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REVIEW

The Danish Stroke Registry

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Søren Paaske Johnsen[1]
Annette Ingeman[1,2]
Heidi Holmager Hundborg[1]
Susanne Zielke Schaarup[3]
Jesper Gyllenborg[4]

[1]Department of Clinical Epidemiology, Aarhus University Hospital, [2]Registry Support Center of Clinical Quality & Health Informatics (West), The Danish Clinical Registries, Aarhus, [3]Department of Neurology, Bispebjerg Hospital, Copenhagen, [4]Department of Neurology, Zealand University Hopital, Roskilde, Denmark

Aim of database: The aim of the Danish Stroke Registry is to monitor and improve the quality of care among all patients with acute stroke and transient ischemic attack (TIA) treated at Danish hospitals.

Study population: All patients with acute stroke (from 2003) or TIA (from 2013) treated at Danish hospitals. Reporting is mandatory by law for all hospital departments treating these patients. The registry included >130,000 events by the end of 2014, including 10,822 strokes and 4,227 TIAs registered in 2014.

Main variables: The registry holds prospectively collected data on key processes of care, mainly covering the early phase after stroke, including data on time of delivery of the processes and the eligibility of the individual patients for each process. The data are used for assessing 18 process indicators reflecting recommendations in the national clinical guidelines for patients with acute stroke and TIA. Patient outcomes are currently monitored using 30-day mortality, unplanned readmission, and for patients receiving revascularization therapy, also functional level at 3 months poststroke.

Descriptive data: Sociodemographic, clinical, and lifestyle factors with potential prognostic impact are registered.

Conclusion: The Danish Stroke Registry is a well-established clinical registry which plays a key role for monitoring and improving stroke and TIA care in Denmark. In addition, the registry is increasingly used for research.

Keywords: stroke, transient ischemic attack, quality improvement

Background and aim of the database

A stroke is a medical emergency and can cause permanent neurological damage, complications, and death. Stroke is of major importance for public health internationally as stroke is the second most common cause of death globally and is a major cause of disability worldwide.[1,2] The 30-day case-fatality among patients with stroke has dropped in recent decades but remains overall between 10% and 20% in most Western populations.

Monitoring the quality of stroke care has a high international priority. The World Health Organization (WHO) Cardiovascular Disease Program aims at developing standards of care as well as feasible surveillance methods to monitor prevention and control initiatives for cardiovascular diseases, including stroke. Furthermore, a number of countries monitor the quality of stroke care at a national level in established stroke registries, for example, Sweden, the US, Germany, and Austria. Denmark first launched national clinical guidelines for the acute treatment and care of patients with

Correspondence: Søren Paaske Johnsen
Department of Clinical Epidemiology, Aarhus University Hospital, Olof Palmes Allé 43, 8200 Aarhus, Denmark
Tel +45 8716 8115
Email spj@clin.au.dk

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stroke in 2003, and they have since been updated regularly. These guidelines recommend early initiation of treatment, care, and rehabilitation, and are in line with international consensus guidelines from the American Heart Association and the European Stroke Organisation.

The Danish Stroke Registry (DSR) was established in 2003 as part of the Danish National Indicator Project, which was a national quality improvement initiative aimed at monitoring and improving quality of care using evidence-based quality of care indicators.[3] The DSR is now a nationwide clinical registry and part of The Danish Clinical Registries – a national improvement program, which is an umbrella organization encompassing clinical registries in Denmark. The activities of the registry are coordinated by a multidisciplinary steering group, including physicians, nurses, physiotherapists, and occupational therapists. The members of the steering groups have been appointed by the relevant scientific societies and stakeholders.

Setting

All Danes (total population, aged 18 or older by January 2016: 3,964,146) are provided tax-supported health care by the Danish health care system allowing free access to hospital care and general practitioners. Patients with acute medical conditions, including stroke, are exclusively admitted to public hospitals. All hospitals' departments regularly treating patients with acute stroke and transient ischemic attack (TIA) are required by law to report data to the DSR. Staff members responsible for data collection have been appointed at all participating departments. Data are collected prospectively and reported to the DSR using a web-based interface.

