National Performance Assessment 2011

QUALITY AND EFFICIENCY OF STROKE CARE IN SWEDEN

Socialstyrelsen
THE NATIONAL BOARD OF HEALTH AND WELFARE

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ISBN 978-91-7555-035-0
Article no 2013-3-4

Coverphoto Corbis, Johnér

Layout Edita Västra Aros
Printed by Edita Västra Aros, Västerås, March 2013

Contents

Preface

The National Board of Health and Welfare has undertaken a national assessment of the quality and efficiency of Swedish stroke care. This report comprises conclusions and recommendations of some particularly important areas for improvement and some further in-depth analysis. It is based on two separate assessments: one on the performance of stroke care in county councils and one on stroke care in municipalities.

Stroke is a condition that occurs suddenly and unexpectedly and can lead to major consequences for many of those affected, as well as for their relatives. As part of its efforts to improve treatment and care, the National Board of Health and Welfare published the National Guidelines for Stroke Care in the autumn of 2009. The guidelines provide a set of evidence-based best practices for stroke prevention, acute care, rehabilitation and recovery. The National Guidelines primarily concern stroke care provided by county councils, however stroke care also affects municipalities. For this reason, the National Board of Health and Welfare has assessed performance of both county council and municipal stroke care. This report identifies areas of stroke care where results fall short of the intentions of the National Guidelines and thus provide a basis for improvement at local and regional levels. Hence, National Guidelines and National Performance Assessments are both governmental tools aimed at steering towards high quality efficient care.

This report primarily targets decision-makers at various levels: politicians, civil servants and managers in health care. It may also be useful to other stakeholders such as patient organisations, end-user organisations, health care professionals and media.

The data has been collected via several questionnaires, the National Board of Health and Welfare's National Health Data Registers and Social Services Registers, and from two national quality registers within the field of stroke care. Representatives of quality registers have read the draft reports and contributed with valuable comments. Special thanks to the representatives of these registers as without their cooperation it would not have been possible to undertake these assessments.

The project managers of the assessments have been Matilda Hansson (municipal stroke care) and Björn Nilsson (county council stroke care). Other contributors include Rosita Claesson Wigand, Mikael Fabel, Lena Janzon, Behzad Koucheki, Max Köster, Tsega Muzollo and Karin Nyqvist as well as Professor Kjell Asplund (medical expert), Chief Community Nurse Pia Friberg (expert on municipal health care), Professor Per Wester (medical expert) and Fredrik Westander (consultant). Editor for the National Performance Assessment series is Rosita Claesson Wigand. Marie Lawrence (Head of Performance Assessment Unit) together with Mona Heurgren and Lena Weilandt acted as Steering Committee for the project.

Lars-Erik Holm
Director-General

Summary

Collaboration between municipalities and county councils leads to better outcome for people who have had a stroke. This is proved in the National Board of Health and Welfare's National Performance Assessment of Stroke Care. Data from surveys of stroke units and municipalities shows that, in 44% of municipalities, both county councils and municipalities indicated that they collaborate, or have procedures in place for collaboration regarding rehabilitation of stroke patients. In these municipalities, several outcome indicators such as health and well-being, depression and fulfilled needs for rehabilitation after hospitalisation point at better performance than in municipalities where municipalities and county councils do not collaborate on rehabilitation.

Mortality rates and the ability to manage activities in daily life (ADL) have only improved marginally over the past ten years. The proportion of patients who are readmitted to hospital for stroke or other cardiovascular diseases has not declined to any great extent, despite access to better secondary preventive treatments. Variations between municipalities are considerable, including the proportion of persons who are depressed one year after stroke onset. Based on the findings of this assessment, the National Board of Health and Welfare has identified a number of areas for improvement of stroke care:

- Reduce waiting times for stroke care.
- Increase the proportion of patients receiving care in designated stroke units.
- Improve secondary preventive pharmaceutical treatment.
- Respond to the need for carotid surgery.
- Improve rehabilitation both during and after hospitalisation.
- Provide better psycho-social support.

With more investments in these areas and through better compliance with National Guidelines, the performance in terms of reduced mortality, ADL dependence and depression could be improved and the variations between the county councils and municipalities could also decrease.

Many municipalities do not offer post-stroke rehabilitation, even though they are required to do so by law. The assessment has also found that people in need of rehabilitation and assistive devices after stroke risk not receiving what they need. A county council may enter into different agreements with municipalities regarding home-based medical and nursing care, consequently it may be difficult for people who have had a stroke and their relatives, to know who is responsible and who to turn to if they need rehabilitation or assistive devices.

Persons who live in normal housing where the municipality is responsible for home-based medical and nursing care have better patient-reported outcome in terms of health and well-being, depression and fulfilled needs for support and help after hospitalisation, than persons who live in municipalities where county council primary health care is responsible for their medical care.

Many relatives and family members to persons who have had a stroke report that they are in need of further information and knowledge about stroke as a medical condition and how it develops and progresses, as well as specific information on various treatments. Relatives also report that stroke has major implications for them, for example, their freedom of action becomes limited. Only a small proportion of relatives and families indicate they have received support from the municipality, although the municipality is required to provide this by law.

Approximately twice as many men as women receive day-or team rehabilitation after stroke. Regardless of gender and age, patient-reported outcome appears better for persons with day- or team rehabilitation than those who receive home-based rehabilitative care. It is, however, unclear what is included and who is responsible for the different types of rehabilitation. Women and men should receive day- or team rehabilitation to the same extent and home-based rehabilitation needs improvement.

People who have had a stroke seek dental care to a lesser extent than the population in general. Visits to the dentist play an important role in preventing dental and mouth problems that can arise after a stroke.

The National Board of Health and Welfare will, within a few years, re-assess the performance of stroke care. The recommendations and the areas for improvement identified in this assessment will specifically be monitored. Aspects of stroke care not captured in this report may also be evaluated in the future. The National Board of Health and Welfare expects the county councils and the municipalities to use this report as the basis of their work to further improve stroke care.

Outline of the Report

The report begins with the chapter *Conclusions and recommendations*. This chapter presents the National Board of Health and Welfare's conclusions and recommendations based on the findings from the two assessments; one on stroke care provided by the county councils and one on stroke care provided by municipalities [1-2] and on the further in-depth analysis presented in this report.

Following this there is a chapter describing *stroke* incidence and mortality rates in Sweden as well as in the rest of Europe. Thereafter follows a description of the *continuum of stroke care* in Sweden. The purpose of this section is to provide an overview of the various treatments and interventions that may be relevant for a person who has suffered a stroke, as well as clarifying which provider is responsible for various types of care. In the chapter entitled *Indicator-based comparisons* the results considered to particularly notable in the assessments undertaken in the county councils and the municipalities are presented [1-2]. Diagrams and comments are provided for each indicator. This is followed by some *further analyses* on several important aspects of county council and municipal stroke care. Examples of these aspects include responsibility, collaboration, rehabilitation and care undertaken by relatives. The chapter concludes with some examples of measurements on efficiency of county council and/or municipal stroke care. *Annex 1* presents a list of project participants and others who have contributed in undertaking the assessments. *Annex 2* provides an overview of the methodology used including data collection methods and sources. *Annex 3* lists the process and outcome indicators used to assess performance of stroke care. Finally, *Annex 4* is a separate document containing all of the graphical presentations from the two assessments. *Annex 4* can be downloaded from www.socialstyrelsen.se/nationellutvardering.

Conclusions and Recommendations

In this section the National Board of Health and Welfare presents a number of conclusions and recommendations about stroke care based the collected and analysed data. These selected recommendations and conclusions concern the areas of stroke care where none, or only a few county councils, hospitals or municipalities, achieved the desired level or where municipalities and county councils show deficiencies in their responsibilities under the law. They also relate to areas where there are considerable differences in practice between different county councils, hospitals and municipalities in terms of the treatment and care they offer.

All indicators are labelled with one letter and one number, for example A01. The letter specifies which type of care the indicator refers to. A complete list of all the indicators can be found in *Annex 2: List of Process and Outcome Indicators*.

The recommendations below should facilitate the municipalities', county councils' and hospitals' regular work aimed at improving stroke care. Our aim is to highlight areas where stroke care does not reach a desirable level in the country as a whole. However, there are few municipalities, county councils and hospitals who have already achieved a sufficiently high level in one or more of these indicators.

The National Board of Health and Welfare will in particular monitor performance of the indicators on which their recommendations are based. This will be carried out in connection with the next assessment of stroke care, which will be initiated in a few years' time. The municipalities, county councils and hospitals reporting weaker results should be able to improve their performance by then. This assessment also forms an important basis for the National Board of Health and Welfare's supervisory activities.

Clarify areas of responsibility and coordinate stroke care

The National Board of Health and Welfare has identified compliance deficiencies with:

- The National Board of Health and Welfare's regulations and general advice on the coordination of activities for habilitation and rehabilitation (SOSFS 2007:10)
- The National Board of Health and Welfare's regulations on collaboration at admission and discharge of patients into/from hospital care (SOSFS 2005:27).

The National Board of Health and Welfare expects municipalities and county councils to:

- Jointly establish care programmes for rehabilitation after stroke.
- Work together to a greater extent on rehabilitation after stroke.

To some extent, it is unclear who is responsible for providing rehabilitation and assistive devices after a patient has suffered a stroke. It is unclear which stroke patients the county council and the municipality is responsible for. In fact different municipalities within the same county council may have entered into different agreements with the very same county council. These ambiguities primarily concern agreements related to home-based medical and nursing care in normal housing. Several municipalities apply what is known as the threshold principle in which the responsibility depends on whether the person can get to a health care facility or not. Other municipalities state, for example, that their responsibility depends on municipal assistance decisions or the person's care needs. Do municipalities and county councils know who they are responsible for in terms of home-based medical and nursing care, rehabilitation and assistive devices for persons who have had a stroke?

Municipal home-based medical and nursing care in normal housing appears to result in better patient-reported outcome in terms of health and well-being than home-based primary health care services funded by the county council. This may depend on how well the collaboration between the county council and municipality works, but there may be other, multiple, causes.

Only 58% of the municipalities report that they have procedures in place to coordinate rehabilitation with the county council, generally or specifically for stroke. The National Board of Health and Welfare's regulation (SOSFS 2007:10) states that the county council and municipality must jointly take the necessary measures to coordinate their rehabilitative care services. The coordination procedures should comply with the regulations. For instance personnel responsible for coordination should be appointed by name, and municipalities and county councils should also ensure that resources are available for successful coordination of activities to take place. There are also instructions on collaboration at admission and discharge of patients into/from hospital care (SOSFS 2005:27) and, according to these, county council and municipalities must establish proper arrangements for care planning before a patient is discharged. They must also have procedures in place for how they transfer information to one another.

In the National Board of Health and Welfare's survey of stroke units, 28% reported that there was no joint plan in place for collaboration between the stroke unit and the municipality which is responsible for stroke care after hospital care. Neither do all municipalities and county councils appear to agree that they have a collaboration plan or procedures for collaboration. Only in 44% of municipalities are responses from both stroke units and municipalities consistent. This indicates that many collaboration plans or procedures are not used since at least one party is not aware of any current plans or routines. In the municipalities where stroke units and municipalities both reported having joint procedures in place, patient outcome as illustrated by several indicators is better than in the other municipalities.

Only a small proportion of the municipalities indicate that they have a care programme or similar to guide rehabilitation after stroke. Such care programmes can provide staff with support and help in their daily work, as well as contributing to more equitable and good quality rehabilitation. If care programmes are based on scientific knowledge, the resources devoted to rehabilitation after strokes will give good effect, enabling high levels of quality and efficiency in operations.

Improve treatment in the acute phase

The National Board of Health and Welfare expects that health care providers:

- Increase the number of thrombolysis alerts for suspected stroke cases (A02).
- Reduce the time elapsed between arrival at hospital and administration of thrombolytic therapy (A03, A03b).
- Admit more stroke patients to designated stroke units (A06).
- Admit more stroke patients directly to designated stroke units (A07).
- Perform a swallow test for more stroke patients upon their arrival at hospital, as well as document that test have been made (A08).

In most of the county councils, the proportion of thrombolysis alerts is low (A02). A thrombolysis alert means that the ambulance alerts the receiving hospital that a patient with suspected stroke is about to arrive. With improved procedures for emergency thrombolysis alerts increases the chances of rapid and effective treatment of the patient upon arrival at the hospital.

In many hospitals, patients have to wait for a long period between arrival at the hospital and the initiation of thrombolytic treatment (A03, A03b). The aim should be that thrombolytic treatment should begin as soon as possible if the patient meets treatment criteria for thrombolysis. Today, the median waiting time is longer than one hour, which means that half the patients have to wait longer than that. The National Board of Health and Welfare believes that the results could be significantly improved.

The proportion of patients treated in designated stroke units (A06) and the proportion of admissions directly to stroke units (A07) has increased in recent years. Nevertheless, the comparisons show that there are relatively large differences between county councils and between hospitals when it comes to admission to designated stroke units. In addition, the proportion is too low in the country as a whole. There is also evidence that fewer older people receive care in stroke units, which is contrary to the recommendations in the National Guidelines. The National Board of Health and Welfare deems it possible to increase the proportion of patients cared for in designated stroke units in the future, and that more patients can be directly admitted to stroke units.

To undertake a simple swallowing test with water on patients who are diagnosed with stroke (A08) is a simple and effective way of assessing the risk of aspiration meaning that the patient might inhale food or drink into their airways due to an impaired swallowing reflex. This is a high priority measure according to the National Guidelines, but differences in practice in the country are considerable. The National Board of Health and Welfare believes that all stroke patients should do a swallow test as long as they are conscious and fit enough to do it.

Improve rehabilitation during and after hospitalisation

The National Board of Health and Welfare expects municipalities and county councils to:

- Improve rehabilitation by better compliance with the recommendations in the National Guideline in order to reduce stroke case-fatality (C01, C02, C02b, C03), reduce readmission to hospital due to cardio-vascular diseases (C04) and increase ADL independence after stroke (C05, C05b).

The proportion of dead or ADL dependent after stroke (C03) has been essentially unchanged over the last ten year period, as has the proportion who has suffered a second stroke or other cardiovascular diseases (C04). The unchanged proportion of recurring cases may be a sign that secondary prevention efforts are not sufficiently effective. The differences in results between county councils and between hospitals also suggest that results can be improved in both these areas. The National Board of Health and Welfare has also compared mortality after stroke with mortality after myocardial infarction over the same period, and can observe a certain advantage to the heart attack patients.

The proportion of patients who, without help, manage their daily living (ADL) varies greatly between municipalities (C05, C05b). At national level, the proportion is the same 12 months after stroke and 3 months after stroke, however patient functions can be improved with good rehabilitation and appropriate adjustments, especially during the first few months after the stroke.

The National Board of Health and Welfare strongly believes that mortality and ADL dependency after stroke can be reduced, as can the number of readmissions due cardiovascular disease, if county councils and municipalities comply better with the recommendations in the National Guidelines.

Increase availability of rehabilitation and assistive devices

The National Board of Health and Welfare has identified deficiencies in the compliance with:

- Section 18 of the Health and Medical Care Act (1982:763) concerning the provision of rehabilitation and assistive devices for persons who have had a stroke and who live in special housing, including short-term housing, and for those living in normal housing under the agreements that have been entered between municipalities and county councils.
- The Housing Adaption Grant Act (1992:1574) on housing adaptation grants etc.

The National Board of Health and Welfare expects municipalities and county councils to:

- Examine the differences between home-based rehabilitation and day- or team rehabilitation, and resolve any deficiencies.
- Provide women and men with day- or team rehabilitation to the same extent.

Several municipalities report that they offer no rehabilitation after stroke in spite of their statutory duty to do so. This means that people who need rehabilitation after suffering a stroke do not receive it, which is serious as this increases the risk of disability and other post-stroke symptoms. In addition, municipalities probably incur higher costs because this group need more support and help for a longer period of time.

Day- or team rehabilitation appears to perform better than home-based rehabilitation, regardless of gender and age. What is included in each rehabilitation type and who offers which form is unclear. The data collected show that there are fewer women than men who receive day- or team rehabilitation. This means that fewer women are granted the rehabilitation that leads to best outcome for patients which the National Board of Health and Welfare finds unacceptable.

There are also many people who do not receive any assessment of their need for assistive devices and housing adaptation. Among them there are also probably a number who need equipment or housing adaptation but who are thus unable to access them. Hence there are municipalities who fail in their responsibility and these shortcomings will probably eventually lead to increased need for support and help.

Improve secondary prevention

The National Board of Health and Welfare expects health care providers to:

- Treat more stroke patients aged 20–74 years with atrial fibrillation with Warfarin (B03, B03b).
- Treat more patients with statins after stroke (B06, B06b).
- Assist more people to quit smoking after stroke (B08).

Patients with cerebral infarction who also have atrial fibrillation are at increased risk of a new stroke, or some other cardiovascular illness. It is therefore vital that these patients are treated with the blood thinning drug, Warfarin, in order to reduce the risk of further blood clots (B03, B03b). The comparisons in this report show that the proportion of stroke patients with atrial fibrillation in the age group 20 to 74 years treated with Warfarin is too low in relationship to a reasonable level of approximately 70%. The variation across the country is also unacceptably large. The National Board of Health and Welfare regards it important that a larger proportion of this group be treated with Warfarin in the future.

The National Board of Health and Welfare also recommends statins after stroke to reduce the risk of recurrence of stroke or other cardiovascular diseases (B06, B06b). The proportion in the country that receives this treatment is too low. In addition the prescription of statins varies considerably, mainly between hospitals. The conclusion is that most county councils and hospitals should increase the proportion of patients treated with statins.

Patients who have smoked before their stroke should receive support and help to quit smoking as this reduces the risk of suffering a second stroke or other cardiovascular illnesses. Patients need assistance to stop smoking very soon after they become ill, as this increases the chances of them succeeding (B08). This performance assessment shows that less than half the patients who smoked before their stroke had stopped 3 months after their stroke. Variations between county councils are also considerable. County councils can improve their smoking-cessation activities and the National Board of Health and Welfare reckons that a higher proportion of stroke patients should then be able to give up the habit.

