The evolution and utility of a national stroke registry: the Swedish experience

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Riks Stroke Swedish Stroke Register

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RIKS-STROKE
The Swedish registry for quality assessment of stroke care

- from 1994 onwards
- funded publicly
- all 79 hospitals admitting acute stroke patients
- all ages
- questionnaire follow-up at 3 months after stroke (a 12-month follow-up is underway)
AIMS OF RIKS-STROKE
The Swedish registry for quality assessment of stroke care

- **Primary:** to improve quality of stroke care in **all** hospitals (and after discharge from hospital)
  - processes (adherence to evidence-based national guidelines on stroke care)
  - outcome, including patient-oriented variables

- **Secondary:** Research
WHAT STRATEGY?

COMPRE-HENSIVE? = in-depth information

SIMPLE? = good coverage
RIKS-STROKE: MULTIDIMENSIONAL MONITORING OF STROKE CARE QUALITY

Processes

Entire stroke care chain

IoM dimensions of quality and outcome
RIKS-STROKE TECHNICALITIES

- Paper protocols → diskettes → Internet-based registrations → pilot studies for direct transfer of data from computerized medical records

- Hospitals have immediate access to own data, using a simple statistical and presentation package

- Annual feedback to individual hospitals (time trends, relative to other hospitals, etc.)

- Open-access website with comparisons between counties and hospitals
COVERAGE

- 87-93% in various validation studies
- Less likely to be covered: early deaths, not admitted to a stroke unit, elderly in nursing homes
- Follow-up data at 3 months: 89% of all included in the acute phase
4 YEARS TO INCLUDE ALL HOSPITALS

Per cent of hospitals

5 YEARS TO ACHIEVE NEXT-TO-FULL COVERAGE:
CUMULATED NO. OF EVENTS IN RIKS-STROKE

Approx 25,000 events per year
What is done in health care should be …

- based on evidence/knowledge
- safe
- provided in time
- distributed fairly
- patient-orientated
- cost-effective (optimal use of resources)

From: Institute of Medicine, Crossing the Quality Chasm: A New Health System for the Twenty-First Century (Washington: National Academy Press, 2001)
EVIDENCE-BASED?
PROPORTION OF ACUTE STROKE PATIENTS TREATED IN A STROKE UNIT 1994-2006
Evidence-based?
PROPORTION TREATED IN A STROKE UNIT BY HOSPITAL 2006
Evidence-based?

THROMBOLYSIS FOR ACUTE ISCHEMIC STROKE BY REGION:

Proportion treated 2006

- Västerbotten
- Halland
- Gävleborg
- Södermanland
- Skåne
- Stockholm
- Uppsala
- Kalmar
- Jönköping

NATIONAL AVERAGE

- Örebro
- Dalarna
- Norrbotten
- Västra Götaland
- Gotland
- Västernorrland
- Jämtland
- Östergötland
- Västmanland
- Värmland
- Kronoberg
- Blekinge

0 2 4 6 8 10 %
Safe?

ADHERENCE TO NATIONAL GUIDELINES: PROPORTION OF PATIENTS WITH ISCHEMIC STROKE TREATED WITH HEPARIN

per cent

2002  2003  2004  2005  2006
SAFE?
SEVERE COMPLICATIONS IN CAROTID SURGERY

Stroke or death <30 days,%

data from the Swedvasc quality register
In time?
DELAY FROM ONSET TO ARRIVAL IN HOSPITAL

Hours, median

Distributed fairly?

SEX DIFFERENCES

After age adjustment, no differences in …

- admission to a stroke unit
- thrombolysis
- anticoagulation after embolic stroke
- other antithrombotic secondary prevention
- antihypertensives

More men than women treated with statins after stroke
Patient-oriented?
DISSATISFIED WITH ACUTE CARE BY COUNTY

Proportion dissatisfied, %

- Halland
- Blekinge
- Skaraborg
- Dalarna
- Kronoberg
- Bohuslän
- Västerbotten
- Norrbotten
- Västernorrland
- Ålvsborg
- Örebro
- Malmö
- Jönköping
- Östergötland
- Kristianstad
- Göteborg
- Västmanland
- Gotland
- Malmöhus
- Stockholm (N)
- Stockholm (NE)
- Värmland
- Uppsala
- Kalmar
- Jämtland
- Gävleborg
- Södermanland
- Stockholm (SW)
- Stockholm (S)
- Stockholm (NW)
Patient-oriented?

UNMET NEEDS OF COMMUNITY SUPPORT AFTER DISCHARGE

Proportion claiming unmet needs, %
Cost-effective?

OPTIMAL USE OF RESOURCES

Preliminary analyses only.
Pilot cost estimates based on 6,824 patients in Riks-Stroke.

<table>
<thead>
<tr>
<th>Cost Category</th>
<th>Cost</th>
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<tbody>
<tr>
<td>Initial hospitalisation</td>
<td>€ 6,920</td>
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<tr>
<td>(range € 222-84,478)</td>
<td></td>
</tr>
<tr>
<td>Later direct costs</td>
<td>€ 54,950</td>
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<tr>
<td>Indirect costs (premature death, early retirement)</td>
<td>€ 14,810</td>
</tr>
<tr>
<td>Total costs</td>
<td>€ 76,680</td>
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</tbody>
</table>
KEY QUALITY INDICATORS ON OUTCOME

- Survival
- Primary ADL functions at 3 months
- Institutionalisation at 3 months
- Support from family members and social services
- Low mood
- Smoking cessation
- Self-assessed general health
- Quality of life (EQ-5)
OPPORTUNITIES TO EXPAND THE USE OF RIKS-STROKE DATA

Linkage to other registers by personal identification numbers:

- cause-of-death
- hospital admissions (partly also out-patient care)
- prescribed drugs
- socioeconomic
- demography/geneology
EXAMPLE OF LINKAGE TO NATIONAL REGISTER ON PRESCRIBED DRUGS: PROPORTION RETAINED ON SECONDARY PREVENTION

n=11,077

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Preliminary analyses!