Stroke Monitoring on a National Level

PERFECT Stroke, a Comprehensive, Registry-Linkage Stroke Database in Finland

Atte Meretoja, MD, MSc; Risto O. Roine, MD, PhD; Markku Kaste, MD, PhD; Miika Linna, DSc; Merja Juntunen, MSc; Terttu Erilä, MD, PhD; Matti Hillbom, MD, PhD; Reijo Marttila, MD, PhD; Aimo Rissanen, MD, PhD; Juhani Sivenius, MD, PhD; Unto Häkkinen, PhD

Background and Purpose—Stroke databases are established to systematically evaluate both the treatment and outcome of stroke patients and the structure and processes of stroke services. Comprehensive data collection on this common disease is resource-intensive, and national stroke databases often include only patients from selected hospitals. Here we describe an alternative national stroke database.

Methods—We established a nationwide stroke database with multiple administrative registry linkages at the individual-patient level. Information on comorbidities; treatments before, during, and after stroke; living status; recurrences; case fatality; and costs were collected for each hospital-treated stroke patient.

Results—The current database includes 94 316 patients with incident stroke between January 1999 and December 2007, with follow-up until December 2008. Annually, 10 500 new patients are being added. One-year recurrence was 13% and case fatality was 27% during the study period. In 2007, 86% of patients survived 1 month and 77% were living at home at 3 months, but the proportion treated in stroke centers (62%) or with nationally recommended secondary preventive medication after ischemic stroke (49%) was still suboptimal.

Conclusions—In comparison with other national stroke databases, our method enables higher coverage and more thorough follow-up of patients. Information on long-term recurrences, case fatality, or costs is not often included in national stroke databases. Our database has low maintenance costs, but it lacks detailed data on in-hospital processes. Use of national administrative data, where such linkage is possible, saves resources, achieves high rates of long-term follow-up, and allows for comprehensive monitoring of the burden of the disease. (Stroke. 2010;41:2239-2246.)

Key Words: acute stroke ■ organized stroke care ■ registry

Stroke databases are established for 3 purposes: to gather information for scientific research, to gain epidemiologic data for healthcare planning, and to get feedback for evaluating and improving the quality of care. The main data requisite for scientific research is extreme accuracy; for epidemiologic data, maximal coverage; and for quality improvement, clinically relevant process and outcome indicators.

An optimal outcome and quality assessment system should include, according to the Helsingborg Declaration, the following components: assessment of structure (for example, availability of stroke services), assessment of process (for example, proportion of patients treated in stroke units, with thrombolytic therapy, and with appropriate secondary preventive medication), assessment of outcome (for example, case fatality and place of residence at 3 months), and assessment...
of stroke prevention and management at the macro level (for example, population-based incidence and prevalence).\textsuperscript{1} All of this information would be very useful to clinicians, healthcare administrators, politicians, and researchers alike. Then why have comprehensive national stroke registries not yet been established? This is largely a question of money and effort. Current registries with reasonable coverage require many people for data input and register maintenance, with an associated high cost.

The aim of the PERformance, Effectiveness, and Cost of Treatment episodes in Stroke (PERFECT Stroke) study was to establish a comprehensive nationwide stroke database with information on structure, process, outcome, and costs of treatment of stroke patients in Finland.

**Methods**

**Design and Setting**
We established a national stroke database in Finland (population of 5.3 million at the end of 2007) by using multiple, national, administrative registry linkages at the individual-patient level. Ethics committee approval or informed consent was not required by Finnish legislature, as patients were not contacted or, with anonymized data, identifiable to the researchers.

The funding sources for this study had no role in the design and conduct of the study; in the collection, management, analysis, and interpretation of the data; or in the preparation, review, or approval of the manuscript.

**Patients**
Patients were selected from the national hospital discharge register (HDR) with the International Classification of Diseases (ICD),\textsuperscript{10} 10th revision, codes G45 (transient ischemic attack), I60 (subarachnoid hemorrhage), I61 (intracerebral hemorrhage), I63 (ischemic stroke, IS), and I62, I64–68 (other cerebrovascular disease). Patients with the cerebrovascular syndrome code ICD-10 G46 were classified according to etiologic subcode (ICD-10 I60-I67; for example, G46*I63.4 equals IS). The HDR is maintained by the government and comprehensively includes all public and private inpatient care in hospitals and institutions in Finland, including ongoing care.\textsuperscript{24} Stroke diagnosis in the HDR has been shown to be reasonably valid, with 94% of patients coded with acute stroke, according to our definition, as truly having had acute stroke.\textsuperscript{25}

Only patients with a first-ever, that is, incident, stroke were included in the database. Patients with a previous stroke diagnosis (ICD-10 codes I60-I69, ICD-9 codes 430 to 434 or 436 to 438) in the HDR, checked backward to January 1, 1987, were excluded. The initial hospitalization for first-ever stroke and the subsequent chain of inpatient care in any other hospitals were merged to form an episode that represented the total chain of stroke inpatient care for each patient. We were unable to include patients treated completely as outpatients.