Study population

All patients (≥18 years) admitted to Danish hospitals with acute stroke, as defined by WHO criteria, that is, an acute disturbance of focal or global cerebral function with symptoms lasting more than 24 hours or leading to death of presumed vascular origin, are eligible for inclusion in the DSR. Only patients with symptom onset within the last week are included. This includes patients with intracerebral hemorrhage and ischemic stroke (International Classification of Diseases tenth edition: I63, infarction; I61, hemorrhage; and I64, unspecified). In addition, patients with TIA (ie, patients with symptoms lasting up to 24 hours) are included. Patients with subarachnoidal or epidural hemorrhage, subdural hematoma, retinal infarct, and infarct caused by trauma, infection, or an intracranial malignant process are excluded. Patients with diffuse symptoms, such as isolated vertigo or headache, and asymptomatic patients with infarct detected only by computed tomography or magnetic resonance imaging scan are also excluded.

The registry included >130,000 events by the end of 2014, including 10,822 strokes and 4,227 TIAs registered in 2014. The sensitivity and predictive value of the registration of patients in the DSR was estimated to be >90% in 2009.[4] Although it cannot entirely be excluded that the completeness of the registration and regular assessments of the validity of the registration is always to be recommended in clinical registries, there is no indication based on the number of registered patients and the diagnostic work up of the patients that the registration practice has changed substantially over time.

Quality indicators

A total of 18 process and four result indicators covering the early phase of stroke have been identified by the steering group (Table 1). The process indicators reflect key recommendations from the national clinical guidelines and the DSR consequently monitors the implementation of these guidelines at Danish hospitals. Patients are classified as eligible or noneligible for the specific processes of care depending on whether the stroke team or physician treating the patient identifies contraindications; for example, severe dementia in a patient with ischemic stroke and atrial fibrillation precluding oral anticoagulant therapy or rapid spontaneous recovery of motoric symptoms, making early assessment by a physiotherapist and an occupational therapist irrelevant.

A structured audit process is carried out regularly (every year) on a national, regional, and local basis to assess critically the quality of the dataset and results. After the audit process is completed, the data are released publicly with department-level data, including comments on the results from the audit groups and recommendations on how to improve quality of care.[5] Improvements over the years have been observed for all quality indicators and for some process indicators the improvements have been dramatic, for example, the proportion of relevant patients fulfilling the indicator has doubled or even tripled.

Main variables

Selected key variables in the DSR are presented in Table 2. Besides the variables used to assess the quality indicators, the DSR also includes data on a range of prognostic factors. These factors are used to characterize the included patients and to take differences in case-mix into account when benchmarking departments or when comparing the same department over time. In addition, supplementary

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Table 1 Indicators and standards in the Danish Stroke Register