Respond to the need for carotid surgery

The National Board of Health and Welfare expects health care providers to:

- Increase the number of carotid procedures performed to meet the actual need for such surgery (E01).
- Make efforts to ensure that the waiting time for surgery for patients with symptomatic carotid stenosis does not exceed 14 days (E02).

Narrowing of the carotid arteries (carotid stenosis) increases the risk of stroke. Constrictions can produce symptoms of a transient ischemic attack (TIA) or a minor stroke, and an operation within 14 days effectively reduces the risk of a severe stroke. However, there are major differences between the county councils in how many patients undergo surgery (E01), and the variation in median waiting time for patients with symptomatic carotid stenosis is also unacceptably large between county councils (E02). Half of the county councils have a median waiting period of more than 14 days, which means that at least half of the patients have to wait longer than the recommended period. The National Board of Health and Welfare expects county councils with poor performance to increase the number of carotid operations in this patient group and reduce waiting time for this surgery.

Provide better psycho-social support and improved information to patients

The National Board of Health and Welfare expects municipalities and county councils to:

- Provide better psycho-social support and increasingly collaborate on treatments aimed at reducing the proportion of patients who are depressed (C09, C09b).
- Provide better information and more support and help to increase the proportion of persons who feel that their needs for support and help are fulfilled after hospitalisation (D02).

This assessment shows that a large proportion of persons who have had a stroke are often or always depressed 12 months after their stroke (C09b). This proportion is also slightly higher 12 months after stroke, than 3 months after stroke. Depression may reduce the success of rehabilitation, however rehabilitation results may also affect people's mood. Psycho-social support and medical treatment can reduce the occurrence of depression after stroke. In the long run, these activities probably also improve the group's health and well-being in general which means that fewer people need support and help and more people can return to work.

The proportion of persons who feel that their needs for support and help are fulfilled 3 months after stroke (D02) should be increased, for example by providing information that encourages reasonable expectations, or providing more support and help. The variations between municipalities indicate that this is possible.

Provide more information and support to relatives

The National Board of Health and Welfare expects municipalities to:

- Examine how they offer and provide support to relatives according to Chapter 5, Section 10 of the Social Services Act (2001:453).

The National Board of Health and Welfare expects municipalities and county councils to:

- Provide relatives with more information, particularly about stroke and how it develops, specific treatment therapies and opportunities for support to families and relatives.

Relatives and family members are an important group in this context and their inputs are often extensive and critical to good rehabilitation results. Stroke units state that there are procedures to inform both patients and relatives about stroke, recovery after stroke and the support and help available, but many relatives still feel they need more knowledge. In particular they would like more knowledge about stroke as a medical condition and how it progresses, as well as knowledge of specific treatments and the provision of assistance for relatives.

Since 1 July 2009, municipalities must offer support to people who care for relatives who are chronically ill or elderly, as well as family members who support a relative with disabilities (Chapter 5, Section 10 Social Services Act). A very small proportion of the families feel that they have received any support from the municipality.

Improve opportunities to monitor and evaluate stroke care

The National Board of Health and Welfare expects:

- registration of diagnostic codes and interventions in stroke care to be carried out according to established classifications and codes.

Stroke cares organisation varies between county councils and hospitals and there is also a variety of practices on how care providers register, for example, secondary diagnoses and interventions. This makes it difficult to compare the data for consumption and costs of stroke care between county councils and between hospitals. A more uniform registration of diagnoses and interventions would facilitate comparisons of stroke care consumption and its costs.

What is Stroke?

Stroke is a leading cause of adult disability and the third most common cause of death, after heart attack and cancer in Sweden. Of all chronic illnesses, stroke is the most impactful. Stroke is the result of either an interruption in the blood flow to one part of the brain (ischemic stroke) or bleeding into and around the brain due to a ruptured artery (intracerebral or subarachnoid haemorrhage). Approximately 85 per cent of strokes are ischemic [1]. Intracerebral bleeding occurs in 10 per cent of the cases and usually associated with hypertension. Both types of stroke result in a lack of oxygen in the affected part of the brain causing brain damage of varying degree.

Stroke may be regarded as a brain attack – it occurs suddenly and symptoms may be temporary. The primary warning signs are sudden loss of speech or vision, or weakness in the face, arm or leg. Other symptoms include sudden, severe and unusual headache or sudden loss of balance, often accompanied by one of the other warning signs. Preceding a major stroke, some people experience fleeting stroke symptoms called transient ischemic attack or TIA. Ten per cent of those who have had had a TIA risk getting a stroke within two days [3].

Every year in Sweden approximately 30,000 persons have a first or recurrent stroke. More than 80 per cent of them are over the age of 65 years, and in this age group more men than women fall ill. In general, men are five years younger than women when they get a stroke. In 2009, the average age of stroke patients was 73.4 years for men and 78.3 year for women. In addition, 8,000 persons experience a TIA yearly [1].

The most common cause of death in Sweden is cardiovascular diseases such as acute myocardial infarction (AMI) and stroke [4]. In 2009, 37 per cent of all women and 40 per cent of all men died of cardio-vascular diseases. Between the years 1987 and 2009 mortality from stroke dropped. For women the decrease was from 150 to 101 deaths per 100,000 inhabitants. The figures for men were, from 183 to 128 deaths per 100,000 inhabitants. However, during the same period the reduction in mortality from stroke was more modest than the reduction in mortality from ischemic heart diseases such as AMI and heart failure.

In 2008, cardio-vascular diseases including stroke accounted for approximately one-fourth of all deaths within Europe [5]. Stroke alone amounted to 10 per cent of the mortality, though the figure varied between countries. On average 64 women per 100,000 inhabitants and 82 men per 100,000 inhabitants died from stroke that year. Bulgaria, Rumania, Latvia, Lithuania, Slovenia and Hungary had the highest stroke mortality among both men and women. Lowest stroke mortality was found in Switzerland, France, Iceland and the Netherlands. The equivalent figures for Sweden were 38 women per 100,000 inhabitants and 46 men per 100,000 inhabitants. Consequently, Sweden had lower stroke mortality than the European average, and the mortality was closer to that of the countries with the lowest mortality within Europe.

Over the time period 1994 to 2008, stroke mortality has declined in almost all European countries, with Slovakia and Poland being the exceptions. The decline is most notable since the year 1999. During this period mortality from stroke has declined 50 per cent or more in Italy, Estonia, Portugal, Austria, Germany and the Czech Republic.

However, international comparisons of mortality must be interpreted with caution as the quality of the causes-of-death statistics varies between countries. The above figures cannot be compared with the data presented in the rest of this report as the OECD data includes more diagnosis regarding illness in the brain than are included in this assessment of the quality and efficiency of Swedish stroke care.

Stroke Care

Stroke often occurs suddenly and unexpectedly. It is common for those who suddenly become ill to experience a depressed level of consciousness and paralysis symptoms. However, sometimes symptoms are less clearly observable and hence difficult to interpret. A person can experience weakness in an arm or exhibit speech difficulties. Regardless of symptoms, it is important that the person is treated quickly. Therefore the awareness of the signs and symptoms of stroke among the general population is as important as the efforts of the paramedics.

Emergency care primarily aims at limiting any brain damage that may result from stroke and consequently reduce the risk of death or disability. However, it is also important to begin rehabilitation as early as possible, since the interventions have more impact in the early stages. This rehabilitation may take place either at the hospital while the patient is admitted or in the patient's own environment which is known as home-based rehabilitation.

When emergency treatment has been completed, the patient is discharged from hospital. Many return to their own home with the help and support of the municipality and county council, but some need additional care in municipal special housing or the equivalent. Rehabilitation must, however, continue after discharge so that the individual concerned will enjoy all possible opportunities to live a good life.

Acute care

Pre-hospital emergency care when stroke is suspected

A person who has a stroke must get professional care as soon as possible, but for this to happen someone must call an ambulance. This in turn presupposes that the general population knows how stroke is expressed and that a person with stroke symptoms must access health care services immediately. During the past year county councils launched a campaign to inform the public about stroke and stroke symptoms in order to reduce the period between symptom onset and arrival at hospital. This campaign is currently on-going.

Another important factor in the continuum of care is the action taken by the rescue services alarm centre when a stroke is suspected. It is possible to cut the time period from onset to medical care by placing a high priority on the ambulance alert. Ambulance staff can, in turn, speed up the processing by triggering a thrombolysis alarm, that is, warn the receiving hospital that a person with suspected stroke is about to arrive. The hospital can then take some preparatory steps to cut waiting time for clot-dissolving therapy or other emergency intervention. Ambulance service is a key player in the emergency phase of the disease.

Arrival at hospital

Initial medical examination and treatment at hospital will vary depending on how the hospital has chosen to organise its stroke care. In some hospitals there are procedures for transporting the patient directly from ambulance to X-ray or a designated stroke unit in order to start treatment as rapidly as possible. At other hospitals the patient is first examined in the emergency department before going to X-ray. The organisational form depends on several factors, but the important thing is that treatment starts rapidly and safely, as well as in a structured manner.

In order to provide optimal treatment, early diagnosis is essential. Stroke can be attributed to either bleeding in the brain or a blood clot and therefore diagnosis must be established by means of an X-ray, most commonly a CT scan, before the correct treatment can be given.

Acute thrombolytic therapy

In the emergency phase, clot-dissolving therapy called acute thrombolytic therapy or thrombolysis may have a significant effect. Acute thrombolytic therapy involves injecting blood clot inhibiting drugs into the bloodstream under close supervision. The drug helps to break down the blood clot that is blocking the blood vessel in the brain. This allows the blood supply and the oxygenation to brain cells to be restored, and brain damage can be minimised or avoided completely. However, there are some important prerequisites. Before the patient can receive thrombolytic therapy, she or he must be diagnosed using CT scans or any equivalent examination to ensure that the stroke is not due to haemorrhage in the brain. Consequently, patients may not receive thrombolytic therapy directly in the ambulance. If it is found that the stroke has been caused by a blood clot (cerebral infarction) thrombolysis is suitable, provided the patient meets a number of criteria. In addition, no more than 4.5 hours should have passed from symptom onset to administration of acute thrombolytic therapy. For best outcome treatment should be given as early as possible after symptom onset.

Thrombolytic therapy increases the risk of brain haemorrhage. This risk is highest in elderly patients, therefore the drug used is not recommended for patients over the age of 80 years. In some cases there may be good reasons to treat elderly patients, but only after a particularly thorough medical assessment by a physician.

In the National Guidelines for stroke care [3], thrombolytic therapy for patients up to 80 years old with cerebral infarction has been allocated priority 1 (highest priority) on a 10-point scale if the treatment is given within 3 hours. It has priority 2 if it is given 3 to 4.5 hours after symptom onset.

In-patient care

Admission to designated stroke unit

According to the National Guidelines, patients with stroke should be admitted to and treated at a designated stroke unit in order to provide them with good care. A stroke unit is a clearly-defined, identifiable entity in a hospital where only (or almost exclusively) stroke patients are treated. A designated stroke unit should for example have personnel with expertise in stroke and rehabilitation, multidisciplinary teams with specific competencies, defined care programmes for registration and for interventions in the acute phase and in the rehabilitation phase, and clear procedures for disseminating information to patients and their relatives. Patients treated at a designated stroke unit enjoy a higher rate of survival and better ability to cope with activities of daily living (ADL) even in the longer term [6-8]. Care in a designated stroke unit results in a positive outcome regardless of the patient's gender or age, or the severity of the brain damage. The National Guidelines [3] allocate admission to designated stroke units highest priority (priority 1 of 10).

Rehabilitation in the acute phase

Purposeful rehabilitation is a very important measure, both in the acute and in the subsequent stage of stroke. The purpose of rehabilitation is for the patient to regain or relearn the functions that have deteriorated or disappeared as a consequence of brain damage. The sooner rehabilitation begins, the more opportunities the patient will have to regain important body functions. Patients with moderate or mild residual symptoms of stroke may leave hospital relatively early and receive their rehabilitation at home instead. Through home-based rehabilitation, patients gain opportunities to hone their functions in the home environment and this probably generates results as good as if the patient had stayed in hospital and received rehabilitation there. If home-based rehabilitation is to replace rehabilitation in hospital, it must be coordinated or provided by a special, multidisciplinary rehabilitation team which also includes physicians. The National Guidelines for stroke care award a high priority (3 of 10) to early hospital discharge in combination with home-based rehabilitation for patients with mild or moderate symptoms. Rehabilitation in hospital also has a high priority according to the Guidelines, priority 2 on the 10-point scale [3].

Discharge from hospital

When the acute phase of the illness is considered to be over, it is time for the patient to be discharged from hospital. Many return to their own accommodation with or without support, but some need additional assistance. They may then be eligible for short-term accommodation or a special housing under the auspices of the municipality. In order to determine the correct level of assistance to be provide after discharge, there must be a written plan in place governing collaboration on patient admission into and discharge from hospital care (Chapter 2, Section 3

SOSFS 2005:27). These plans must specify how and what care is planned for after discharge and how information should be transferred between the different care providers. At a specific planning meeting, decisions must be taken as to the level of care and assistance the person needs after discharge from hospital.

Rehabilitation and assistive devices

After discharge from hospital, rehabilitation should continue in the primary health care services which can be provided both by the county council and the municipality. With regard to persons in special housing, including short-term accommodation, the municipality is responsible for providing rehabilitation and assistive devices. If the person lives in normal housing, either the county council or the municipality are responsible for their rehabilitation and any equipment they may need depending on the relevant agreement between the county council and the municipality in accordance with Section18 of the Health and Medical Care Act (1982:763). The county council is always responsible for all medical procedures performed by physicians.

The municipality and county council should jointly develop procedures to coordinate rehabilitation efforts for persons with major and long-term needs of health care and social services (SOSFS 2007:10). Each person should be allocated a named coordinator responsible for developing a coordination plan. These routines must also ensure that these coordinators enjoy the resources required to be able to carry out this task. According to regulations, both the municipality and the county council should consider the person's overall needs, no matter which organisation he or she initially comes into contact with. Different providers and individual professionals are, however, responsible for their respective rehabilitation measures and services provided.

Indicator-based Comparisons

Process and outcome indicators – a selection

The performance assessments made – one on stroke care in county councils and one on stroke care in municipalities – contain 55 indicators for stroke care [1-2]. About 35 of these reflect in-patient care provided by county councils, while more than 20 indicators describe the outcome of rehabilitation after hospitalisation. Rehabilitation measures can occur under the auspices of the county council within specialised care or within primary care, or under the auspices of municipal health and medical care system. This chapter highlights a selection of these indicators, namely those underlying the recommendations.

The indicators are divided into five categories:

A. Acute care
B. Secondary prevention
C. Outcome of stroke care
D. Patient satisfaction
E. Carotid surgery

The letter in the name of the indicator shows which category the indicator belongs to. Thus Indicator C05 falls into category C – Outcome of stroke care. Some indicators are monitored at two points in time: 3 months and 12 months after stroke. In order to distinguish between these indicators, the letter b has been added to show the second follow-up point, for example, C05b.

Indicators are presented in graphical format and, where relevant, developments over time are shown at national level. The indicators applying to county council stroke care show results at county council level while those reflecting rehabilitation after in-patient care show data at county level with the variations between the relevant municipalities.

There are several factors that may confound results and make them difficult to interpret, for example differences in age structure and levels of consciousness at the arrival to hospital. In order to increase comparability, the National Board of Health and Welfare has for some indicators standardised for age or level of consciousness where such factors may influence results.

Data was not collected on primary health care provided by county councils, as there is no register-based data available on such care. However, some of the indicators mirror care provided by both the municipal health and medical care services and the primary health care services provided by the county councils. Annex 3 shows all the indicators included in the assessment clearly marking if the indicators reflect stroke care provided by the municipality or the county council, or both.

Acute care

Time elapsed between arrival at hospital and administration of acute thrombolytic therapy (A03)

When a patient with a suspected stroke arrives at hospital, it is important to make an accurate diagnosis quickly by clinical examination and CT scan of the brain. There is a clear time limit of 4.5 hours after symptom onset that it is possible to administer acute thrombolytic therapy (thrombolysis). Consequently for this treatment to work well it is vital to reduce any unnecessary delays in the acute phase. Patients should receive thrombolytic therapy as soon as possible and always within an hour after arriving at the hospital.

Results

Between 2003 and 2009, the median time between arrival at hospital and administration of acute thrombolytic therapy decreased by 15 minutes to 66 minutes. In recent years, however, the curve has leveled out. In 2009, 40% of patients were treated with thrombolysis within 60 minutes from arrival, and the proportion of patients treated within 30 minutes was only about 5% throughout the period. Increasingly, treatment is given within 45 minutes which is an improvement of 11.5 percentage points since 2003.

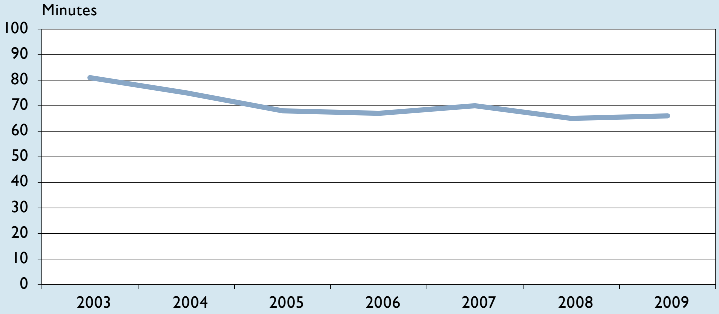
There was a 56 minute difference between the shortest and longest median time in the various county councils. Four county councils had a median door-to-needle time of more than 90 minutes. There were also substantial differences between county councils in the proportion of patients receiving acute thrombolytic therapy within 30 minutes. In three county councils, the proportion treated within 30 minutes was more than 12%, while in 2009 there were six county councils who did not start a single thrombolysis during the first half hour the patient was at the hospital.