Data for each patient were linked with the national register of prescribed medicines, kept by the Social Insurance Institution, and the national register of causes of death, kept by Statistics Finland, according to a personal identification number.\textsuperscript{24} This number uniquely identifies any Finnish resident and is used uniformly across all governmental registers (Figure 1). Place and form of residence, hospitalizations and their causes, outpatient visits, medication purchases, and associated costs were recorded on a daily basis starting from 1 year before stroke to when the patient died.

Detailed information on patient comorbidities were collected from multiple overlapping sources: HDR diagnoses were checked backward until 1987; national Social Insurance Institution reimbursement codes for long-standing chronic diseases were utilized; and information on medication purchased 1 year before stroke was used.

**Assessment of Structure**
Information on facilities and procedures available for acute stroke care was collected in a separate national audit performed in 2003. In this audit, all hospitals with >20 annual stroke patients (n=36) were visited, and the smaller hospitals and institutions were evaluated on the basis of mailed questionnaires or over-the-phone interviews, with a response rate of 96%. A second audit was performed in 2006. From these audits, those hospitals that met all Brain Attack Coalition criteria were classified as comprehensive or primary stroke centers.\textsuperscript{26}

**Assessment of Process**
Lengths-of-stay at individual stages of the treatment episode (acute hospital, subsequent hospitals, nursing home, or other long-term care
facilities) were routinely registered. The proportion of patients with access to primary or comprehensive stroke centers was reported. Prescription medication purchases for the 1 year before and after stroke pinpointed the medical intervention of stroke secondary prevention. Several acute and secondary preventive procedures with a procedure code in the HDR were recorded, including thrombolytic therapy, but we had no information on most in-hospital medications, as they lacked procedure codes. All direct healthcare costs were analyzed at the individual-patient level.

Assessment of Outcome

There were 4 clinical outcome measures: case fatality, stroke recurrence, need for institutional care, and days spent at home during the subsequent year after stroke. Recurrence was defined as a new clinical event of stroke (defined as continuous inpatient care for 90 days before the stroke) in the treatment episode during the first week of stroke. Early recurrences during the first-ever-stroke hospital episode could not be extracted from the registries. Outcomes were recorded on a daily basis but were reported at 28, 90, and 365 days (case fatality and institutional care) or 365 days only (recurrence and days spent at home).

Benchmarking

One of the main objectives in setting up the database was to provide benchmark indicators for the assessment of cost-effectiveness. For a hospital to be able to compare its performance with that of other hospitals or with itself over the years, the case mix would have to be comparable. Therefore, lengths-of-stay, costs, and outcome measures were reported both as crude measures and adjusted for differences in baseline characteristics. Adjusted values with 95% CIs were estimated with suitable regression models, where parameter estimates for baseline characteristics (age, sex, all comorbidities, previous use of statins or warfarin, and year of stroke) were used to assess risks for individual patients. Patients already living in an institution before their stroke (defined as continuous inpatient care for 90 days before stroke), nonresidents of Finland, residents of the archipelago of Åland (population 27 000), and patients <18 years of age were excluded from the benchmarking comparisons but were included in the registry. The database currently includes hospital-treated patients with first-ever stroke in Finland from January 1, 1999. Annual reports are produced after 1-year follow-up data are available. Two sets of reports are produced, with patients grouped either by hospital district (population range from 60 000 to 1.5 million) based on patient municipality or by treating hospital. treating hospital was defined as the highest level of care (local, regional, or university hospital) in the treatment episode during the first week of stroke.

Results

The PERFECT Stroke database currently includes 94 316 incident-stroke patients between January 1, 1999, and December 31, 2007, with follow-up for each patient until December 31, 2008 (Table 1). Annual incidence has ranged between 10 225 and 10 763. Of all patients, 79% had IS, 14% had intracerebral hemorrhage, and 7% had subarachnoid hemorrhage as their initial stroke. The IS patients were older and had more comorbidities. Of all stroke patients, 48 977 were alive as of December 31, 2008, which translates to a
Finnish stroke prevalence of 82,000, or 1.5% of the national population.