Indicator area	Indicator	Type	Standard (%)
Fast admission	Proportion of all patients with stroke who are admitted to hospital within 3 hours after symptom onset	Process	≥30
	Proportion of all patients with stroke who are admitted to hospital within 4.5 hours after symptom onset	Process	≥40
Thrombolysis	Proportion of patients treated with thrombolysis who have a door to needle time ≤1 hour	Process	≥75
	Proportion of patients with ischemic stroke receiving thrombolysis	Process	≥15
Endovascular therapy	Proportion of patients treated with endovascular therapy who have a door (first hospital) to groin puncture time of ≤3 hours	Process	≥90
	Proportion of patients treated with endovascular therapy who achieve a TICI posttreatment reperfusion grade ≥2B	Process	≥70
	Proportion of patients treated with endovascular therapy who 3 months posttreatment achieve a modified Rankin Scale score <3	Result	≥30
Organization of treatment and rehabilitation in stroke unit	Proportion of patients with acute stroke who are admitted to a stroke unit within the second day of admission	Process	≥90
Pharmacological secondary prophylaxis	Proportion of patients with acute ischemic stroke without atrial fibrillation who receive platelet inhibitor therapy within the second day of admission	Process	≥95
	Proportion of patients with TIA without atrial fibrillation who receive platelet inhibitor therapy within the second day after first contact with a hospital	Process	≥95
	Proportion of patients with ischemic stroke and atrial fibrillation who receive oral anticoagulation therapy within 14 days after admission	Process	≥95
	Proportion of patients with TIA and atrial fibrillation who receive oral anticoagulation therapy within 14 days after first contact with a hospital	Process	≥95
Diagnosis by CT/MR scan	Proportion of patients with acute stroke who receive CT/MR scan on the day of admission	Process	≥80
	Proportion of patients with TIA who receive a CT/MR scan on the day of first contact with a hospital	Process	≥80
Assessment by physiotherapist	Proportion of patients with acute stroke, which is assessed by a physiotherapist regarding need of rehabilitation (including type and extent) within the second day of admission	Process	≥90
Assessment by occupational therapist	Proportion of patients with acute stroke, which is assessed by an occupational therapist regarding need of rehabilitation (including type and extent) within the second day of admission	Process	≥90
Early mobilization	Proportion of patients with acute stroke who are mobilized on the day of admission	Process	≥80
Assessment of nutritional risk	Proportion of patients with acute stroke who receive a nutritional risk assessment within the second day of admission	Process	≥90
Screening for dysphagia	Proportion of patients with acute stroke, which is assessed by a swallowing test (indirect and direct) on the day of admission before receiving food or fluids in order to assess swallowing function and risk of aspiration	Process	≥80
Ultrasound CT-/MR-angiography of carotid arteries	Proportion of patients with acute ischemic stroke who are examined with ultrasound CT-/MR-angiography of carotid arteries within the fourth day of admission	Process	≥90
	Proportion of patients with TIA who are examined with ultrasound CT-/MR-angiography of carotid arteries within the fourth day after first contact with a hospital	Process	≥90
Waiting time to carotid endarterectomy	Proportion of patients with acute ischemic stroke undergoing carotid endarterectomy in whom time from admission to surgery is ≤14 days	Process	≥90

(*Continued*)

Table 1 (*Continued*)

Indicator area	Indicator	Type	Standard (%)
	Proportion of patients with TIA undergoing carotid endarterectomy in whom time from first contact with a hospital to surgery is ≤14 days	Process	≥90
Mortality	Proportion of patients with acute stroke (any type) who die within 30 days after admission	Result	≤15
	Proportion of patients with acute ischemic stroke who die within 30 days after admission	Result	≤12
	Proportion of patients with intracerebral hemorrhage who die within 30 days after admission	Result	≤40
Nonplanned readmission	Proportion of acute stroke patients with unplanned all-cause readmission within 30 days after discharge	Result	≤15

Abbreviations: CT/MR, computed tomography/magnetic resonance; TIA, transient ischemic attack; TICI, Thrombolysis in Cerebral Infarction scale.

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data on intravenous thrombolysis and endovascular therapy are obtained in order to characterize the provided treatments.

Formal validation studies on the registered data have not been conducted; however, the overall quality of the recorded data is most likely high since detailed instructions, including explicit data definitions, are available and data recording practices are examined and discussed by representatives of the hospitals departments reporting to the registry at the yearly audits.

Follow-up

All patients are followed up by individual-level record linkage to other public registries using the civil registry number,