Conclusion

The results show that it takes too long for patients to receive thrombolytic therapy. The time delay varies widely between county councils and this is probably due to the fact that county councils have different processes for emergency care of stroke patients. Only a small percentage of patients receive thrombolysis within 30 minutes of arrival at the hospital and this proportion is the same as seven years ago. More county councils should be able to start treatment much more rapidly than they do today.

Figure A03
Sweden

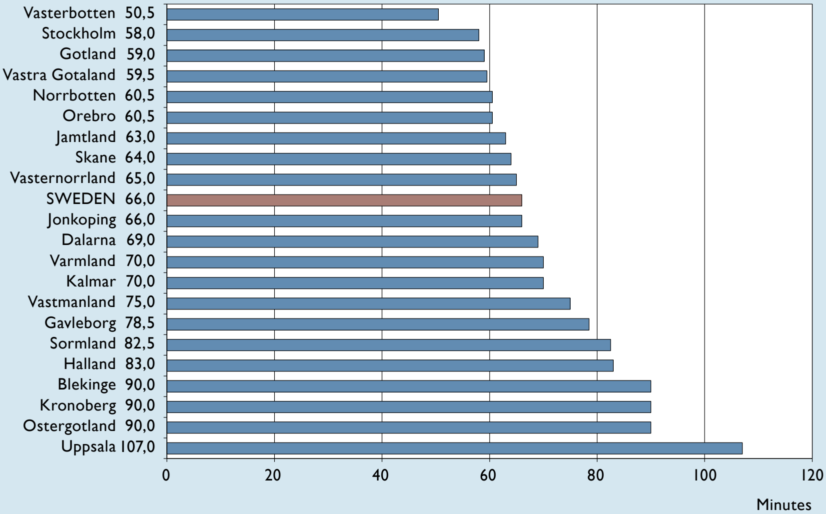
Median door-to-needle (arrival to administration) time for acute thrombolytic therapy



Source: Swedish Stroke Register

Figure A03
County Council

Median door-to-needle (arrival to administration) time for acute thrombolytic therapy, 2009



Source: Swedish Stroke Register

Admission to designated stroke unit (A06)

Patients who have suffered a stroke should be cared for at a stroke unit, which is awarded a high priority in the National Guidelines. Stroke units are medical wards organised primarily to nurse patients diagnosed with stroke. They have staff with expertise in stroke treatment and care inputs are conducted in multidisciplinary teams with a specific composition of employees. Stroke units also work according to established care programmes and clearly-stated procedures. There are studies which have shown that people who are nursed at stroke units have better survival rates and better functional ability post stroke. These positive effects apply to all stroke patients across the entire age, gender and brain injury severity range. This measure has the highest priority (priority 1 of 10) in the National Guidelines.

Results

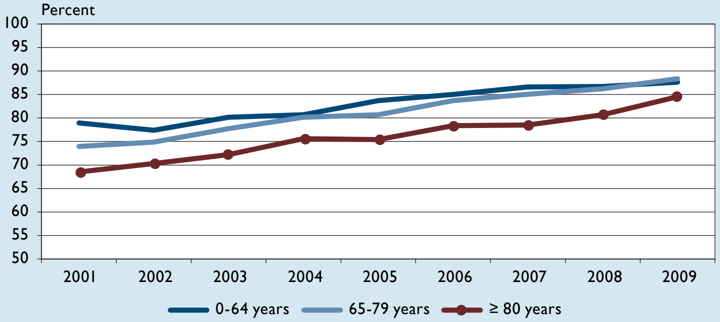
The proportion of stroke patients admitted to designated stroke unit has increased steadily over the past ten years and was 87% in 2009. The increase was 14 per cent between 2001 and 2009 with a slight difference between women and men. However, there were fewer patients over the age of 80 years at stroke units compared with other age groups. This difference has narrowed somewhat over the last few years. The variation between county councils was 12 percentage points in 2009 for men and women combined, but slightly higher for women: about 15 per cent. The difference was greater between hospitals, a difference of 42.5 percentage points between the highest and the lowest. Several of the country's major hospitals had a relatively low proportion of stroke patients admitted to stroke units which may be due to a higher proportion of stroke patients who instead needed treatment in an intensive care unit.

Conclusions

The proportion of patients admitted to a designated stroke unit has increased in recent years. This measure has a high priority in the National Guidelines and consequently the aim should be that more than 90% of stroke patients receive such care. Currently, only one third of hospitals achieve this level. In addition, fewer of the oldest patients are treated in stroke units, which is not consistent with the recommendations in the Guidelines. The comparison concerns data from 2009, and the situation might be different today as an increase in the number of places in stroke units can rapidly change the results for individual hospitals.

Figure A06
Sweden

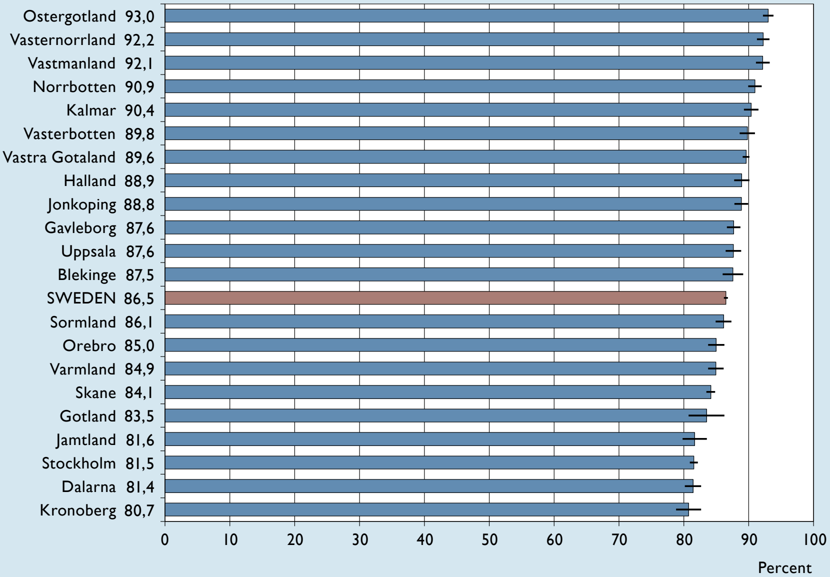
Proportion of stroke patients admitted to designated stroke unit during any part of hospital stay



Source: Swedish Stroke Register

Figure A06
County Council

Proportion of stroke patients admitted to designated stroke unit during any part of hospital stay, 2009



Source: Swedish Stroke Register

Admission directly to designated stroke unit (A07)

Designated stroke units provide higher quality care for people who have suffered a stroke and consequently patients should be admitted directly to the stroke unit on arrival at hospital. In the National Guidelines, this indicator is formulated as follows: “Proportion of patients with stroke who initially spend part of the acute care period at a hospital unit other than a designated stroke unit.” In this comparison, the National Board of Health and Welfare changed the definition of the indicator to “Proportion of patients with stroke admitted directly to a designated stroke unit on admission to hospital.”

Results

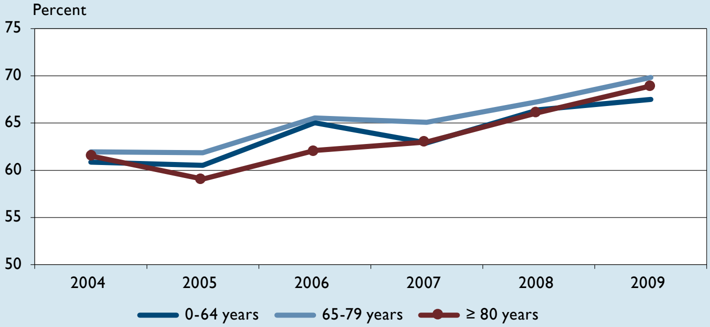
The proportion of stroke patients admitted directly to a designated stroke unit has increased over the past ten years, to 69% in 2009. In previous years there was also a difference between women and men which has now basically disappeared. The proportion of direct admissions has increased more in the age group 80 years and older than in other age groups over the past three years. In 2009, the proportion admitted directly to stroke units was higher in the oldest age group than in the youngest age group. In the county council comparison there was a difference of 23 percentage points between the highest and the lowest proportions. No county council achieved more than 80% and six of them did not reach even 65%.

Conclusions

Most hospitals should be able to admit 80% of stroke patients directly to the designated stroke unit. This result has improved in recent years but the national average is still a little below the desired level. No county council achieves 80% and there are considerable differences between county councils and between hospitals.

Figure A07
Sweden

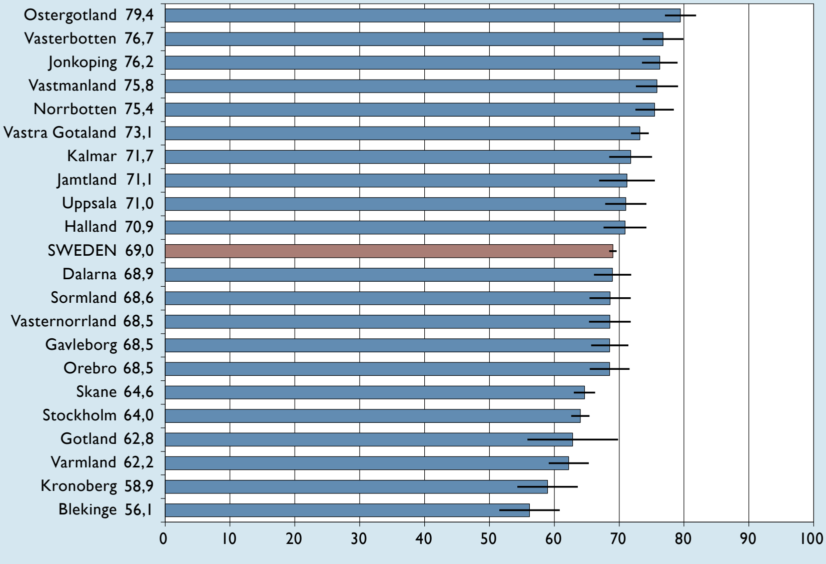
Proportion of stroke patients admitted directly to designated stroke unit



Source: Swedish Stroke Register

Figure A07
County Council

Proportion of stroke patients admitted directly to designated stroke unit, 2009



Source: Swedish Stroke Register

Documented swallowing assessment upon arrival to hospital (A08)

Many persons who suffer a stroke experience a reduced ability to swallow. Food can then enter the trachea which, in a worst case scenario, could lead to respiratory failure or severe pneumonia. Upon admission to hospital, staff should routinely assess the patient's swallowing ability with a simple swallow test with water. This measure has the highest priority (priority 1 of 10) in the National Guidelines.

Results

In the nation as a whole, the proportion of swallow tests increased from 69% in 2007 to 78% in 2009. There were no clear age or gender differences. The proportion of patients undergoing the swallow test was 67–91% in the county councils – a difference of 24 percentage points between highest and lowest. The figures to the right in the diagram depict the proportion of patients who on arrival at the hospital were candidates for a swallow test, that is, those who were conscious. The results indicated no significant gender differences although there were some slight differences between men and women in some county councils, but results went in both directions.

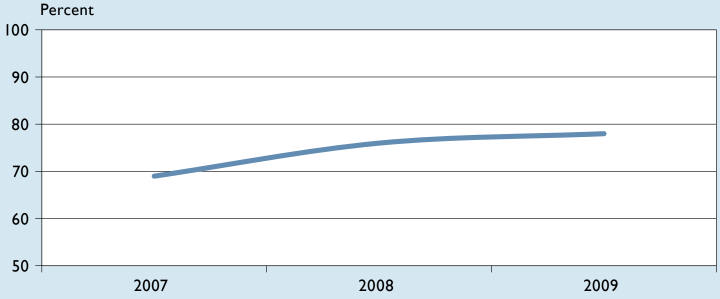
During the same period, the variation was greater between hospitals with a range from 36% to 100%. At 48 of the in total 76 hospitals, more than 80% of patients underwent a documented swallow test. On arrival 86–97% of patients were conscious.

Conclusions

All patients who are conscious on arrival at hospital should undergo a swallow test. This test should be documented so that all staff involved is aware of the results. Consequently the majority of county councils and hospitals could test up to 90% of their patients. At some hospitals the proportion of those tested is still low, and results for the nation as a whole do not reach the target set in the National Guideline. Hospitals that test fewer than 80% should seek to improve their routines.

Figure A08
Sweden

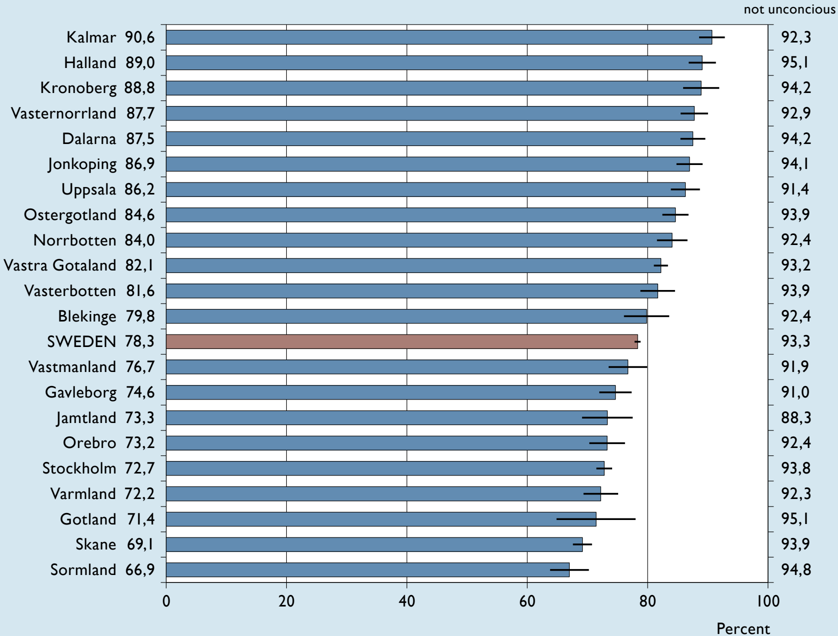
Proportion of stroke patients having had their ability to swallow assessed upon arrival to hospital



Source: Swedish Stroke Register

Figure A08
County Council

Proportion of stroke patients having had their ability to swallow assessed upon arrival to hospital, 2009



Source: Swedish Stroke Register

Secondary prevention

Warfarin treatment for patients with atrial fibrillation (B03)

Patients with atrial fibrillation who get an ischemic stroke will require treatment with Warfarin (anti-platelet medication) as secondary prevention to reduce the possibility of a new stroke. Treatment with Warfarin does, however, bring some risks especially for elderly patients. Consequently the age group 20–74 years old is the focus of this comparison. Many of these patients have an increased risk of bleeding which is a contraindication for this treatment. However the trend in many county councils shows that it is possible to treat two-thirds or more of the patient group with atrial fibrillation after stroke. This measure has high priority in the National Guidelines (priority 2 of 10).

Results

In the nation as a whole, 60% of current patients in the younger age groups were treated with Warfarin at time of discharge in 2009. The proportion of those treated with Warfarin has increased marginally in recent years and there seems to be no gender difference in this group. In the elderly population (aged 75 and older) the increase over time is more significant, and the proportion treated now stands at 31%. In this age group however, a significantly smaller proportion of women are treated with Warfarin. One explanation may be that women are overrepresented among the oldest in the group or that there are more contraindications in this age group.

There was considerable variation between county councils, 42–86% in 2008 in the younger patient group. Four county councils reported a treatment rate of over 70%. Results were uncertain as they were based on relatively few patients, consequently gender-segregated data could not be presented.

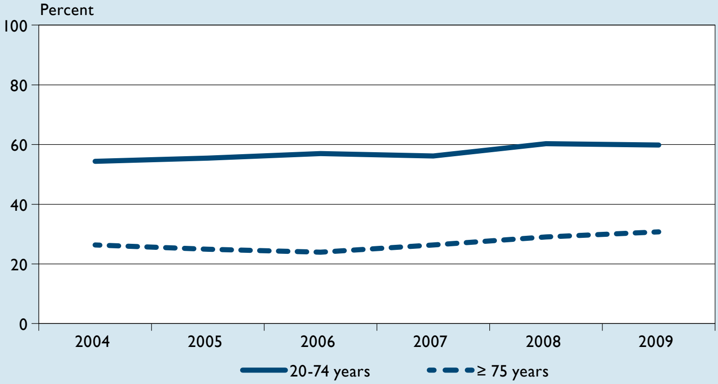
After 12–18 months, the proportion of patients treated with Warfarin was somewhat higher, 68% in the younger age group and 38% in the elderly population. The reason might be that Warfarin sometimes is prescribed in out-patient care after discharge or it might be because premature death is more common among those not being treated with Warfarin.

Conclusions

In age group 20–74 years old, approximately 70% of patients with atrial fibrillation ought to be candidates for Warfarin treatment. In 2009, there were large variations between county councils and those with a low proportion should examine their treatment practices and fully utilise this opportunity to prevent stroke recurrence.