Assessment of Structure
The number of stroke units in Finland increased from 11 in the 1999 to 16 in 2006. Five hospitals fulfilled the criteria for a comprehensive stroke center, and 7 met the criteria for a primary stroke center in 2006.

Assessment of Process
Of all stroke patients, 54% were treated at stroke centers, more so for those with hemorrhagic stroke (Table 1). Treatment at a stroke center was mainly related to the patients’ home address, with 73% of those patients living in the catchment area of a stroke center treated in one, whereas only 9% (2478/28,514) of patients living in a hospital district without a stroke center were referred to one. The patients were treated, on average, for 17 days in their initial hospital and 25 days in other hospitals thereafter. Carotid endarterectomy (2% of IS) and thrombolytic therapy (1% of IS) rates were low during the whole study period, with the latter increasing to 3.4% by 2007.

Assessment of Outcome
Of all patients, 27% died and 13% had a stroke recurrence during the first year after their incident stroke. Both acute- and long-term mortality was higher with hemorrhagic stroke, but there was little difference in the proportion of patients still residing in a long-term institutional care facility 1 year from their stroke (Figure 2). By 2007, only some of the goals of the Helsingborg Declaration had been met (Table 2).

Discussion
Most Finnish in-hospital stroke patients were included in our database. This did not require any extra data collection or entry, consumed no manpower in participating hospitals, and the database maintenance and administration costs were only $40,000 annually for the whole nation. All health districts and major hospitals receive an annual report on their performance, effectiveness, and costs of stroke treatment, including benchmarking data for national comparisons. All results are published online for citizens and politicians to scrutinize.

Comparison With Other National Databases
When compared with other national stroke databases, the Finnish database includes more hospitals and institutions, has better nationwide coverage of patients, and provides the most thorough follow-up (Table 3). On the other hand, the database is less robust for capturing many in-hospital process indicators; for example, it does not include information on swallowing tests, early mobilization, or any in-hospital time flags (Table 4). For thrombolytic therapy, detailed time flags are available through the SITS registry. To our knowledge, no other national database routinely reports on costs or the success of secondary prevention, that is, stroke recurrence rate.
Organization of stroke services

All patients in Europe with stroke will have access to a continuum of care from organized stroke units in the acute phase to appropriate rehabilitation and secondary prevention measures.

Management of acute stroke

>85% of stroke patients survive the first month after stroke.

Prevention

Stroke mortality is reduced by at least 20% from the level of 2005.

Rehabilitation after stroke

3 months after stroke onset, >70% of surviving patients are independent in their activities of daily living.

Evaluation of stroke outcome and quality assessment

All countries aim to establish a system for the routine collection of data needed to evaluate the quality of stroke management, including patient safety issues.

Performance Level in Finland in 2007

62% of stroke patients nationwide were treated in qualified stroke centers; 49% of IS patients were treated with a combination of secondary preventive medication as per guidelines.*

86% of hospital-treated patients survive at least 30 days.

78% of all ischemic stroke patients were treated in a hospital with thrombolytic capacity; Highest per capita thrombolytic therapy rate among European countries in 2002 to 2006.†

Total No. of deaths due to stroke was reduced by 18%, and age-standardized death rate was reduced by 35% in the previous 10 years (1997–2007);† Primary prevention was not discussed in this article.

77% of surviving patients live at home 3 months after stroke, but activities of daily living function is unknown.

This has been achieved with the PERFECT Stroke database.

Novel Methodology

Before the PERFECT Stroke database was instituted, there were basically 2 methods for national stroke databases, namely, comprehensive data collection or audit sampling. Comprehensive patient-level data extraction and input seem to be the most common method. If the data collection and entry take 30 minutes per patient, for example, this would require 1 full-time person for approximately every 3000 patients. Often, this is done by the nursing staff, but in many countries, the data are collected and input by physicians, a major investment and not always feasible due to a lack of manpower. The associated costs and time taken away from the diagnosis and treatment of patients are huge, and therefore, such registries do not include all stroke patients nationwide. The annual cost of the Canadian stroke registry was $1 million annually, 30 times as much as ours, and included only one fifth the number of patients.22 Resource-intensive organization of databases may in part explain low participation, reflected by only a few selected centers in most countries. The Swedish RIKS-Stroke registry (≈80%) and the Scottish Stroke Care Audit (≈60%) have been most successful in including a major portion of patients nationwide, whereas most national registries include only a small fraction of patients. Many countries, such as Canada and Germany, have found comprehensive data collection to be too resource-intensive, with many centers having left the initially larger registry. There is a tendency for comprehensive registries to expand with new data elements added constantly, with associated increasing costs.4

