. Diagnoses of hypertension, diabetes, or atrial fibrillation were associated with a lower or equal chance of follow-up within 90 days. There were no differences in follow-up within 90 days between stroke subtypes (ischemic stroke versus ICH).

Associations between baseline patient characteristics and the probability of stroke follow-up within 90 days in a multivariate model

In an age-adjusted Cox regression multivariate model (Table 3) with a doctor's visit within 90 days after

Table 2. Proportions of the 6771 90-day survivors that were followed up by a doctor within 90-days after discharge from hospital or inpatient rehabilitation unit.^a

Variable	Follow-up within 90 days, N (%)	Chi square test p value
Age		<0.0001
<65	1182/1441 (82)	
65–74	1298/1669 (77.8)	
75–84	1680/2234 (75.2)	
85+	975/1427 (68.3)	
Sex		0.19
Female	2425/3228 (75.1)	
Male	2710/3543 (76.5)	
Living conditions pre-stroke		<0.0001
One-person household	2300/3124 (73.6)	
Co-living	2820/3624 (77.8)	
Functional status pre-stroke		<0.0001
ADL dependent	307/488 (62.9)	
ADL independent	4771/6199 (77)	
Hypertension		0.89
Yes	2977/3929 (75.8)	
No	2139/2817 (75.9)	
Diabetes		0.20
Yes	976/1263 (77.3)	
No	4154/5499 (75.5)	
Atrial fibrillation		0.001
Yes	1168/1604 (72.8)	
No	3952/5147 (76.8)	
Level of consciousness on admission		<0.0001
Alert	4644/6108 (76.4)	
Drowsy	378/503 (75.1)	
Comatose	66/124 (53.2)	
Prior stroke		<0.0001
Yes	923/1333 (69.2)	
No	4198/5417 (77.5)	
Stroke subtype		0.96
Ischemic stroke	4611/6081 (75.8)	
Intracerebral hemorrhage	524/690 (75.9)	

^aMissing data in <1.4%.

discharge as the dependent variable, censoring those who died within in the 365-day follow-up period, the following variables were entered into the model: age, sex, living alone (one-person household) pre-stroke, pre-stroke ADL-dependency, diabetes, atrial fibrillation, level of consciousness on admission to hospital, and prior stroke. The same analysis was performed in a backward stepwise manner to find the best fitted model in the following groups: all patients, patients discharged straight to own home, and patients discharged to assisted living. Variables with no significant impact on 90-day follow-up were excluded from the final models that are shown in Table 3.

Table 3. Cox regression model of baseline factors: sex, age, living alone pre-stroke, ADL dependency at baseline, diabetes, atrial fibrillation, prior stroke, and level of consciousness on admission, that influenced the probability of receiving a doctor's follow-up within 90 days (hazard ratio (HR)) using a backwards elimination model.^a

Variables	HR	95.0% CI lower	Upper	p value
Cox regression: all patients (n = 8164)				
Sex (male ref.)	1.066	1.014	1.121	0.013
Age (<65 ref.)				<0.0001
Age 65–74	0.928	0.863	0.999	0.047
Age (75–84)	0.943	0.880	1.011	0.099
Age (85+)	0.836	0.774	0.904	<0.0001
Pre-stroke ADL dependency	0.902	0.819	0.994	0.038
Diabetes	1.101	1.033	1.172	0.003
Prior stroke	0.816	0.764	0.872	<0.0001
Level of consciousness (alert ref.)				<0.0001
Drowsy	1.064	0.970	1.167	0.187
Comatose	0.506	0.407	0.629	<0.0001
Cox regression: patients discharged straight to own home (n = 4665)				
Age (<65 ref.)				<0.0001
Age 65–74	0.920	0.848	0.999	0.048
Age (75–84)	0.901	0.831	0.976	0.01
Age (85+)	0.765	0.695	0.843	<0.0001
Pre-stroke ADL dependency	1.249	1.046	1.492	0.014
Diabetes	1.119	1.037	1.209	0.004
Prior stroke	0.920	0.847	0.999	0.05
Cox regression: patients discharged to assisted living (n = 1501)				
Living alone pre-stroke	0.836	0.736	0.949	0.006
Pre-stroke ADL dependency	0.887	0.775	0.991	0.035

^aTop section includes all patients, second section includes patients discharged straight to own home, and bottom section includes patients discharged to assisted living.

In all patients ($n=8164$), baseline factors that were positively associated with the probability of receiving an early follow-up were diabetes (hazard ratio (HR)=1.101 (95% CI: 1.033–1.172) and female sex (HR=1.066 (95% CI: 1.014–1.121)). All other baseline factors were negatively associated with the probability of follow-up within 90 days. Prior stroke and severe stroke (comatose on hospital admission) were associated with a lower probability of follow-up within 90 days: HR=0.816 (95% CI: 0.764–0.872) and HR=0.506 (95% CI: 0.407–0.629). Patients with pre-stroke dependency had an HR of 0.902 (95% CI: 0.819–0.994) of receiving a follow-up within 90 days compared to those who were ADL independent pre-stroke.