Figure B03
Sweden

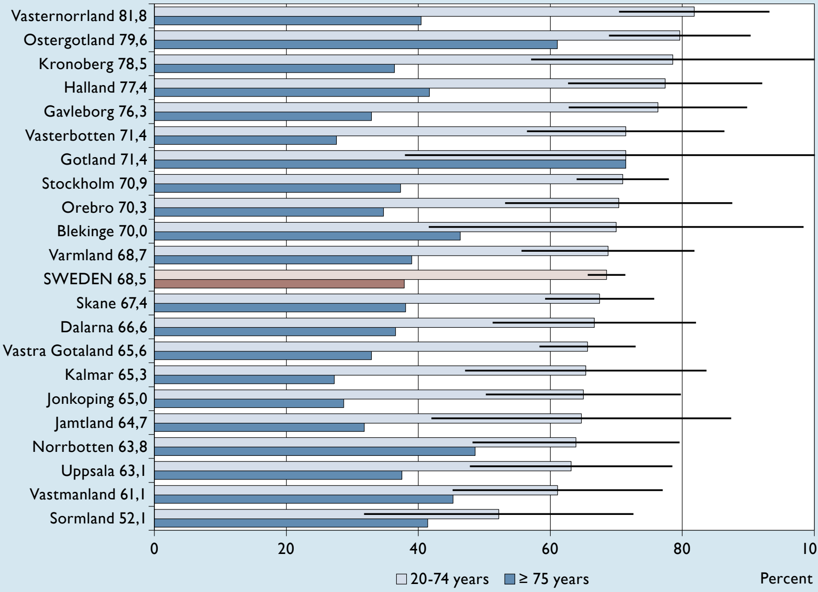
Proportion of stroke patients with atrial fibrillation prescribed warfarin at discharge



Source: Swedish Stroke Register

Figure B03b
County Council

Proportion of stroke patients with atrial fibrillation prescribed warfarin 12-18 months after hospitalisation, 2008



Source: Swedish Stroke Register, Prescribed Drug Register

Lipid lowering treatment after stroke (B06, B06b)

Lipid lowering treatment with statins has proven effective as secondary prevention after a cerebral infarction. In the National Guidelines, the measure has been awarded high priority (priority 3 of 10), and in principle all patients with cerebral infarction should receive generic statins. However, there are risks with this treatment and some patients experience side effects. Primarily, elderly patients' muscles are affected. Statins may also interact adversely with other drugs. When simplifying the medication list of patient taking many drugs, poly-pharmacy, it is common to refrain from statins.

Results

In 2009, at national level, almost 60% of patients were being treated with statins when they were discharged (B06). However this proportion has increased by 28 percentage points over the last five-year period. Men were treated to a greater extent than women; there was a difference of five percentage points between the genders. This gender difference might be due to a higher proportion of men being treated with statins before their stroke as medication for heart disease. In the 80 years and older group, the proportion of patients treated with statins was lower than for other age groups, which was not especially surprising. This was probably due to the risk of muscular side effects being high or wishing to avoid poly pharmacy.

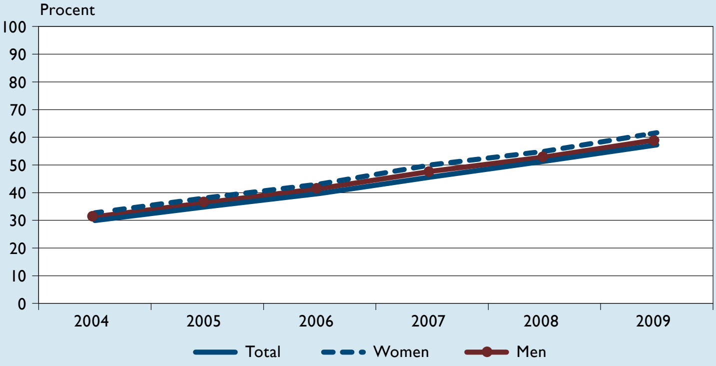
At county council level the proportion of patients treated with statins was 40–70% – a difference of 30 percentage points between highest and lowest scores. In six county councils the proportion of treated was less than 50%. Some county councils also showed major differences between men and women: at most the difference was 13 percentage point . Even at hospital level there were significant variations: over 50 percentage points during the period 2007–2009. When the prescription of statins was monitored 12–18 months after discharge from hospital, the proportion of patients treated was essentially unchanged in the nation as a whole. The differences between men and women also remained.

Conclusions

The proportion of patients treated with statins has increased in recent years, but there are still major variations between county councils and particularly between hospitals. There are also some gender differences worth noting. In order to comply with the Guidelines, most county councils should increase their prescription of statins for patients with cerebral infarction.

Figure B06
Sweden

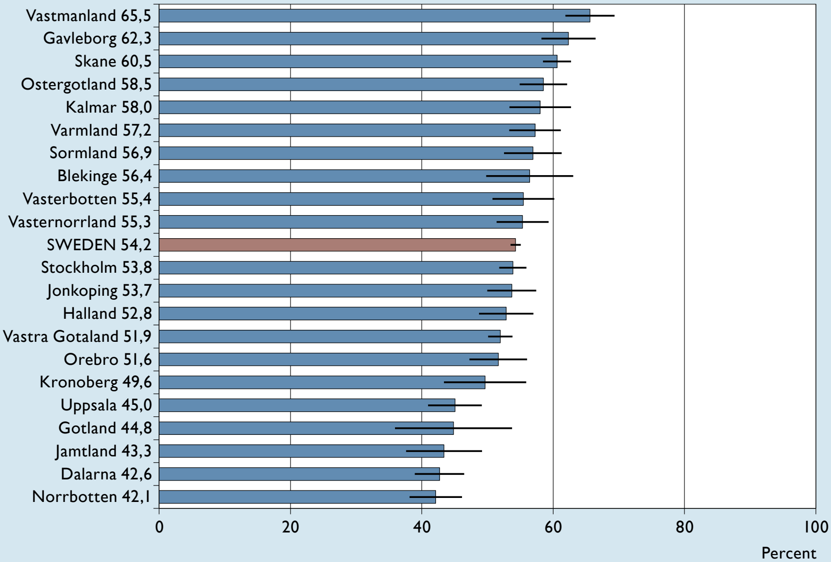
Proportion of stroke patients prescribed lipid-lowering treatment at discharge



Source: Swedish Stroke Register

Figure B06b
County Council

Proportion of stroke patients prescribed lipid-lowering treatment 12-18 months after hospitalisation, 2008



Source: Swedish Stroke Register, Prescribed Drug Register

Smoking cessation after stroke (B08, B08b)

After a stroke, patients who smoke need help to stop smoking. This is an important and effective measure to prevent a recurrent stroke or any other cardiovascular disease. Of all the patients who suffered strokes in 2009, almost 20% were smokers. Actually, all patients should quit smoking, but this is not really a realistic goal.

Results

In the nation as a whole, 45% of smokers in 2009 reported that they had quit smoking three months after their stroke. This is a marginal decrease since 2004, and the trend is the same regardless of gender or age group. Women succeed to a higher extent than men to give up smoking, and older persons were more successful than younger ones.

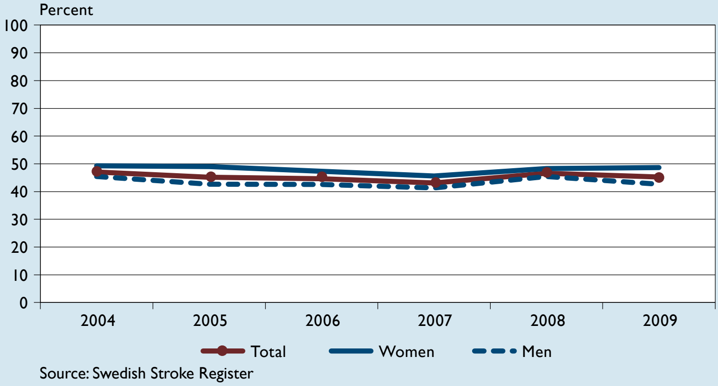
The proportion of patients who had stopped smoking three months after their stroke varied between county councils. The variation in 2009 was 29–59%, which is a difference of 30 percentage points between highest and lowest scores. At hospital level the difference was more than 30 percentage points for the period 2007–2009. When smoking cessation was monitored 12 months after stroke, the proportion who had stopped smoking was slightly lower, which might suggest that some persons had started smoking again (B08b). The proportion of smokers was then 4.5%.

Conclusions

County councils are able to affect the results of this indicator by providing appropriate smoking cessation interventions. The proportion of persons who smoke after stroke has not declined over the past five years. The current national average of 45% of smokers having quit smoking three months after their stroke is slightly lower than the corresponding figures for patients who had suffered heart attacks. There are significant differences between county councils and between hospitals, which indicates that there are different routines for dealing with tobacco issues in different parts of the country. Overall, much remains for the county councils to do to assist people stop smoking after stroke.

Figure B08
Sweden

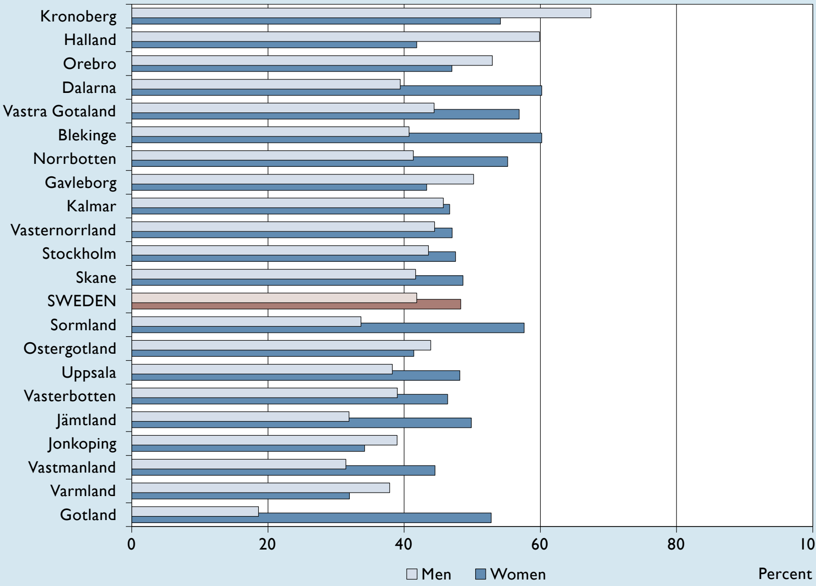
Proportion of smokers who had quit smoking three months after stroke



Source: Swedish Stroke Register

Figure B08
Women/men

Proportion of smokers who had quit smoking three months after stroke, 2009



Source: Swedish Stroke Register

Outcome of care

ADL independence (C05, C05b)

The proportion of patients who become disabled after stroke is an indication of the quality of care: both at the acute stage at hospitals and in special housing, and during the subsequent rehabilitation. In this case, disability is defined as "depending on help from others to cope with activities of daily living, ADL", or what in home care is labelled as personal care. ADL independence refers to a person who manages to dress and undress and visit the toilet without help.

Results

During the period 2001–2009, the proportion of persons being ADL independent 3 months after their stroke increased by almost 2 percentage points at the national level, and reached 79% in 2009. However, since 2006 the curve has levelled off and in 2009 the result was actually somewhat lower.

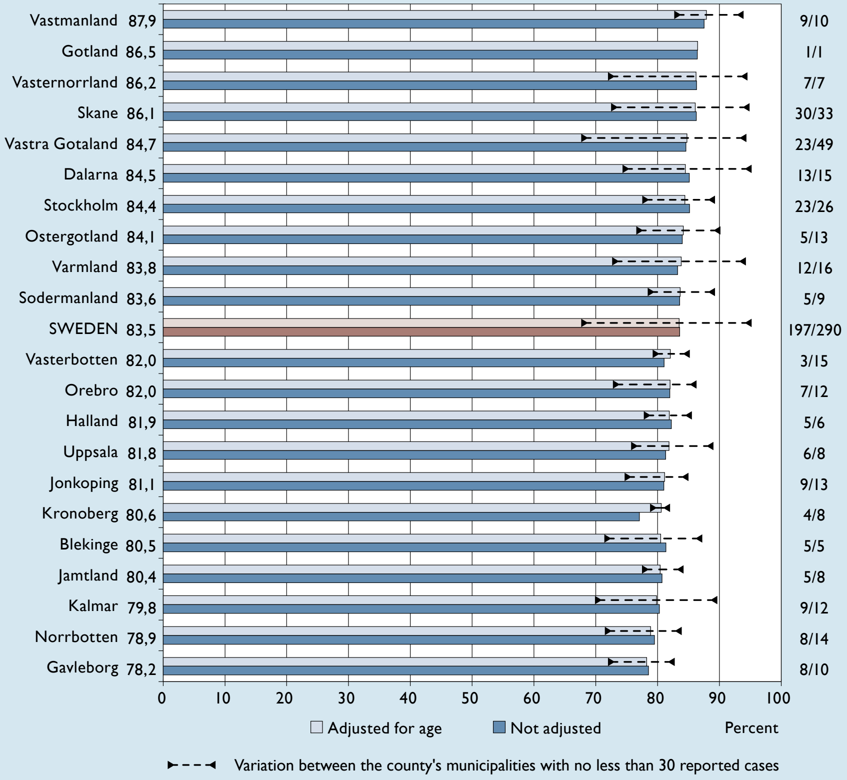
Three months after stroke, 68–95% of patients reported being ADL independent, and after 12 months the variation was 67–97% between the counties. At county level the variation between highest and lowest was smaller: 78–88% after 3 months and 77–86% after 12 months.

Conclusions

Results for the nation as a whole did not change during the period 2001–2009 and the differences between municipalities were medium. The data also shows that the results neither improved nor deteriorated between the two points in time when monitoring was undertaken. One reason may be that people become older and thus more became dependent on help with ADL. It is also likely that rehabilitation after stroke is not functioning in a satisfactory manner.

Figure C05
County

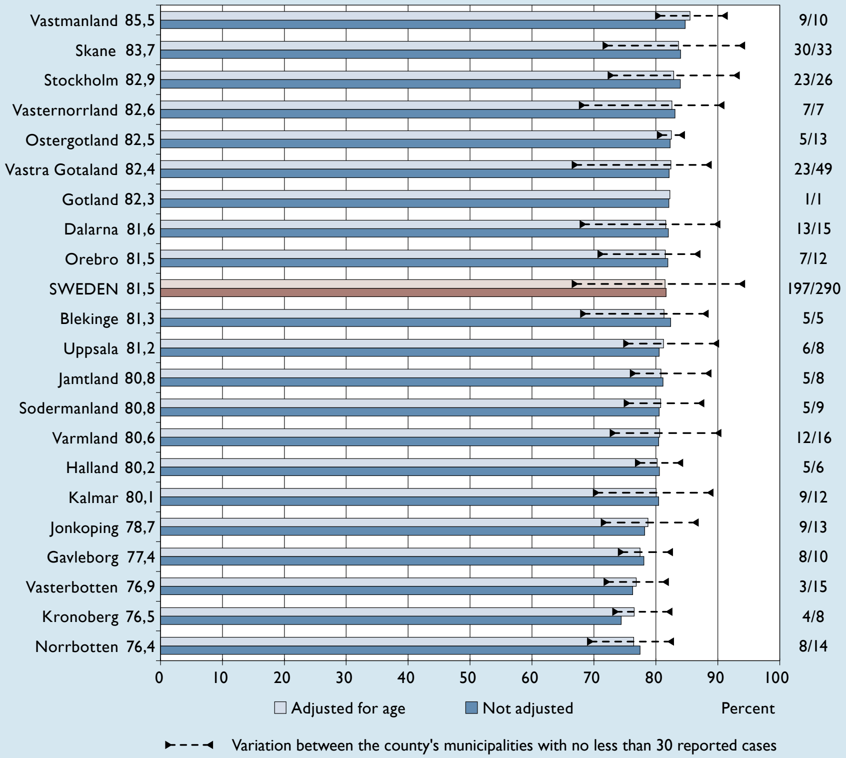
Proportion of persons who could handle their ADL independently 3 months after stroke, 2008-2009. Adjusted for age



Source: Swedish Stroke Register

Figure C05b
County

Proportion of persons who could handle their ADL independently 12 months after stroke, 2008-2009. Adjusted for age



Source: Swedish Stroke Register

Depression (C09, C09b)

People who have a stroke may also suffer from depression, partly due to the actual brain injury and partly as a reaction to the changes in their life style caused by stroke. Depression can reduce the effectiveness of the rehabilitation, but may also depend on the outcome of the rehabilitation. People who have suffered a stroke experience higher incidences of depression than the general population.

Results

During 2004–2009 there was around 13% nationally who reported that they were often or always depressed 3 months after their stroke. More women than men stated that they were often or always depressed.

The proportion varied between municipalities. Three months after stroke, 0–23% reported they were depressed and 12 months after the stroke the proportion was 2–42%. Even at county level there were differences, but these were smaller: 6–14% three months after stroke and 9–19% after 12 months.

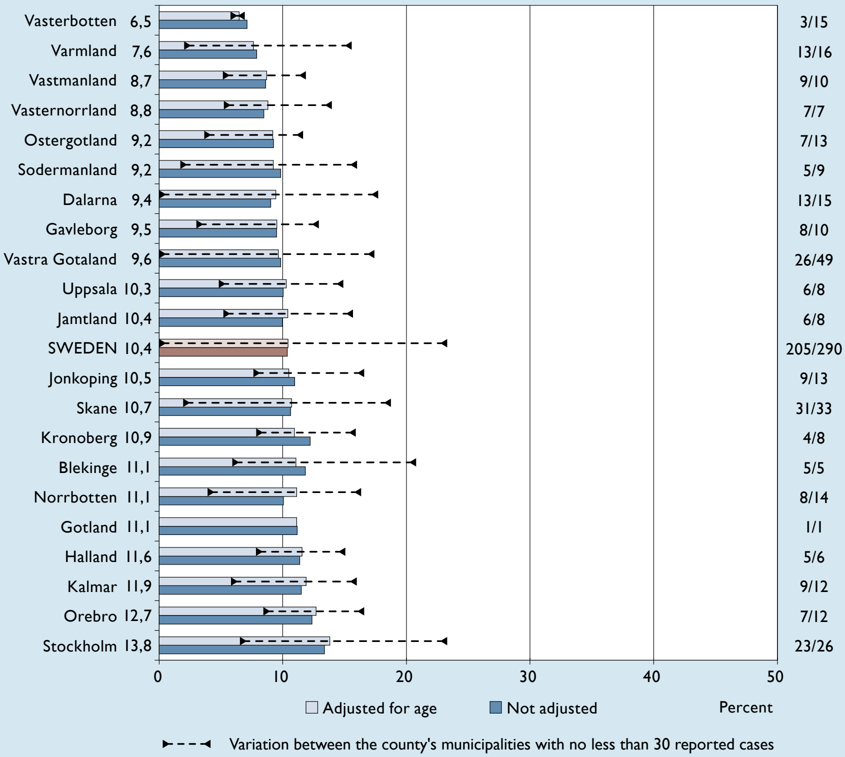
Conclusions

More women say they are depressed after a stroke, but this does not necessarily have to be due to any differences in rehabilitation. According to the Swedish Living Conditions Survey (ULF/SLC) conducted by Statistics Sweden, women report more depression and their consumption of antidepressants is also generally higher than men's consumption [9].