Audit sampling every 2 years, as in the UK Stroke audit, saves many resources compared with a comprehensive registry and succeeds in measuring and emphasizing stroke care at regular intervals. Furthermore, these audits allow sufficient time to resolve previous known issues.5–9 Legislation may be an obstacle to comprehensive registries. The Registry of the Canadian Stroke Network could only include patients who gave consent, which was obtainable for only 51% of patients.22 Especially long-term follow-up information is difficult to obtain in conventional registries owing to the extra work or “red tape” involved.12

Database Weaknesses

Despite its ambitious name, the Finnish stroke database is far from perfect. First, the most important predictor of outcome for benchmarking purposes, severity of stroke at onset,28,29 was not recorded. Training all national physicians to use stroke severity scales, such as the National Institutes of Health Stroke Scale, would be a huge effort and could easily fail.

Second, there is no information on diagnostic work-up, stroke unit bed utilization, rehabilitation, or any in-hospital medications except for thrombolytic therapy. Major in-hospital procedures, such as carotid endarterectomy or surgery for intracerebral and subarachnoid hemorrhage, are...
included in the database, however. On the other hand, medication purchases before and after stroke are comprehensively recorded at the pharmacies in the national register of prescribed medicine. This information probably is more reliable than in many registries, which rely on available history for medications on admission and discharge prescriptions for medications at discharge. Prescribing a medication, buying it, taking it, and reporting taking it probably never reliably coincide.

Third, our database was not population based, as out-of-hospital patients were not included. However, the Finnish hospitalization rate for stroke is 95% to 98%, and therefore only a few elderly, already institutionalized patients, those who died before hospital admission, and those who were treated entirely as outpatients, were not included in our database. Coding errors between stroke subtypes, transient ischemic attack, and noncerebrovascular diagnoses do occur, and the sensitivity to recognize all population-based stroke patients with our method is 85% to 90%.

Fourth, recurrences are most common very early after stroke, and thus occur during the initial hospital episode. We were unable to register these early recurrences. Also, the later coding of recurrent strokes may have been less correct than for first-ever strokes, and thus, data on recurrences must be interpreted with caution.

Fifth, coding of thrombolysis is deficient in the HDR. The license for alteplase use in IS was granted in 2003.
Thrombolysis per population was the highest in Finland of all European countries (years 2002 to 2006, n = 590). In addition, a large number of patients were treated off-label. More than 700 thrombolyses for Finnish incident-stroke patients were registered in the SITS registry during the same time frame (www.acutestroke.org). Only 409 of these were registered in the HDR, reflecting deficient routine coding practices with this new procedure. Taking this into account, the thrombolysis rate in Finland may be even higher.}

### Table 4. Helsingborg Declaration Indicator Availability in National Stroke Databases

<table>
<thead>
<tr>
<th>Helsingborg Declaration Indicators</th>
<th>PERFECT Stroke</th>
<th>RIKS Stroke</th>
<th>UK National Sentinel Stroke Audit</th>
<th>Scottish Stroke Audit</th>
<th>Paul Coverdell National Acute Stroke Registry</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assessment of structure</td>
<td>+</td>
<td>-</td>
<td>+</td>
<td>+</td>
<td>-</td>
</tr>
<tr>
<td>Availability and quality of care in a stroke unit</td>
<td>+</td>
<td>-</td>
<td>+</td>
<td>+</td>
<td>-</td>
</tr>
<tr>
<td>Availability and quality of the rest of the stroke service</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Coverage by a quality assessment program</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Assessment of process</td>
<td>+*</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td>Proportion of patients admitted to care in a stroke unit</td>
<td>-</td>
<td>-</td>
<td>+</td>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td>Proportion of patients undergoing neuroimaging within 24 hours of hospital admission</td>
<td>+</td>
<td>+</td>
<td>-</td>
<td>-</td>
<td>+</td>
</tr>
<tr>
<td>Proportion of patients treated with thrombolysis</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Proportion of patients treated with adequate secondary prevention†</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Proportion of patients given adequate advice about a healthy lifestyle</td>
<td>+§</td>
<td>+</td>
<td>-</td>
<td>-</td>
<td>+</td>
</tr>
<tr>
<td>Proportion of patients with a TIA evaluated and a treatment plan implemented within 48 hours of the first symptoms</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>+</td>
</tr>
<tr>
<td>Assessment of outcome</td>
<td>+/-</td>
<td>+/-</td>
<td>+/-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Case fatality at 1 and 3 months</td>
<td>+</td>
<td>+</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Place of residence at 3 months</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Functional status at 3 months</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>measured with a validated score</td>
<td>+</td>
<td>+</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Proportion of patients with bleeding complications after thrombolysis</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>+</td>
</tr>
<tr>
<td>Complication rates of carotid artery interventions</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Assessment of stroke management at the macro level</td>
<td>+</td>
<td></td>
<td></td>
<td>+</td>
<td></td>
</tr>
<tr>
<td>Population-based monitoring of incidence of stroke</td>
<td>+</td>
<td></td>
<td></td>
<td>+</td>
<td></td>
</tr>
<tr>
<td>Population-based monitoring of prevalence of stroke</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Population-based monitoring of stroke case fatality</td>
<td>+</td>
<td></td>
<td></td>
<td>+</td>
<td></td>
</tr>
<tr>
<td>Population-based monitoring of stroke disability</td>
<td>+</td>
<td></td>
<td></td>
<td>+</td>
<td></td>
</tr>
<tr>
<td>Routine reporting of long-term medication and hospital use, case fatality, recurrence, and cost¶</td>
<td>+</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