In a Cox regression model analyzing only patients who were discharged to own home ($n=5665$), baseline patient characteristics that were associated with doctor's follow-up differed from the previous analysis (Table 3) in that the HR was higher in patients with pre-stroke ADL dependency (HR=1.249 (95% CI: 1.046–1.492), but the number of patients with

pre-stroke ADL dependency who were discharged directly to home was small (129 patients; 2.8%). An age gradient with lower HR of a doctor's follow-up in the older age categories was seen, as well as lower HR for prior stroke and a higher HR in patients with diabetes.

Analyzing patients discharged to assisted living ($n=1501$), the two factors that were negatively associated with the probability of a follow-up within 90 days were pre-stroke ADL dependency HR=0.887 (95%CI: 0.775, 0.991) and living alone pre-stroke HR=0.836 (95%CI: 0.736, 0.949).

Pre-stroke characteristics and three-month functional outcome in patients lacking 90-day follow-up

The number of three-month survivors that did not receive a follow-up visit within 90 days was 1636. Mean age was 76.1 years (SD 11.8) in patients who did not receive 90-day follow-up compared to 73.3 (SD 12.5) ($p<0.0001$) in patients who did receive follow-up. The proportion of pre-stroke ADL

dependent among not followed up patients was 11.2% ($n=181$) compared to 6% ($n=307$) among those followed up ($p<0.0001$). Previous stroke was present in 25.2% ($n=410$) of the not followed up, compared to 18% ($n=923$) among those followed up within 90 days ($p<0.0001$). Data were missing in 1.3%.

Vascular risk factor profiles (atrial fibrillation, hypertension and diabetes) in patients who lacked versus received follow-up within 90 days are shown in Figure 1(a). Smoking data were not analyzed due to missing data in >8%. Atrial fibrillation was present in 26.7% ($n=436$), hypertension in 58.2% ($n=952$), and diabetes in 17.5% ($n=287$) of patients who were not followed up. The distribution of vascular risk factors did not differ between patients who lacked and who received 90-day follow-up. Figure 1(b) shows the proportions of patients who presented with zero, one, two, and three risk factors. One risk factor was present in 39% ($n=637$); two risk factors were present in 26% ($n=417$); and three risk factors in 4% (66 patients) of not followed up patients. The numbers of vascular risk factors were similarly distributed among those who lacked and who received follow-up within 90 days. Data on risk factors were missing in 0.6%.

At three months, the proportion of ADL dependent among patients who were not followed up was 33.4%

($n=506$), compared to 27.1% ($n=1358$) among those who were followed up ($p<0.0001$) in unadjusted data. Data were missing in 3.8%.

Discussion

The main finding of this study was that one in four stroke patients did not receive a doctor's follow-up within three months after hospital discharge. Vulnerable patients with high age, pre-stroke disability, prior, and severe stroke had lesser chance of a follow-up visit within three months. Not followed up patients were approximately three years older and had more pre-stroke disability.

Results are comparable to previous studies in which 14–25% were not seen by a doctor within three months,^{6,7} and old and severely disabled patients were less likely to receive follow-up, despite not having less vascular risk factors.⁶ In our study, 26% of not followed up patients had two vascular risk factors, and 4% had three, and the distribution of risk factors was similar to patients who did receive follow-up within 90 days. Patients with diabetes had a higher probability of receiving a follow-up visit, but patients with hypertension or atrial fibrillation did not. Inadequate healthcare follow-up and prescription of secondary prevention drugs are barriers for risk factor control,^{7,8} but patient self-management and information provision to patients also play a role.⁹ Old and severely disabled are also more likely non-treated with secondary preventive medications,^{7,9} even though their benefit from secondary prevention is not proven lower. Inadequate cardiovascular risk management may cause stroke recurrence and death.^{10,11} Persistent use of secondary preventive medication declines rapidly following stroke,¹² but only two out of five studies assessing complex interventions on stroke survivors to overcome treatment barriers demonstrated improved effects on some risk factor management outcomes (blood pressure control, body mass index and physical activity).^{13–17}

A large proportion of patients report long-term unmet care and rehabilitation needs after stroke.^{18–24} Emotional and social problems are common,^{21,22,24} as are problems concerning transition of care,²⁵ information,^{21,23} service provided,^{23,24} rehabilitation,^{18–20} and communication.^{23,24} This requires stroke after-care to have a broad focus, but how can health care resources best be used in order to meet the patients' needs? The benefit of doctor's follow-up after stroke on care needs and hard clinical endpoints has not yet been proven. Three studies have assessed intensified follow-up by doctor/stroke nurse/rehab team after stroke, with no significant effect on functional outcomes in the intervention groups compared with standard care.^{25–27}

Figure 1. Panel (a) shows vascular risk factor profile (diabetes, hypertension and atrial fibrillation) at discharge in 5135 stroke patients who were followed up within 90 days and 1636 patients not followed up within 90 days. Data were missing in 0.6%. Panel (b) compares number of risk factors between patients who were, and were not followed up within 90 days.