It is worrying that the proportion of frequently or constantly depressed persons increases between the two monitoring occasions. Variations between municipalities are quite small 3 months after stroke, but large after 12 months. There is a lot to do in this field in many municipalities and county councils.

Figure C09
County

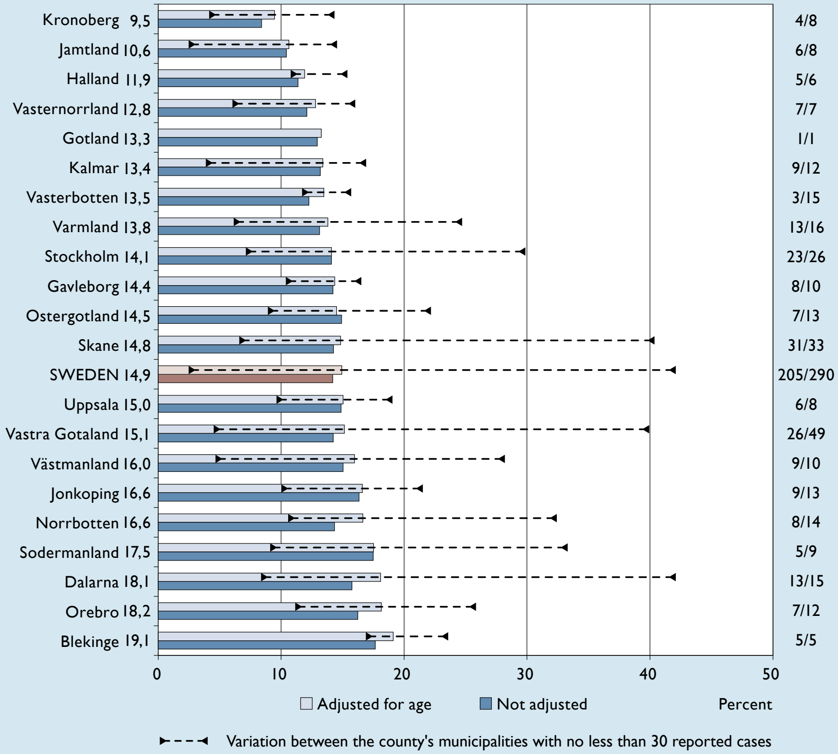
Proportion of persons reporting being often or always depressed 3 months after stroke, 2008-2009. Adjusted for age



Source: Swedish Stroke Register

Figure C09b
County

Proportion of persons reporting being often or always depressed 12 months after stroke, 2008-2009. Adjusted for age



Source: Swedish Stroke Register

Patient satisfaction

Fulfilled needs for support and help after hospitalisation (D02)

The proportion of stroke patients with fulfilled needs of support and help after hospitalisation provides a picture of the availability of support and assistance after stroke.

Results

In the municipalities, 53–100% of the patients stated that they had received the support and help they needed after their hospital stay. At county level, the variations were smaller: 62–78%.

Out of persons living in special housing, 62% stated that their needs for support and help were completely satisfied and the corresponding figure for persons living in normal housing was 64% of those with help in the home and 74% for those without domestic assistance. Results could not be presented at municipal level as data collected involved relatively few cases.

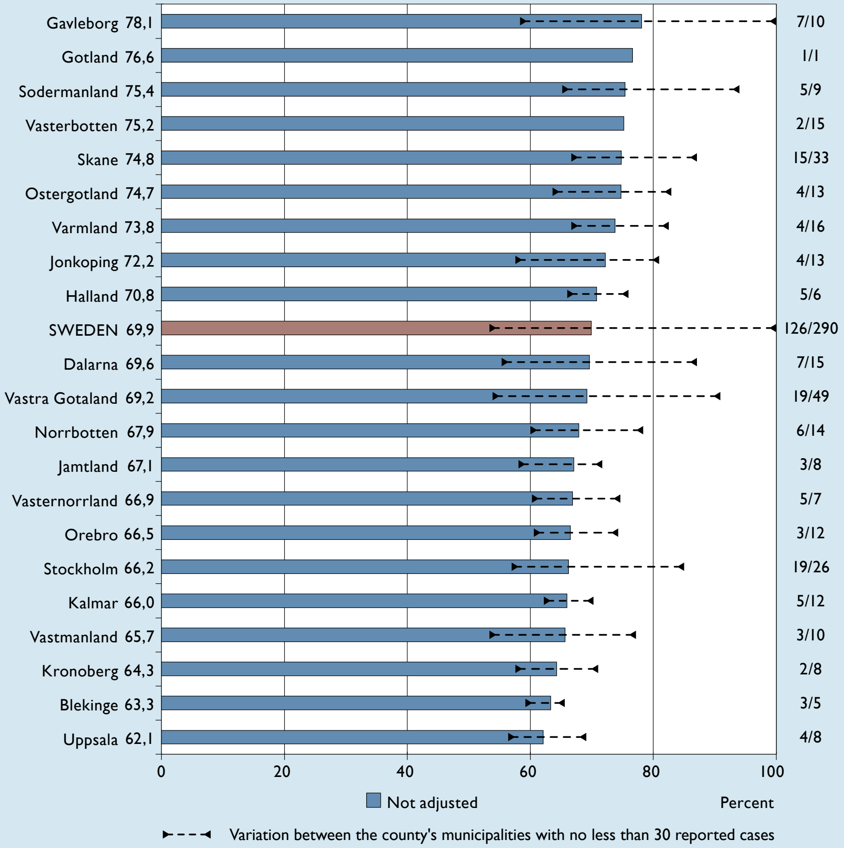
Conclusions

Persons who do receive assistance from the municipalities report to a higher extent that they do not get enough support and help, compared with persons who get no assistance at all from the municipalities. The reasons for the results may be partly due to their high expectations of support and help, and partly because people have unfulfilled needs that municipalities and county councils have not met.

The National Board of Health and Welfare estimates that the proportion of persons whose needs have been fulfilled is too low among people with municipal assistance. This indicator reflects county council, municipal and relatives' contributions, but demonstrates that there are relatively large variations between municipalities even within the same county. This implies that help and support after stroke can be improved in many municipalities.

Figure D02
County

Proportion of persons reporting that their needs for support and help after hospitalisation were fullfilled 3 months after stroke, 2009



Source: Swedish Stroke Register

Fulfilled need for rehabilitation after hospitalisation, reported 12 months after stroke (D04)

Persons who have suffered a stroke may need rehabilitation for a long period of time. Consequently it is also important to highlight the extent to which needs for rehabilitation are satisfied one year after onset.

Results

In the municipalities, 36–80% of the patients felt their rehabilitation needs had been met 12 months after hospitalisation. The variation between counties was smaller, 48–67%.

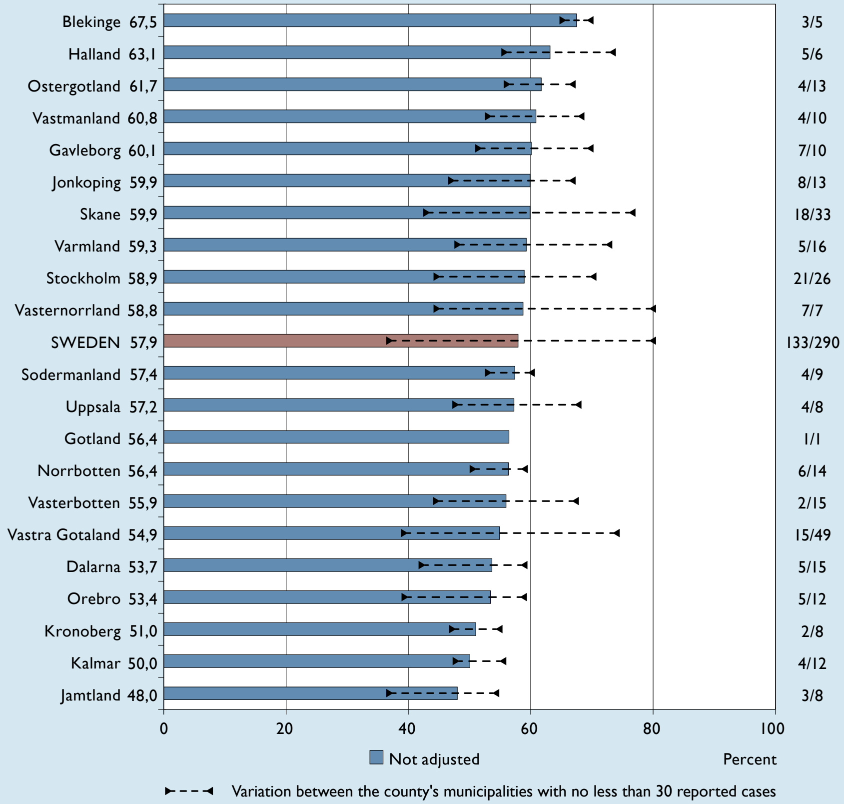
Conclusions

The variation between municipalities is considered major and in many municipalities there are people who feel that they have not received enough rehabilitation after their hospitalisation. This may be partly due to their high level of expectations, but probably there are also needs that municipalities and county councils have not fulfilled.

It is a surprisingly large proportion of persons who feel that their needs have not been fulfilled, and the variation suggests that rehabilitation can be improved in many municipalities.

Figure D04
County

Proportion of persons reporting that their needs for rehabilitation after hospitalisation were completely fulfilled 12 months after stroke, 2008-2009



Source: Swedish Stroke Register

Carotid surgery

Carotid surgery on patients with symptomatic carotid stenosis (E01)

Narrowing (stenosis) of the carotid arteries can cause small blood clots. These can break loose and cause minor, often transient, episodes of hypoxia in the brain with symptoms similar to those of a cerebral infarction. Anyone who has had such a transient ischemic attack (TIA) or mild stroke has a greatly increased risk of soon facing a full-scale brain infarction. The risk of cerebral infarction can be reduced significantly by prompt surgery on patients with symptomatic stenosis of the carotid arteries. Carotid surgery or endarterectomy is the removal of material or plaque on the inside of an artery. In the case of tight narrowing of an artery (over 70% occlusion) urgent surgery becomes a high priority (priority 1 of 10) in the National Guidelines.

Results

In the nation as a whole, 12.6 carotid operations per 100,000 inhabitants were performed in 2009. More than 80% of the operations were on patients with symptomatic carotid stenosis. Of these patients, twice as many were men as women, 17.2 compared to 8.1 per 100 000 inhabitants. The gender difference can largely be explained by the fact that men have a higher risk of developing carotid stenosis compared with women of the same age.

In this comparison, it is most important to study patients with symptomatic carotid stenosis, as the necessity of urgent surgery is greatest for them. Variation between the lowest and highest number of operations was just over 8 per 100,000 population, where the county council that performed the fewest number of procedures in 2009 performed 5.5 operations per 100,000 inhabitants. The national average was almost double for the same year.

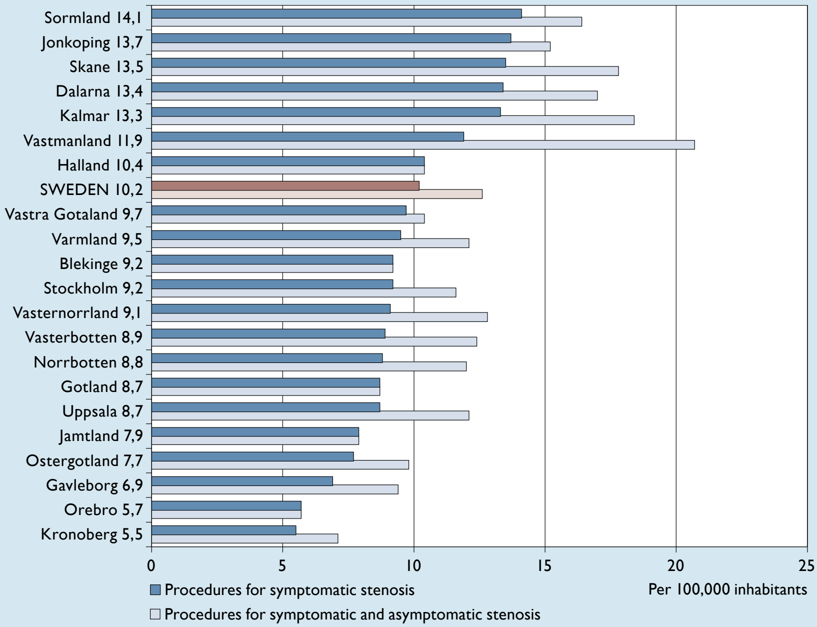
The risk of complications after this surgery is small, which emphasises the value of the operation. The entire nation experienced 1.6% serious complications in 2009. As there were so few complications, it is not meaningful to comment on any gender or age differences for this indicator.

Conclusions

There is no clear correlation between the number of carotid operations and the prevalence of cardiovascular diseases in different parts of the country. There is no set target level for how many procedures should be carried out annually. According to the National Guidelines, however, many county councils need to operate more if all patients who need this surgery are to be treated. The substantial variations between county councils also suggest that some of them are not identifying all patients who need this surgery. Considering the major preventive benefits of this operation, county councils should improve their procedures to identify and correct symptomatic carotid stenosis. Of the patients operated on, very few suffer serious complications which indicate that this intervention maintains a high medical safety and quality level.

Figure E01
County council

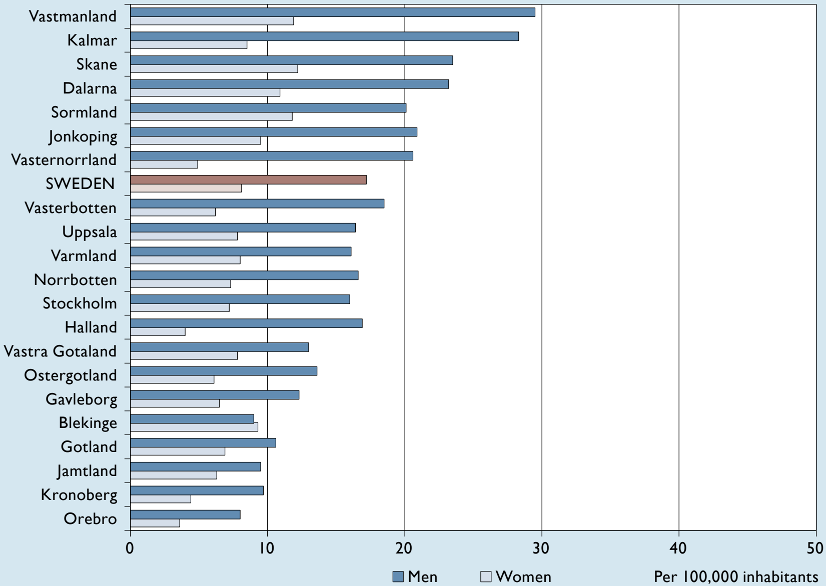
Number of carotid surgery procedures performed per 100,000 inhabitants, 2009



Source: Swedvasc

Figure E01
Women/men

Number of carotid surgery procedures performed per 100,000 inhabitants, 2009



Source: Swedvasc

Waiting time to carotid surgery for patients with symptomatic carotid stenosis (E02)

For symptomatic high-grade carotid stenosis (narrowing of the artery), where the patient has neurological symptoms of TIA for example, it is important that the constriction is operated on as soon as possible. The National Guidelines recommend that patients should undergo surgery within fourteen days after onset of symptoms in order to provide the best preventive effect against stroke. Operation of symptomatic high-grade and medium-grade carotid stenosis has been awarded high priority (priority 1 and 4 of 10) in the National Guidelines. For carotid stenosis which produces no symptoms, the priority is lower (priority 6 of 10).

Results

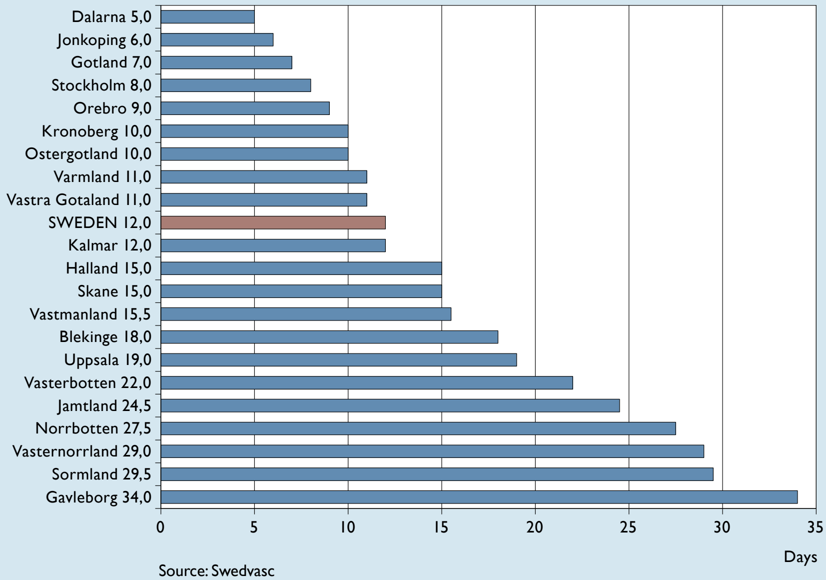
Median waiting time in the country was 12 days between symptom onset and operation for patients undergoing surgery in 2009. The shortest waiting time was 0 days and the longest was 759 days. The results indicated no gender difference in the country as a whole. At county council level the variation in median waiting time was 29 days: ranging from 5 to 34 days. In half the county councils, the median waiting period was longer than 14 days. In eleven county councils, the median waiting period was longer than 14 days and eight had median waiting times that were significantly longer than 14 days.