TIA indicates transient ischemic attack.

*The PERFECT Stroke database reports whether the patient was admitted to a qualified stroke center, not stroke unit bed use.

†Acetylsalicylic acid or other antithrombotics; atrial fibrillation treated with anticoagulants; carotid endarterectomy, if appropriate; therapy to lower blood pressure and cholesterol.

‡Scanning information on arrival and by 48 hours.

§Smoking advice only.

¶Hospital-based data approaches population-based data (hospitalization rate 95–98% in Finland and 84–92% in Sweden).

¶These measures not included in the Helsingborg Declaration.
account, the Finnish thrombolysis rate in 2007 was 6.0% for all incident ISs.

Conclusions

Information on the structure, process, outcome, and cost of treatment of stroke patients is abundant but fragmented. The prime requisite for collecting such data nationwide is a common identifier, such as the personal identification number unique to all Finnish residents. Successful data linkage requires evasion of organizational and legislative obstacles. In Finland, we have been able to pool these data and have formed a comprehensive national stroke database with high coverage. This allows for continuous monitoring of the effectiveness and costs of stroke care. Our approach is probably applicable to other countries, but only if high-quality, nationwide registries with a common identifier can be used. An ideal stroke database would be integrated with hospital patient records and require minimal extra data entry, which would thus allow healthcare workers to concentrate on their main task, the management of acute stroke patients.

Sources of Funding

This study has been supported by unrestricted grants from the Finnish Academy, Finnish Neurological Foundation, Finnish Innovation Fund SITRA, Aarne Koskelo Foundation, Orion-Farmos Research Foundation, Maire Taponen Foundation, Paavo Ahvenainen Foundation, Instrumentarium Science Foundation, Helsinki University Central Hospital EVO Funding, Marja Virmio Memorial Fund, Bayer Schering Pharma Research Foundation, Finnish Medical Foundation, Yrjö Jahnsson Foundation, Emil Aaltonen Foundation, and Finnish-Norwegian Medical Foundation.

Disclosures

None.

References

Stroke Monitoring on a National Level: PERFECT Stroke, a Comprehensive, Registry-Linkage Stroke Database in Finland
Atte Meretoja, Risto O. Roine, Markku Kaste, Miika Linna, Merja Juntunen, Terttu Erilä, Matti Hillbom, Reijo Marttila, Aimo Rissanen, Juhani Sivenius and Unto Häkkinen

Stroke. 2010;41:2239-2246; originally published online August 26, 2010; doi: 10.1161/STROKEAHA.110.595173
Stroke is published by the American Heart Association, 7272 Greenville Avenue, Dallas, TX 75231
Copyright © 2010 American Heart Association, Inc. All rights reserved.
Print ISSN: 0039-2499. Online ISSN: 1524-4628

The online version of this article, along with updated information and services, is located on the World Wide Web at:
http://stroke.ahajournals.org/content/41/10/2239

Permissions: Requests for permissions to reproduce figures, tables, or portions of articles originally published in Stroke can be obtained via RightsLink, a service of the Copyright Clearance Center, not the Editorial Office. Once the online version of the published article for which permission is being requested is located, click Request Permissions in the middle column of the Web page under Services. Further information about this process is available in the Permissions and Rights Question and Answer document.

Reprints: Information about reprints can be found online at:
http://www.lww.com/reprints

Subscriptions: Information about subscribing to Stroke is online at:
http://stroke.ahajournals.org//subscriptions/