Organization of acute stroke management has led to large improvements in overall outcome for acute stroke patients. Stroke unit care reduces the odds of death and dependency one year post-stroke,²⁸ and the reduction in death is mostly achieved by preventing complications.²⁹ A recent Canadian study demonstrated lower 30-day mortality rates in areas with integrated systems of stroke care, even though a causal effect could not be proven due to the nonrandomized observation design.³⁰ Patients in regions with integrated stroke care systems had greater access to all modalities of stroke care, showing that full-spectrum stroke systems improve stroke mortality.³¹

The major causes of death after hospital discharge in stroke patients are recurrent stroke, pneumonia, and heart disease.³² To maintain the positive effects of stroke unit care, organization of stroke management in the longer perspective is thought to be equally important. In 2012, the Global Stroke Community Advisory (GSCAP) developed the Post Stroke Checklist,³³ in order to standardize the process of identifying long-term problems experienced by stroke survivors. The Post Stroke Checklist addresses 11 important post-stroke problems amenable to treatment and/or referral, and was evaluated in 2014.³⁴ In the Swedish National Guidelines for Stroke Care, there is a clear recommendation for long-term stroke follow-up, but no systematic approach has been developed within primary health care for problem identification and service coordination for stroke patients, and the multidisciplinary stroke team has not been implemented in general practice. In the UK, the Sentinel Stroke National Audit Programme (SSNAP) has implemented a compulsory six-month follow-up assessment after stroke,³⁵ the timing of which was developed out of a consensus view.³⁶ The value of the six-month follow-up is currently under study.³⁷

The patients' perspective on stroke follow-up was assessed in a Swedish qualitative study where half of the study subjects were dissatisfied with the care provided from their general practitioner after stroke. Some did not understand that they had had a follow-up visit after hospitalization, and some were dissatisfied with having to organize follow-up themselves.³⁸ Another study assessing the patients perspective on the transition of care from hospital to community care from showed dissatisfaction with information provided, support services and follow-up therapy received.³⁹ A large responsibility put on the patients to organize follow-up might reflect the findings in our study that the most vulnerable patients groups were less likely to receive follow-up.

Strengths of this study are the large number of patients included and the presence of administrative rather than self-reported data on follow-up. Doctor's follow-up after stroke and associated factors

have not been previously studied in a large unselected stroke cohort material. Limitations of the study are that care administrative data were not stroke specific and may be confounded with attendance for other conditions. Hospitalizations were not included, and absence of follow-up within 90 days may in a minority of cases be due to readmissions. In a study on readmission the first year after stroke, 32% were readmitted within one year with a median of 118 days after stroke.⁴⁰ Data on doctor's visits for patients with assisted living and domiciliary visits were included, but results showing a very low probability of follow-up in the most severely affected patients (comatose at admittance, comprising 1.8% of those who survived 90 days) indicate that those data may be incomplete. Nurse visits were not the focus of this study, but housebound patients who were not reviewed by a physician might have had other healthcare interactions, including nurse visits.

The lack of a systematic approach to stroke follow-up and a large responsibility on stroke patients to organize follow-up may explain why vulnerable patient groups of high age and low functional status have lesser chance of a follow-up visit within 90 days. Implementation of a structured follow-up program could lead to a more equal long-term stroke care, but the effect on patient needs and hard clinical endpoints requires further study.

Conclusion

One in four patients with acute stroke did not receive a doctor's follow-up within three months after hospital discharge. Vulnerable groups of patients with high age, previous stroke, and pre-stroke dependency had lesser chance of receiving doctor's follow-up.

Provenance

Didier Leys (Vice Editor) acted as Editor-in-Chief for this manuscript. Bo Norrving (Editor-in-Chief) was not involved in the peer review process.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Ethical approval

This study was approved by the local Ethics Board 2012/453.

Informed consent

All patients are informed about registration in Riksstroke, that data may be used for research purposes, and their rights to deny participation (opt-out consent). Consent is not collected for specific research projects. Data were de-identified prior to being received by the researchers.

Trial Registration

Not applicable.

Guarantor

TU.

Contributorship

All authors are responsible for the study concept and design. TU analyzed the data and prepared the manuscript. All authors carried out a critical revision of the manuscript, contributed with comments and approved the final version.

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