Conclusions

Median waiting time of 12 days means that half of the patients have to wait longer than that for surgery. It may also mean that nearly half of patients with symptomatic carotid stenosis are operated on later than recommended in the National Guidelines (14 days). This is not a satisfactory result, given that carotid surgery performed in good time exerts a good preventive effect on stroke. If resources are limited for carotid operations, it makes sense to shift resources from operations of patients with asymptomatic carotid stenosis to those with symptomatic stenosis in order to better comply with the recommendations in the Guidelines.

Figure E02
County council

Median waiting time to carotid surgery for patients with symptomatic carotid stenosis, 2009



Source: Swedvasc

Further Analysis

Responsibility for health care, rehabilitation and assistive devices

The responsibility for health care including rehabilitation and assistive devices is shared between the relevant county council and the municipality. The Health and Medical Services Act of 1982 and the agreements that municipalities and county councils have entered on home-based care clarify the different providers' responsibility.

Home-based medical and nursing care and rehabilitation for persons living in normal housing

Agreements between municipalities and county councils regarding the responsibility for home-based medical and nursing care for patients living in normal housing varied as to which provider was responsible. Several municipalities used what is known as the threshold principle, which means that the municipality has the responsibility for home-based medical and nursing care for patients who cannot themselves, or with an escort, reach a health care facility. Other municipalities stated that home-based medical and nursing care responsibilities were determined by municipal assistance decisions, the person's care needs, or some other more or less diffuse boundary. 72% of municipalities with home-based medical and nursing care responsibilities in normal housing took care of all age groups, while 17% of them were solely responsible for people over 17 or 18 years of age. Other municipalities had responsibility for patients who were seven and older alternatively those who were 65 years and above, or those who were 18–65 years old.

There were also differences in the type of care that municipalities were responsible for. Some municipalities were responsible for rehabilitation, others not. Of the municipalities with responsibility for both home-based medical and nursing care and rehabilitation, 88% had the responsibility for both care types. In a few municipalities there were, however, differences in the areas of responsibility. Some municipalities were for instance responsible for home-based medical and nursing care for all age groups while their rehabilitation liability only applied to those aged 21 and over. Activities carried out by nurses were also more often included in home-based medical and nursing care than in rehabilitation. It was mainly occupational therapists and physiotherapists who were involved in rehabilitation.

A few municipalities stated that the rehabilitation responsibility for stroke patients differed from the municipality's other responsibilities. The difference was primarily that they had a joint organisation with the primary health care services (provided by the county council) in order to provide team rehabilitation for persons who had suffered a stroke.

Nurses were funded under the home-based medical and nursing care organisation in all municipalities who were responsible for such care in normal housing. The funding of occupational therapists, physiotherapists and auxiliary nurses was also included in this responsibility. In one or two municipalities it also included other professional groups such as care managers, family coordinators and vision/hearing specialists.

Patient outcome and the responsibility for home-based medical and nursing care

Since the responsibility for home-based medical and nursing care varied between municipalities and county councils, it was interesting to compare the performance of the municipalities that had assumed responsibility for home-based medical and nursing care in normal housing with the municipalities where the county council was still in charge. Consequently, the National Board of Health and Welfare analysed a selection of the outcome indicators related to home-based medical and nursing care. The differences in responsibility concerned normal housing and therefore the analysis included persons who 3 or 12 months after their stroke were living in normal housing, with or without assistance according to the Social Services Act.

Results

For most outcome indicators there were no differences in the results, meaning it did not matter whether the municipality or the county council was responsible for home-based medical and nursing care. For the following indicators, however, patient outcome was better when the municipality had the responsibility for home-based medical and nursing care in normal housing:

- Health and well-being, reported 3 months after stroke (C08)
- Depression, reported 12 months after stroke (C09b)
- Fulfilled needs for support and help after hospitalisation, reported 3 months after stroke (D02)
- Fulfilled needs for assistive devices, reported 12 months after stroke (D09).

Conclusions

The municipalities that have taken over the responsibility for home-based medical and nursing care in normal housing have achieved better patient outcome in some areas and there may be many reasons for this. One theory is that many people have daily contact with municipal social services which therefore can easily note if a person needs further assistance or care. Another is that cooperation within the municipality might work better than that between the municipal social services and the county council primary health care services.

Collaboration between municipalities and county councils

When assessing treatment and care needs, it is important to consider all areas of life and all criteria for quality of life that are relevant to each individual, however this requires collaboration between all actors concerned.

Regulations governing collaboration and coordination

Collaboration at admission and discharge of patients into/from in-patient care

According to the National Board of Health and Welfare regulations (SOSFS 2005:27) on collaboration at admission and discharge of patients into/from in-patient care the following applies: county councils and municipalities must, in consultation, develop routines for care planning prior to discharge for patients and for the transfer of information, e.g. current plan between care providers, in connection with admission and discharge of patients from in-patient to out-patient care and social services (Chapter 2, Section 3 SOSFS 2005:27). These procedures must be documented and be consistent within a county or region, and they must also include information about who is responsible for sending and receiving admission/discharge notifications and who is to be called to care planning meetings.

Care planning meetings are to result in a Care Plan stating the patients' needed care from both out-patient health services and social services after discharge from in-patient care. Examples of such information could include medical treatments, current pharmaceutical treatments, general and specific care instructions as well as rehabilitative and habilitative measures to be taken. The name or names of the responsible physician/s should also be stated.

The Care Plan must also include other information that may be important for the patient's continued care and treatment. Such information may, for example, include a summary and evaluation of the care, treatment and rehabilitation the patient received in in-patient care, the patient's current health and functional status and a risk assessment based on the patient's health status. This Care Plan and all other important information should then be transferred to the concerned out-patient and social services, no later than the day the patient is discharged from in-patient care.

Coordination of rehabilitation and habilitation

The National Board of Health and Welfare has issued regulations on the coordination of rehabilitation and habilitation (SOSFS 2007:10), which primarily apply to people with extensive and long-term care needs requiring assistance from both health care and social services. The essence of these regulations is the requirement that municipalities and county councils should jointly develop procedures to coordinate rehabilitation efforts. The patient must also be allocated a named coordinator to develop his/her plan. These regulations also state that coordinators should enjoy the adequate resources to be able to carry out their tasks. According to regulations, both the municipality and the county council should consider the person's overall needs, no matter which organisation he or she initially comes into contact with. Different providers and individual professionals are, however, responsible for their respective rehabilitative measures and services provided [10].

Collaborative training

For this particular National Performance Assessment, the National Board of Health and Welfare has also collected data via two questionnaires. One questionnaire was directed at designated stroke units in hospital and the second was answered by Chief Community Nurses in the municipalities. The Chief Community Nurse is responsible for health and medical care in a municipality. The designated stroke units were among other things asked whether the county council regularly provides training in care and rehabilitation of stroke patients for municipal care staff. A total of 18 stroke units, whose catchment areas total 63 municipalities, responded that they regularly offered such training. The Chief Community Nurse in some municipalities also stated that staff was offered training and continuing education under the auspices of the county council.

Different views on collaboration

In the questionnaire to hospital stroke units the following question was asked: "Is there a joint Collaboration Plan for structured cooperation between stroke unit staff and after-care units within the social services? "A total of 59 of 77 stroke units responded that there was such a joint plan in place. A similar question was put to municipalities: "Do the municipality and county council have jointly-developed coordination procedures in place for rehabilitation?" In order to be able to compare responses to these questions, each municipality was linked to a hospital. Consequently the response from one particular hospital applies to several municipalities.

In 65% of the municipalities, both the designated stroke unit and the municipality responded to their question about collaboration. Of these, 44% stated they had a joint collaboration plan and jointly-developed coordination procedures (see Table 1). In 32% of the cases the stroke units stated that there was a collaboration plan while the municipality stated that there were no joint procedures for the coordination of rehabilitation. In 16% of cases, municipalities responded that there were procedures while the relevant stroke unit stated that there was no collaboration plan and in 9% there was neither a joint collaboration plan nor any common routines for coordination of rehabilitation.

Patient outcome and collaboration between municipalities and county councils

The idea behind collaboration between county councils and municipalities regarding rehabilitation and assistive devices is that the care and treatment provided should result in the highest possible quality and in the best possible outcome for the patients. The National Board of Health and Welfare has analysed the results

Table 1. Stroke units' and municipalities' responses concerning collaboration plans and jointly-developed routines for coordination of rehabilitation

		Municipalities' responses	
		Routines for coordination in place	Routines for coordination not in place
Stroke Units' responses	Collaboration Plan in place	44 %	32 %
	Collaboration Plan not in place	16 %	7 %

Source: The National Board of Health and Welfare questionnaires to designated stroke units in hospitals and to municipalities.

from a number of outcome indicators to ascertain whether collaboration does, in fact, produce better patient outcome. The data on cooperation was collected via questionnaires to designated stroke units and municipalities. In the cases where both the stroke unit and the municipality indicated that there was a collaboration plan or procedures for collaboration in place, this has been interpreted as that they collaborate. However if the relevant stroke unit and municipality gave different answers, this has been interpreted as there being no collaboration. The municipalities who did not respond to the survey were not included in the material analysed.

Results

Several indicators showed that patient outcome was different for persons living in municipalities with or without collaboration or coordination between the municipality and the county council. The outcome seemed to be better in municipalities where both the designated stroke unit and municipality indicated that there was a plan or procedures in place for collaboration or coordination. This applied to the following indicators:

- General health status 12 months after stroke (C08b)
- Depression 3 and 12 months after stroke (C09, C09b)
- Fulfilled needs for support and help after hospitalisation, reported 3 months after stroke (D02)
- Patient satisfaction with rehabilitation after hospitalisation, reported 3 months after stroke (D03)
- Fulfilled needs for rehabilitation after hospitalisation, reported 12 months after stroke (D04)
- Fulfilled needs for home-based medical and nursing care, reported 12 months after stroke (D07).

Sources of error and interpretation issues

It is unclear to which extent the municipalities and stroke units actually collaborated concerning rehabilitation after stroke as the survey did not exhaust the topic in-depth. If both parties said that there were such procedures in place, then it is likely that the collaboration was more structured and thus worked better in practice. Even when designated stroke units and municipalities responded differently, it is possible that there were procedures in place but that they were not followed.

Conclusions

It is likely that coordination functions better in the county councils and municipalities where both parties indicate that there are such practices in place. Coordination also appears to improve patient outcome for persons who have had a stroke.

Rehabilitation after stroke

There are various types of rehabilitation for stroke victims. After in-patient stay they can receive rehabilitation from hospital specialised care, county council and municipal home-based medical and nursing care (primary health care) or municipal short term special housing care or other support from physicians, nurses, physiotherapists, occupational therapists, social workers or speech therapists.

Patient outcome and the different types of rehabilitation

The Swedish Stroke Register (Riks-Stroke) monitors various aspects of stroke care after a patient has been discharged from hospital. At the monitoring occasion 3 months after stroke, patients may specify the type of support or help they have received from the hospital or municipality after their in-patient stay. This data has been used to analyse if the patient outcome differ depending on the type of rehabilitation received. The outcome for two different types of rehabilitation have been compared, namely day-or team rehabilitation and home-based rehabilitation. In order to make comparison groups as similar as possible, individuals were selected who:

- were conscious upon arrival at hospital.
- were discharged to normal housing.
- at the point of monitoring were living in normal housing.
- stated that they had received day- or team rehabilitation or home-based rehabilitation.

Gender, age and duration of in-patient stay were also been taken into consideration.

Results

Patient outcome appeared better for day- or team rehabilitation than for home-based rehabilitation. However, there were no differences among the indicators reflecting patient satisfaction. The following indicators showed better patient outcomes for day- or team rehabilitation than for home-based rehabilitation:

- ADL-independence 3 and 12 months after stroke (C05, C05b).
- IADL-independence 12 months after stroke (C06).
- Mobility 3 and 12 months after stroke (C07, C07b).
- Health and well-being 3 and 12 months after stroke (C08, C08b).
- Depression 3 months after stroke (C09).

Of those receiving day- or team rehabilitation, men amounted to 61.3% and women to 38.7% of those who had a stroke in 2008 and 2009. There were 51.4% men and 48.6% women who received home-based rehabilitation. The data showed that women received day- or team rehabilitation to a lesser extent than men: 6.3% versus 9.6%. These differences were found in all age groups. Corresponding figures for those receiving home-based rehabilitation were 5.5% women and 5.6% men.

Sources of error and interpretation issues

There are clear signs that day- or team rehabilitation leads to better patient outcomes as indicated by several indicators however there are some difficulties in interpretation. The monitoring questionnaire sent to the patients 3 months after hospital discharge does not define day- or team rehabilitation and home-based rehabilitation. Consequently it is up to the respondent to define the different types of rehabilitation and they may have interpreted them in different ways. Therefore, it is difficult to know who is carrying out the various types of rehabilitation and what is actually included in them. One interpretation may be that day- or team rehabilitation is conducted under the auspices of the county council specialised care while home-based rehabilitation is conducted within the primary health care services under county council or municipal management. In addition, there may be differences between comparison groups with regard to their needs for rehabilitation after stroke. The National Board of Health and Welfare has, to the greatest possible degree, taken this into account but patient needs may still vary between those who have received day- or team rehabilitation and those who have received home-based rehabilitation.

Conclusions

Results suggest that day- or team rehabilitation leads to better patient outcome than home-based rehabilitation does. It is unclear what is meant by day-or team rehabilitation versus home-based rehabilitation. It is important that municipalities and county councils attempt to identify these differences and take the necessary actions in order to ensure that the best possible services are provided for those receiving rehabilitation services, regardless of in what form. The National Board of Health and Welfare also believes that municipalities and county councils must even out the inequalities between women and men in terms of the types of rehabilitation given.

Table 2. Comparison of results for day- or team rehabilitation and home-based rehabilitation by gender and age, percent

	Women	Men	20–64 years	65–79 years	80-w years
ADL-independence 3 months after stroke (C05)[1]					
Day/team rehabilitation	92	90	95	89	83
Home-based rehabilitation	84	80	91	82	76
ADL-independence 12 months after stroke (C05b)[1]					
Day/team rehabilitation	91	88	94	88	82
Home-based rehabilitation	83	80	88	82	76
IADL-independence 12 months after stroke (C06)[1]					
Day/team rehabilitation	44	45	63	38	15
Home-based rehabilitation	23	31	50	30	10
Mobility 3 months after stroke (C07)[2]					
Day/team rehabilitation	4	5	2	6	7
Home-based rehabilitation	8	10	7	9	11
Mobility 12 months after stroke (C07b)[2]					
Day/team rehabilitation	3	3	2	4	7
Home-based rehabilitation	6	9	5	6	9
Health and well-being 3 months after stroke (C08)[1]					
Day/team rehabilitation	81	84	84	82	79
Home-based rehabilitation	77	77	74	78	76
Health and well-being 12 months after stroke (C08b)[1]					
Day/team rehabilitation	81	79	82	80	74
Home-based rehabilitation	75	76	75	77	75
Depression 3 months after stroke (C09)[2]					
Day/team rehabilitation	12	8	11	8	10
Home-based rehabilitation	15	11	17	12	12

[1] The higher the proportion the better the result.
[2] The lower the proportion the better the result.
Source: Swedish Stroke Register (Riks-Stroke)

Care and support provided by relatives

Often stroke exerts a significant impact on relatives and families. It is important to identify the consequences for them and what support they receive from the health and social services. In order to further explore the topic, the National Board of Health and Welfare, in collaboration with the Swedish Stroke Register (Riks-Stroke) sent out a questionnaire to relatives in 2009 and 2010. This section provides a brief summary of the results of these surveys and the results from the two follow-up surveys undertaken by the Swedish Stroke Register three and 12 months after a person has had a stroke, as well as the results from the two surveys that the National Board of Health and Welfare conducted in connection with this evaluation.

Dependence on support and help from relatives

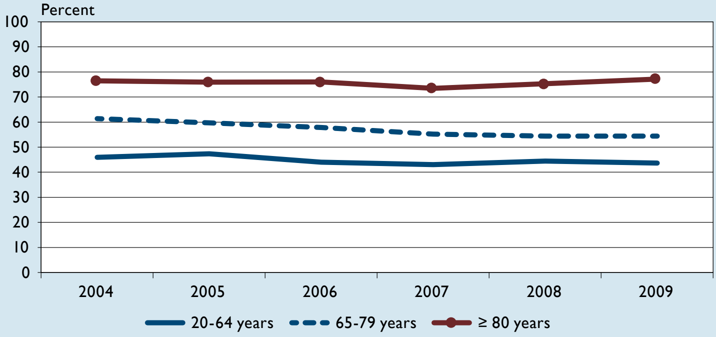
In the Riks-Stroke questionnaire sent to patients 3 and 12 months after in-patient care, the respondents indicated whether they currently relied on support and help from a relative.

Of those who suffered a stroke, 61% were dependent on support and help from family members three months after their stroke. This dependence was linked to the person's age and gender. In all age groups there were fewer women than men who said they needed support and help from relatives. Among persons aged 20–64, 44% received support and help from relatives compared to 54% in the age group 65–79 years old and 77% in the oldest group. This proportion had decreased over time in the 65–79 age group but had increased in the over 80 group. The same applied 12 months after in-patient care, but then there were slightly less persons who reported that they were dependent on support and help from relatives, 57%.

The proportion of those who were dependent on support and assistance from family members three months after their stroke varied greatly among municipalities, 35–85%. At the monitoring occasion 12 months after discharge from hospital, there were fewer who needed support and help from relatives but the variation between municipalities was still 34–83%. The data has been standardised for both gender and age. However, it was not known whether these persons needed support and help from families and relatives prior to their stroke. It is therefore possible that results could have been slightly different had such data been available.