Table 2 Key variables registered in the Danish Stroke Registry

Variable	Content
Administrative	
ID	Unique number for identification of the event.
CPR	Unique 10-digit personal identifier.
Hospital	Unique code for the individual hospital and department.
Sociodemographic prognostic factors	
Age	Age at day of admission.
Sex	
Type of residence	Residence at time of admission (own residence, care home, other, undisclosed).
Civil status	Civil status at time of admission (cohabitant, lives alone, other, undisclosed).
Clinical prognostic factors	
Scandinavian Stroke Scale Score	Used to assess admission stroke severity. Score ranges from 0 to 58 points.
Diabetes mellitus	Documented history or diagnosed during current admission.
Myocardial infarction	Documented history or diagnosed during current admission.
Atrial fibrillation	Documented history or diagnosed during current admission.
Former stroke	Documented history or diagnosed during current admission.
Hypertension	Documented history or diagnosed during current admission.
Intermittent claudication	Documented history or diagnosed during current admission.
Lifestyle prognostic factors	
Body Mass Index	Body Mass Index at the time of admission.
Alcohol intake	Average weekly alcohol intake at the time of admission according to recommendation from the Danish National Board of Health (≤7/14 drinks/week for women and men, respectively).
Smoking	Smoking habits at the time of admission (smoker, ex-smoker, never smoker, undisclosed).
Processes of care[a]	
Thrombolysis	Use of thrombolysis.
Endovascular therapy	Use of endovascular therapy.
Admission to stroke unit	Admission to a specialized stroke unit providing multidisciplinary care.
CT/MR scan	Use of CT/MR scan of the brain.
Antiplatelet therapy	Use of antiplatelet therapy after stroke/TIA.
Oral anticoagulant therapy	Use of oral anticoagulant therapy after stroke/TIA.
Assessment by physiotherapist	Formal assessment by trained physiotherapist regarding need of rehabilitation after admission with acute stroke.
Assessment of occupational therapist	Formal assessment by trained occupational therapist regarding need of rehabilitation after admission with acute stroke.

(*Continued*)

Table 2 (*Continued*)

Variable	Content
Assessment of nutritional risk	Formal assessment of nutritional risk performed after admission with acute stroke
Mobilization	Mobilization (patient out of bed) performed after admission with acute stroke.
Screening for dysphagia	Screening for dysphagia (indirect and direct) performed after admission with acute stroke.
Ultrasound CT-/MR-angiography of carotid arteries	Carotid arteries examined after admission with acute stroke/TIA.
Patient outcomes	
30-day mortality	All-cause mortality within 30 days after date of admission for acute stroke. Information obtained by record linkage with the Civil Registration System.
30-day unplanned readmission	Unplanned all-cause readmission to any Danish hospital within 30 days after discharge. Information is obtained by record linkage with the Danish National Registry of Patients.
Modified Rankin Scale Score	Recorded 3 months after date of admission. Only recorded for patients receiving revascularization therapy.

Note: [a]Registered data include date and time as well as eligibility of the individual patient for each process of care.
Abbreviations: CT/MR, computed tomography/magnetic resonance; TIA, transient ischemic attack; CPR, social security number.

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which is unique to every Danish citizen and enables unambiguous linkages.

Information on mortality is obtained from the Danish Civil Registration System, which stores daily updated electronic records of all changes in vital status and migration for the entire Danish population, including changes in address, date of emigration, and the exact date of death, since 1968.[6]

Information on unplanned readmissions are obtained from the Danish National Registry of Patients, which is an administrative nationwide public registry that covers all discharges from somatic hospitals in Denmark since January 1, 1977.[7] The data include the dates of admission and discharge and up to 20 diagnoses for every discharge classified, since 1994, according to the Danish version of the International Classification of Diseases tenth edition.

Information on functional level 3 months after the day of admission with acute stroke is assessed using the modified Rankin Score for all patients receiving revascularization therapy (intravenous thrombolysis or endovascular therapy) and recorded directly in the DSR.

Examples of research

The DSR has been used in numerous studies covering a broad range of topics, including traditional clinical epidemiological studies on prognosis[8–10] as well as studies on effectiveness of care,[11–13] disparities of care,[14,15] and health economics.[16] The registry has been linked extensively with other public registries in many of these studies.

Administrative issues and funding

The DSR is an approved clinical quality database by the State Serum Institute and the Danish Data Protection Agency. It is funded by the Danish Regions and receives administrative, epidemiological, and biostatistical support from the Danish Clinical Registries. Aggregated data at regional level will be reported annually in a published report, and data will be provided monthly to the regions for use in each region's information system.

Conclusion

The DSR is a national clinical registry which plays an important role as an information source and quality improvement instrument for stroke and TIA care in Denmark.

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Disclosure

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