Figure Rel01
Sweden

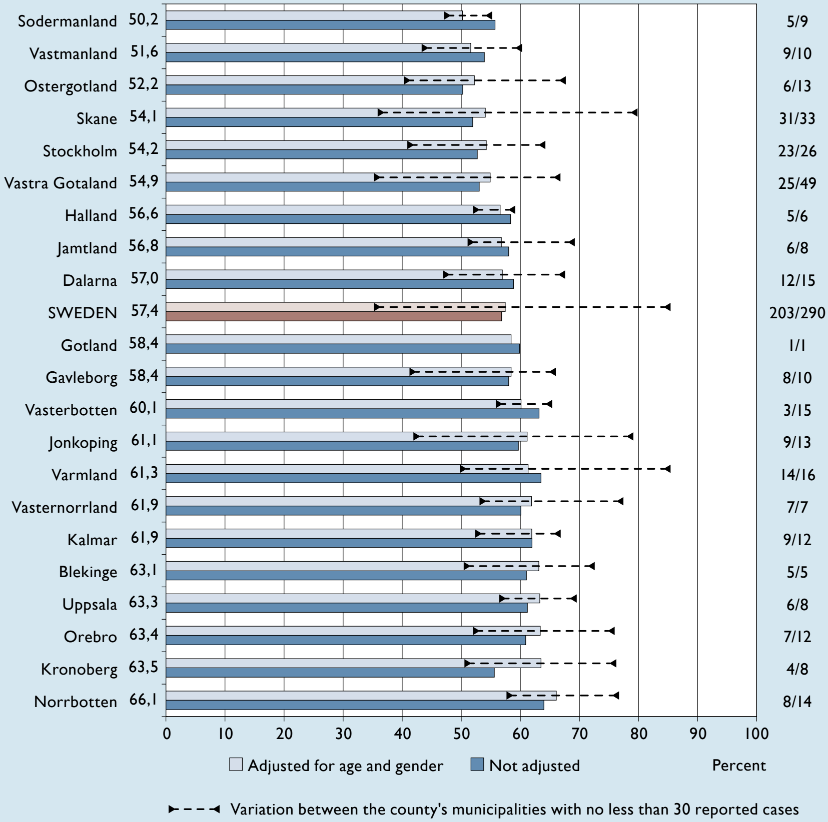
Proportion of persons reporting being dependent on family support and help 3 months after stroke



Source: Swedish Stroke Register

Figure Rel01
County

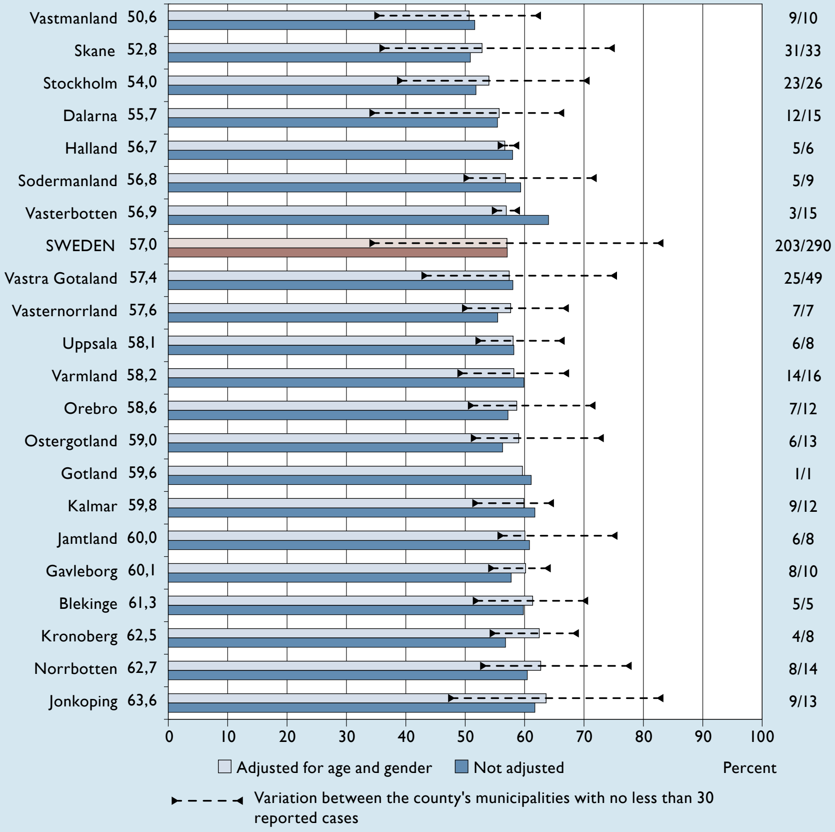
Proportion of persons reporting being dependent on family support and help 3 months after stroke, 2008-2009. Adjusted for age and gender



Source: Swedish Stroke Register

Figure Rel01b
County

Proportion of persons reporting being dependent on family support and help 12 months after stroke, 2008-2009. Adjusted for age and gender



Source: Swedish Stroke Register

Major impact on relatives

When a person suffers a stroke, this brings major consequences for their relatives, particularly for the carers, i.e. those who have stated that their relatives are wholly or partially dependent on their help and support. This group comprised 49% of all respondents who answered the questionnaire sent out to relatives in 2010, or a total of 358 persons.

Table 3. Consequences of a close relative having suffered a stroke, total plus family member carers, 2009 and 2010, percent.

	Total 2009 (n=695)	Total 2010 (N=729)	Family member carers 2009 (n =288)	Family member carers 2010 (n=358)
Limited freedom of action (Relative cannot be left ½ day without care)	48	26	60	45
Participation in rehabilitation	15	17	33	27
Help with ADL	44	49	100	100
”Taken over” other chores	26	35	60	58
Self-assessed health (quite/very poor)	13	12	17	16
Reduced social activities	8	7	16	13
Do not know who to contact in health and social services	36	37	33	34
In contact with stroke association	4	4	6	7
Need more information on stroke	47	50	56	57

Source: The National Board of Health and Welfare

The results in the table above provide an indication of the impact on relatives. Many must become involved in rehabilitation (training and activation), help with ADL and other chores such as managing finances, driving and looking after the home in general (IADL). The families of persons who have suffered a stroke also assessed that their own health was worse than a sample of the population in general of the same ages. 13% and 17% of the relatives said they had quite poor or very poor health. For family member who were carers, the corresponding proportion was 16% or 13%. These figures can be compared to those of the population in general where some 11% felt that their health was quite or very poor. Many relatives, especially family members who were carers, also reported that they had no time for their own social activities. Over a third of the families reported in both 2009 and 2010 that they did not know who within the health and social services they should contact for advice or support.

Need for knowledge

Most stroke units, 88%, stated that they had procedures in place, during the in-patient care period, to inform patients and their families about stroke in general and stroke recovery as well as the help available after discharge from hospital. 10% stated that there were no such procedures. Many, 80%, reported informing patients and their relatives of available patient interest groups and any local associations.

In spite of these responses from stroke units, about half of the relatives stated that they needed more knowledge about stroke. The need for knowledge in general seemed to have increased between 2009 and 2010, but especially among family members who were carers. They were mainly looking for more knowledge about the illness and on treatment options, pharmaceuticals and opportunities for support to families.

Table 4. Relatives' needs for knowledge about stroke, 2009 and 2010, percent.

	Total 2009 (n=695)	Total 2010 (n=729)	Family member carers 2009 (n=288)	Family member carers 2010 (=358)
Need for knowledge about stroke illness	25	27	27	32
Need for knowledge about specific treatment methods	15	18	18	25
Need for knowledge about opportunities for family support	12	15	15	22
Need for knowledge about relationships	3	4	4	4
Need for knowledge about pharmaceuticals	8	11	11	14
Need for knowledge about opportunities for housing adaptation	6	7	7	10
Need for knowledge about opportunities for assistive devices	6	9	9	14
No need for knowledge	53	50	50	43

Source: The National Board of Health and Welfare

Support to relatives

Since July 1, 2009, the Social Welfare Committee is to provide support to persons caring for an elderly relative or a relative who suffer from long-term illness, or persons who support a family member who has a disability (Chapter 5, Section 10, Social Services Act). According to the questionnaire responses from relatives of persons who had suffered a stroke, 6% perceived that they had received some form of support from the social services. Among family member who were carers the proportion was higher –12% – but it still remained very small.

The questionnaire to municipalities showed that 77% of the responding municipalities had procedures in place to inform about municipal support to families, either general procedures or those that were specific to people who have suffered a stroke.

Dental care after stroke

People who suffer a stroke face an increased risk of experiencing problems with their teeth and mouths. This is due to several factors, including the fact that many people with a residual disability find it more difficult to manage their oral hygiene without assistance. Poor false teeth fit and impaired oral motor function due to reduced sensitivity in the mouth after a stroke are also common. Through contact with a dentist or dental hygienist, these problems can be prevented. The comparison between county councils shows considerable differences in the proportion of stroke patients who visited dental care during the first year after they suffered a stroke. The variation between county councils was 37 percent in 2009. A slightly higher proportion of men than women visited dental care in the year after stroke.

This section compares stroke patient dental care visits with the population as a whole. Most stroke patients are older than 60. For this reason, the comparison was limited to individuals 60 years and older. Data refers to the proportion of stroke patients who visited dental care within twelve months of discharge from in-patient care and the proportion of individuals in the population in general who visited dental care in 2009. In 2009, the Swedish Stroke Register (Riks-Stroke) monitored 11,500 patients who suffered a stroke in 2008 that is 12 months after their discharge from hospital. Data relating to the population as a whole was collected from the National Board of Health and Welfare's Dental Health Register. A total of 1,464,992 persons over the age of 60 visited dental care services in 2009.

Few stroke patients visit dental care

It is desirable that as many stroke patients as possible visit dental care for prevention of dental and mouth problems. The comparison showed that a smaller proportion of stroke patients than in the population in general visited dental services during the monitored period. For the nation as a whole the difference was 4 percent but in three county councils it was over 8 percentage points. The fact that the proportion of visits to dentists by persons over 60 years old in the population as a whole was greater than the stroke patient group may indicate that dental care for stroke patients has been neglected or that there were deficiencies in the availability of dental care. A comparison between patients of all ages showed the reverse result: a higher proportion of stroke patients than the general population visited a dentist or a dental hygienist. The reason for this is that a significantly lower proportion of young people visit dental care on an annual basis, which reduces the total number of dental care visits registered in the National Board of Health and

Welfare Dental Health Register. Of stroke patients only 11% were younger than 60 years of age while in the Dental Health Register the corresponding figure was 64%.

Sources of error and interpretation issues

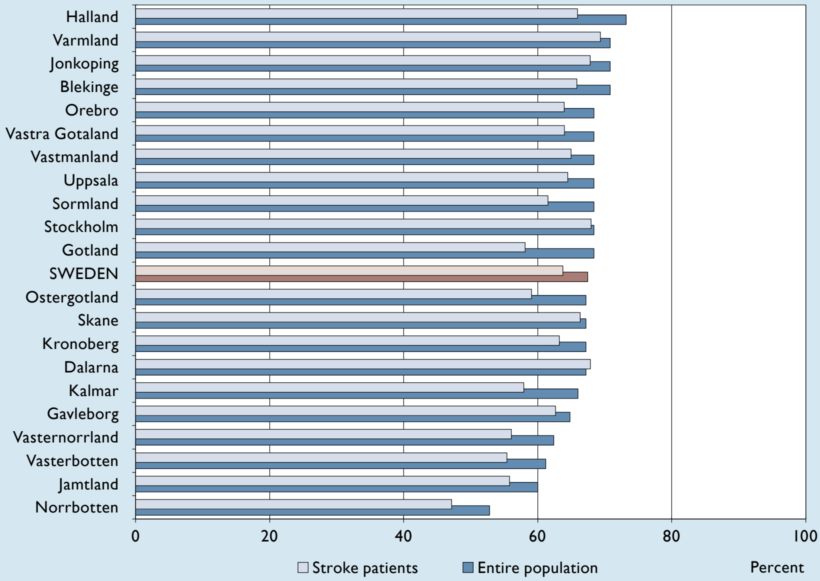
In the comparison between stroke patients and the population as a whole, there are some sources of error and interpretation issues to consider. A number of stroke patients did not respond to the monitoring questionnaire sent out by the Swedish Stroke Register 12 months after discharge. Most of those not responding were people who had experienced severe symptoms after their stroke. A reasonable assumption is that people with severe residual symptoms visited a dentist or dental hygienist to a lesser extent, and consequently the figures for stroke patients described here were in fact too high.

There are also a certain number of dental patients who are not registered in the Dental Health Register. Currently approximately 500,000 people are covered by county council outreach dental care under the Dental Care Act (1985:125) and Dental Care Ordinance (1998:1338). These include everyone living in municipal special housing and/or have been granted dental care under the Provision of Support and Service to Certain Persons under the Disabilities Act. These patients are generally not registered in the National Board of Health and Welfare's Dental Health Register unless the outreach dental care has resulted in an intervention to be undertaken in a dental care clinic. As a result, the actual proportion of dental care visits in the group aged 60 and above is probably higher than the data showed.

A recent report from the National Insurance Office [11] shows that people in socio-economically vulnerable areas visit to dental care to a considerable lesser extent than people from other areas. In this comparison, no adjustments were made for such factors.

Figure B10n
County council

Proportion of persons 60 years of age and older who visited a dentist or dental hygienist, 2009



Source: Swedish Stroke Register, Swedish Dental Health Register
(National Board of Health and Welfare)

Efficiency of stroke care

Efficiency is about using resources in the best way according to established goals. A measure of efficiency may reflect either absolute or relative efficiency. In order to examine absolute efficiency, a target is necessary such as the proportion of fulfilled needs that municipalities or county councils are to achieve. In addition, it must be clear what constitutes high or low levels of resource consumption, or high and low operational costs. If a municipality or a county council succeeds in achieving its target at low cost, operations are efficient. As regards relative efficiency, a comparison is made of municipality or county council results with each other rather than against specific goal and cost levels. The relative efficiency can be measured by cost per person who has attained the goal, for example, has received a satisfactory level of rehabilitation. A lower cost per person for needs fulfilled means that efficiency levels are higher than in other county councils and municipalities.

County council and municipal activities together influence the outcome of treatment and care for people who have suffered a stroke and consequently it is essential to study their joint efficiency. In this chapter the National Board of Health and Welfare, in an attempt to illustrate the efficiency of stroke care, presents two measurements of efficiency:

- Efficiency concerning ADL independence 12 months after stroke (eC05b).
- Efficiency concerning fulfilment of rehabilitation needs 12 months after stroke (eD04).

These measurements show relative efficiency in terms of cost per person who has achieved the target, which also can be expressed a costs per successful case. However, there are shortcomings in all measurements. For both municipalities and county councils estimated costs are used, however some costs have not been possible to calculate, for example county council primary health care costs. The total costs of stroke care in municipalities and county councils are therefore underestimated. There is also some uncertainty in terms of the outcome indicators, for instance the number of cases included (missing cases). It is therefore impossible to draw any conclusions exclusively based on these measurements of efficiency; however they can be used by municipalities and county councils as the basis of their further analyses of efficiency.

Methods

Municipal costs

There is no register-based data on municipal costs of care for persons who have suffered a stroke. Consequently, the National Board of Health and Welfare has estimated cost levels using data from several sources. The National Patient Register has been used and the Register of Social Services for Older People and People with Disabilities. In order to capture the extent to which municipalities provide care and assistance for people who have suffered a stroke. These figures have then been multiplied by the average cost of care municipal care. This is based on data from Statistics Sweden's Annual Accounts from Municipalities and from the National Board of Health and Welfare's Register of Social Services for Older People and People with Disabilities.

County council costs

County council costs are based on estimated costs of in-patient care. In order to estimate the costs of in-patient stroke care, the proportion of such care in relation to all somatic in-patient care was calculated and expressed as a percentage. Thereafter the proportion of in-patient stroke care was multiplied with the county councils' reported total costs for in-patient somatic care per inhabitant, hence giving an estimate of the costs of in-patient stroke care per inhabitant. Then the cost per inhabitant for in-patient stroke care was multiplied by the number of inhabitants of the relevant municipality. Consequently a total cost of in-patient stroke care per municipality was estimated.

Technically speaking, the proportion of in-patient stroke care of all in-patient somatic care was based on Diagnosis-Related Groups (DRG), where stroke care was defined as "stroke with and without complications" (DRG 14A and DRG 14B according to the Nord-DRG System). All DRGs are assigned a weight. The weight sum for in-patient stroke care can be calculated by multiplying the relevant DRG weights by the number of cases. In order to calculate the proportion of stroke care as a percentage of all somatic in-patient care, the weight sum of stroke-care was divided by the weight sum of the entire somatic in-patient care. This proportion or percentage was then used to estimate in-patient stroke care costs as described above.

However, there are several sources of error and interpretation issues with the estimated in-patient stroke care costs. For example, the figure would have been overestimated in a county council where patients were transferred between clinic and hospital during the same illness episode. Data was collected from the National Patient Register, the DRG-statistics and Swedish municipal and county council financial statistics.

Outcome indicators

The National Board of Health and Welfare's goal was to reflect the efficiency of treatment and care of people who have suffered strokes. For this purpose two performance indicators were used; ADL independence 12 months after stroke and fulfilled rehabilitation needs after rehabilitation after hospitalisation, reported 12 months after stroke.

Efficiency was only measured for municipalities with at least 30 cases in the denominator. However, all cases were included in county council data [2]. The efficiency measurements were defined as cost per successful case. The number of successful cases was calculated by multiplying the figure of the outcome indicator by the number of persons in each municipality who suffered a stroke in 2009.

Efficiency concerning ADL independence 12 months after stroke (eC05b)

Anyone who has suffered a stroke may need help, for example, to go to the bathroom or with getting dressed or undressed. Dependency can be reduced by rehabilitation and training. The efficiency measurement of ADL independence 12 months after stroke reflects county council and municipal overall efficiency, both in the acute phase in hospital and during rehabilitation after hospitalisation.

Results

The average national cost was SEK 187,500 per person who was ADL independent 12 months after stroke. Results varied both at county council and municipal levels: from SEK 143, 500 to SEK 229,300 at county council level and from SEK 92,800 to SEK 365,200 per ADL independent person at municipal level.

Sources of error and interpretation issues

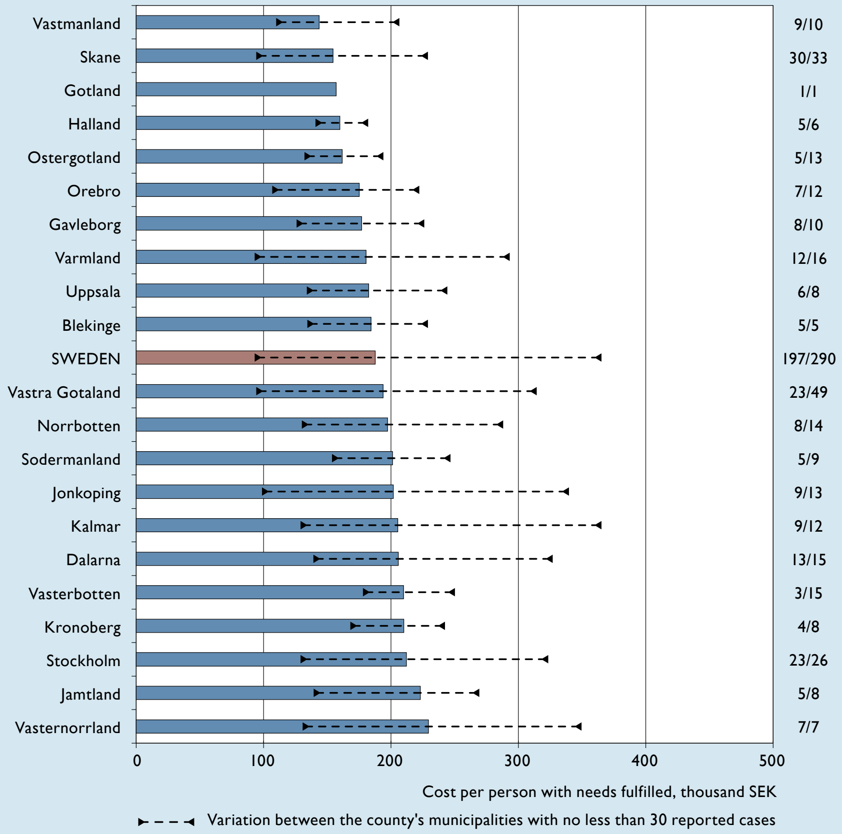
The underlying data is uncertain. It is obvious that the estimated costs are lower than the total, actual cost of municipal and county council stroke care as they do not include, for example, the costs of county council primary care for stroke patients. The efficiency measurements may in fact both be higher or lower than the actual value as costs are estimated. Results do not allow for differences in age, gender or level of stroke severity, which may also affect the measurement.

Conclusion

When measuring efficiency, it is not the size of the costs that is important, but how the costs relate to each other. A low level of cost per ADL independent person indicates that a particular county council or municipality is more efficient than another county council or municipality experiencing a higher cost. The data comes with some uncertainty so it is difficult to point out which municipality or county council is the most efficient. However, the efficiency measurement may be used to assist further county council and municipal work on analysis of efficiency.

Figure eC05b
County

Efficiency measurement concerning ADL independence 12 months after stroke



Source: The National Board of Health and Welfare, Statistics Sweden and Swedish Stroke Register

Efficiency concerning fulfilled needs for rehabilitation after hospitalisation reported 12 months after stroke (eD04)

After suffering a stroke, many people need rehabilitation and exercise. However the extent to which these needs are fulfilled varies. It is important, for example for people to take care of their own hygiene, to be mobile or to return to work. This efficiency measurement highlights the overall efficiency of municipal and county council rehabilitation work after hospitalisation.

Results

The average cost in the country was SEK 271,100 per person who experienced that their rehabilitation needs after hospitalisation was completely fulfilled. The costs varied from SEK 204,900 to SEK 342,400 at county council level and from SEK 136,600 to SEK 535,500 at municipality level.

Sources of error and interpretation issues

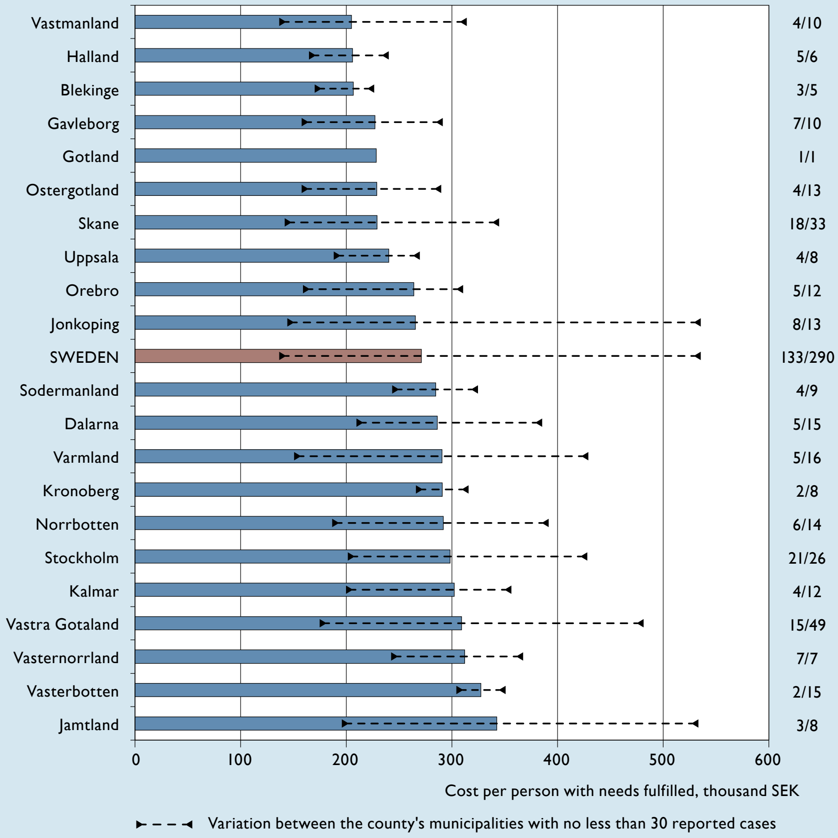
The underlying data is very uncertain, partly because of fact that estimated costs are lower than the total, actual cost of municipality and county council stroke care. The measurement may still be either higher or lower than the actual level as these are estimated costs. Results do not allow for differences in age, gender or degree of stroke severity, which may also affect the measurement. People's expectations of municipal and county council rehabilitation services also affect their experience of it. If expectations are high, results may be understated and vice versa.

Conclusions

Low levels of cost per person with fulfilled rehabilitation needs indicate that operations are more efficient in one county council or municipality than in another with higher costs. The actual cost is not the most interesting aspect here but how it relates to the costs in other county councils and municipalities. The underlying data is very uncertain and it is difficult to point out which municipality or county council is the most efficient. However, the measurement may be used as a basis for further work with efficiency of treatment and care for stroke patients.

Figure eD04
County

Efficiency measurements concerning fulfilment of rehabilitation needs after hospitalisation reported 12 months after stroke



Source: The National Board of Health and Welfare, Statistics Sweden and Swedish Stroke Register

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Annex 1. Project Organisation

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Other

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Annex 2: Methodology

Data collection methods

Data was collected from national registers and via questionnaires. Questionnaires were answered by designated stroke units, Chief Community Nurses in municipalities and relatives and family members of persons who have had a stroke.

Data sources – national registers and health care quality registers

Data sources included National Registers administered by the National Board of Health and Welfare including the Patient Register, the Cause of Death Register, the Prescribed Drug Register, the National Dental Register and the National Register for Social Services to Older Persons and Persons with Disabilities, as well as two National Health Care Quality Registers, namely the Swedish Stroke Register (Riks-Stroke) and the Swedish National Registry for Vascular Surgery (Swedvasc).

Hospitals and county councils are by law obliged to report data to National Registers, but can choose to report data to Health Care Quality Registers, and patients can decline to have their data registered. However, Health Care Quality Registers have the ambition to comprehensively cover all care and all patients within their respective areas.

The National Patient Register covers approximately 1.5 million in-patient cases and nearly 10 million out-patient hospital visits (not primary health care visit) annually. As all in-patient case (primary diagnosis, secondary diagnosis and interventions) are registered using ICD-codes co-morbidities can also be studied.

The Cause of Death Register contains data on persons who were registered in Sweden at the time of death. When this assessment was undertaken the Cause of Death Register contained data from the years 1961 to 2009. Every year all deaths are registered in the register. Between 90,000 and 95,000 deaths are registered yearly. Every year 5–6,000 persons die from stroke. In 2009, 1.2 percent of the persons who died did not have a death certificate. Hence their cause of death was unknown.

The Prescribed Drug Register includes all pharmaceuticals that have been prescribed and that have been sold via pharmacy. Data is updated every two weeks. Every year approximately 90 million drugs are sold and registered. Pharmaceuticals used in in-patient care and drugs sold without prescriptions are not included in the register. The Prescribed Drug Register does not include any diagnosis, therefore the cause for using a particular drug treatment is not known.

The National Dental Health Register contains data on dental status and interventions that have been subsidised by the national dental insurance. These are patients above the age of 20 who have been treated and whose treatment has been paid for via this insurance.

National Register for Social Services to Older Persons and Persons with Disabilities includes data on municipal services and assistance according to the Social Services Act (2001: 453). The register started in 2007 and contains data on approximately 350,000 persons. The register does not include data on the number beds in special housing.

Every year approximately 25,000 cases of stroke is registered in the Swedish Stroke Register (Riks-Stroke), some 18,500 of them are first time stroke cases. All acute care hospitals report to the register. The county council of Vasterbotten is responsible for the register. The register covers acute in-patient stroke care including rehabilitation. The Swedish Stroke Register also monitors patients 3 and 12 months after the acute stroke incidence either via questionnaire or via a telephone call. If the patient cannot respond to the questionnaire by him/herself, a relative is asked to respond to the questionnaire. Collected data is then entered into the register from which it can be retrieved.

On an annual basis, the National Board of Health and Welfare compares the stroke diagnosis and interventions reported to the National Patient Register with that of the Swedish Stroke Register. In 2009, 15 per cent of all stroke cases (hospitalised for the first time) were missing in the Swedish Stroke Register. However, even if the register did not cover all stroke cases, data was both comprehensive and in-depth as it covered interventions at the hospital, as well as rehabilitative measures.

The Swedish National Registry for Vascular Surgery (Swedvasc) started as a local vascular registry in Southern Sweden in 1987, but since 1994 all Swedish hospitals with vascular services register data in Swedvasc. Every year approximately 10,000 registrations are made into the register.

Data entered into the above mentioned registers are based on a Unique Patient Identifier (UPI), the social security number which all residents of Sweden have. The UPI makes it possible to co-run data from different registers over time.

Data sources – questionnaires

Data was also collected via questionnaires. Questionnaires were sent to designated stroke units, Chief Community Nurses in municipalities and relatives/family members of persons who had suffered a stroke.

During the autumn of 2010, the National Board of Health and Welfare in collaboration with the Swedish Stroke Register (Riks-Stroke) undertook a survey of designated stroke units in hospitals. A questionnaire was sent to all 76 stroke units, all of which responded. The aim of the survey was to map the stroke units in terms of their organisation, their available competences and their resources (number of beds, diagnostic equipment, treatment methods and rehabilitation). The questionnaire also included questions regarding care planning with municipalities and routines for such planning, as well as information to patients and relatives.

During the months of April 2011 a questionnaire was sent to all municipalities (321 in total). The response rate was 66 percent (213 out of 321). The questionnaires were answered by the Chief Community Nurse in each municipality. The Chief Community Nurse is responsible for the health care services in the municipality. The objective with this survey was to map: the municipality's responsibility for home-based medical and nursing care for persons living in normal housing; the availability of care programmes for rehabilitation after stroke; the availability of specific training regarding stroke for nursing staff and nurses in the municipalities; and the rehabilitation after stroke that the municipalities offer. The routines for care planning between the county council and the municipality were also mapped.

The Swedish Stroke Register (Riks-Stroke) also monitors patients 3 months and 12 months after discharge from hospital. The objective is to monitor patient outcome (ADL, IADL, depression, returned to work, ability to speak/read/talk) and patient satisfaction with care, rehabilitation and support during and after hospitalisation. The data collected via questionnaires and via telephone is thereafter entered into the Riks-Stroke register, from which the National Board of Health and Welfare accessed the data.

In order to identify the consequences and impact of stroke on relatives and family members, the National Board of Health and Welfare in collaboration with the Swedish Stroke Register (Riks-Stroke) sent a questionnaire to relatives of persons who had been hospitalised for stroke during the year of 2009. The questionnaire was sent out during 2009 and 2010. The questionnaire covered topics such as impact of stroke on relatives, needs for information and knowledge, as well as support and help needed. The response rate was 57% (729 out of 1,291).

Annex 3: List of Process and Outcome Indicators

Indicator		County Council (CC)/ Municipality (M)[1]
A	**Acute Care**	
A01	Time from symptom onset to arrival at hospital	CC
A02	Thrombolysis alerts for suspected stroke cases	CC
A03	Median time to administration of thrombolytic therapy	CC
A03b	Door-to-needle time for thrombolysis	CC
A04	Acute thrombolytic therapy (tPA)	CC
A05	Brain haemorrhage after acute thrombolytic therapy	CC
A06	Admission to designated stroke unit	CC
A07	Admission directly to designated stroke unit	CC
A08	Documented swallowing assessment	CC
A09	Home-based rehabilitation provided by county council	CC
B	**Secondary Prevention**	
B01	Anti-hypertensive treatment at discharge	CC
B01b	Anti-hypertensive treatment 12–18 months after hospitalisation	CC
B02	ARB as anti-hypertensive treatment at discharge	CC
B02b	ARB as anti-hypertensive treatment 12–18 months after hospitalisation	CC
B03	Patients with atrial fibrillation prescribed warfarin at discharge	CC
B03b	Patients with atrial fibrillation prescribed warfarin 12–18 months after hospitalisation	CC
B04	Hospitalisation or death due to haemorrhage after warfarin treatment	CC
B05	Patients without atrial fibrillation prescribed warfarin at discharge	CC
B06	Lipid-lowering treatment at discharge	CC
B06b	Lipid-lowering treatment 12–18 months after hospitalisation	CC
B07	Prescription of generic-lipid-lowering treatment at discharge	CC
B08	Quit smoking 3 months after stroke	CC
B08b	Quit smoking 12 months after stroke	CC
B09	Revisit to physician 3 months after stroke	CC
B09b	Revisit to physician 12 months after stroke	CC
B10	Visit to dentist/dental hygienist 12 months after stroke	CC
B11	Treatment with antidepressants 3 months after stroke	CC
B11b	Treatment with antidepressants 12 months after stroke	CC

[1] Marking if the indicators reflect stroke care provided by the county council or the municipality, or both.

Indicator		County Council (CC)/Municipality (M)[1]
C	**Outcome of Stroke Care**	
C01	28-day case fatality rate following stroke	CC
C02	28- and 365-day in-hospital stroke case fatality rates	CC
C03	Death or ADL-dependence 3 months after stroke	CC, M
C04	Death or readmission due to cardio-vascular disease within 365 days	CC
C05	ADL-independence 3 months after stroke	CC, M
C05b	ADL-independence 12 months after stroke	CC, M
C06	IADL-independence 12 months after stroke	M
C07	Mobility 3 months after stroke	M
C07b	Mobility 12 months after stroke	M
C08	Health and well-being 3 months after stroke	M
C08b	Health and well-being 12 months after stroke	M
C09	Depression 3 months after stroke	M
C09b	Depression 12 months after stroke	M
C10	Difficulties with speaking, reading or writing 3 months after stroke	M
C11	Difficulties with swallowing 3 months after stroke	M
C12	Returned to work 12 months after stroke	M
D	**Patient Satisfaction**	
D01	Patient satisfaction with hospital care following stroke	CC
D02	Fulfilled needs for support and help after hospitalisation, reported 3 months after stroke	M
D03	Patient satisfaction with rehabilitation after hospitalisation, reported 3 months after stroke	M
D04	Fulfilled needs for rehabilitation after hospitalisation, reported 12 months after stroke	M
D05	Fulfilled needs for personal care services (ADL), reported 12 months after stroke	M
D06	Fulfilled needs for domestic assistance services (IADL), reported 12 months after stroke	M
D07	Fulfilled needs for home-based medical and nursing care, reported 12 months after stroke	M
D08	Non-fulfilled needs for pain relief, reported 12 months after stroke	M
D09	Fulfilled needs for assistive devices, reported 12 months after stroke	M
D10	Fulfilled needs for transportation assistance, reported 12 months after stroke	M
E	**Carotid Surgery**	
E01	Number of carotid surgery procedures performed	CC
E02	Median waiting time to carotid surgery for patients with symptomatic carotid stenosis	CC

[1] Marking if the indicators reflect stroke care provided by the county council or the municipality, or both.

National Performance Assessment 2011

The National Performance Assessment 2011 aims to openly compare the quality and the efficiency of stroke care in Sweden. The assessment covers structures, processes, outcomes and costs of stroke care provided by both county councils and municipalities. The assessment is based on the recommendations in the National Guidelines for Stroke Care published by the National Board of Health and Welfare in 2009.

The conclusions and recommendations in this assessment draw on the results from two separate assessments – one on the performance of stroke care in county councils and one on stroke care in municipalities – and complement these with further analyses of some key areas of stroke care.

National Performance Assessment 2011 – Quality and Efficiency of Stroke Care in Sweden is primarily intended to assist decision-makers with priorities and organisational developments in county councils and municipalities. The report identifies areas of stroke care where results fall short of the intentions of the National Guidelines and thus provide a basis for improvement at local and regional level.

National Performance Assessment 2011 – Quality and Efficiency of Stroke Care in Sweden
(Article No. 2013-3-4) can be ordered from
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