

Data Quality of Surgery for Carotid Artery Stenosis. Are the National Vascular Registries Reliable?

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Objectives. To study completeness of reporting carotid endarterectomies, including peri-operative stroke and mortality rate, in a national vascular registry, NorKar, and a national administrative registry, The Norwegian Patient Register (NPR).

Design. Comparative registry-based national study.

Materials. Member hospitals of NorKar, including 89% of carotid endarterectomies in Norway, were compared with relevant data in NPR for the years 2000–2002.

Methods. We compared procedure-codes, diagnosis-codes, in-hospital death and the occurrence of peri-operative stroke after treatment for carotid artery stenosis in the two registries to evaluate completeness.

Results. Compared with the NPR numbers, 16% of carotid endarterectomies were missing in the reports from member hospitals of NorKar. Further, during this three-year period, there was an under-reporting of seven strokes and two deaths. The discrepancy was most pronounced in 2001.

Conclusions. There is an under-reporting of patients operated on for carotid artery stenosis in NorKar according to NPR numbers as well as an under-reporting of early deaths and strokes. There is a need for better quality data in the NorKar Registry. Registry quality would be likely to improve if patient identifiable data were available in both registries.

Keywords: Carotid surgery; Registries; Coding; Completeness.

Introduction

There is an increasing demand for documentation of results following surgical intervention. This is of special importance for prophylactic surgery like carotid endarterectomy. In Norway there are more than 60 official patient registries; one of them is the Norwegian Registry for vascular diseases (NorKar).¹ We have previously demonstrated an under-reporting of early death following abdominal aortic aneurysm surgery to this registry.² Increasingly patient registries are used for scientific studies. Therefore, quality control of the registries becomes more important.^{3–5}

The objective was to study quality of data on carotid endarterectomy in a national vascular registry compared to a national administrative registry. We focused on completeness of reporting procedures, in-hospital death and in the occurrence of perioperative

stroke. Finally, we evaluated how missing post-operative events could influence the results regarding stroke and mortality after carotid surgery.

Material and Methods

The Norwegian vascular registry (NorKar)

The national registry for vascular surgery was established in 1995 and includes various arterial procedures. It belongs to the Norwegian Society for Vascular Surgery. Seventeen out of 23 departments performing vascular surgery are reporting to the registry. NorKar is based on local databases with patient-identifiable data in member hospitals. Data are collected on paper forms and entered into the database. Cases are then reported anonymously to the central registry. The registry contains diagnosis-codes (limited to a maximum of three) and procedure-codes (limited to a maximum of six) for each treatment. Complications following surgery are also

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recorded in addition to other variables. Data from NorKar were retrieved on Microsoft Excel® files.

Norwegian patient register (NPR)

The Norwegian Patient Register was established in 1997 and is an independent registry of all patient treatments in public health care in Norway. The registry is owned by the Norwegian Ministry of Health and Social Affairs. Reporting to the administrative registry is compulsory to formally discharge a patient from hospital. Both hospital stays as well as out-patient consultations are recorded in the registry. The hospitals receive compensation from the authorities on the basis of the volume of reported diagnoses⁶ and procedure codes⁷ according to a DRG (diagnosis related groups)-based system and NPR consists of the reported data. Therefore, there is a strong incentive for the hospitals to report their activity completely.⁸ SPSS® was used to extract data from NPR.

Coding practice

We wanted to examine patients undergoing carotid endarterectomy for carotid artery stenosis during the years 2000–2002. The annual reports from NorKar regarding perioperative stroke and death following carotid endarterectomy are based on the number of patients with indication 'carotid stenosis, symptomatic or asymptomatic'. The use of operation codes PAF20, PAF21 or PAF22⁷ for carotid endarterectomy are recommended, but not compulsory. Based on the indication, endovascular procedures also will be represented in the annual report. The number of strokes occurring during the hospital stay is based on a remark in the NorKar form for post-operative complications, and post-operative deaths are noted with the date and cause of death. Postoperative complications are divided into 'surgical' and 'general', and should be marked in the appropriate box on the register form. Seventeen out of 23 departments of vascular surgery are members reporting to the registry.

In NPR we searched for the operation codes, PAF20-22, or the code I65.2 (ICD 10 1998) for carotid artery stenosis. Operation codes describing thrombectomy, exploration and ligation of the internal carotid artery also were included, as they probably represent procedures performed for carotid artery stenosis. First, we controlled the number of reported carotid endarterectomies from each individual department in both registries. The reported strokes among these patients in the NorKar registry were identified in NPR.

Table 1. Relevant ICD-10 diagnosis codes for patients who were operated for carotid artery stenosis

ICD-10 Chapter IX	Text*
Section I65 I65.2	Occlusion and stenosis of the carotid artery
Section I61 I61.0-8 I61.9	Specific forms of cerebral haemorrhage Unspecific cerebral haemorrhage
Section I63 I63.0-8 I63.9	Specific brain infarction Unspecific brain infarction
Section I64 I64	Stroke, not specified as haemorrhage or infarction
Section I69 I69.0-8	Sequelae following brain vessel diseases

* Translation of the Norwegian version.

We further recorded patients who had strokes reported to NPR, but had not been reported in NorKar at discharge. Whenever a patient had been discharged after more than 5 days in hospital with a secondary and new diagnosis, I61–I61.9, I63–I63.9 or I64,⁶ we presumed that the patient had suffered a peri-operative stroke. Patients with a secondary diagnoses I69.0–I69.8 indicating sequelae following cerebrovascular disease, were excluded because we anticipated that they had suffered from their stroke prior to surgery. Table 1 indicates the different peri-operative diagnosis codes for stroke according to ICD-10. The numbers of hospital deaths also were compared for both registries.

Results

NorKar reported 651 procedures for carotid artery stenosis⁹ and 612 of these fell into the category PAF20-22. After correction of seven double entries and a few inconsistent diagnosis-procedure combinations, 616 patients remained for comparison with NPR data from the same hospitals. One case of double registration and one inconsistent diagnosis-procedure combination were found in NPR, leaving a total of 735 patients for investigation. NorKar reported 22 post-operative strokes, including one fatal stroke and one stroke after balloon angioplasty. Two other deaths reported to NorKar had a diagnosis of acute myocardial infarction and ruptured abdominal aortic aneurysm, respectively. In addition, NPR included four strokes, diagnosed with codes I63.1, I63.3, I63.9 and I63.9, respectively, and three possibly fatal intracerebral haemorrhages with the codes I61.0, I61.0 and I61.9, respectively. Subsequently, there were two peri-operative deaths in NPR that had not been reported to NorKar. One patient had a diagnosis of stroke (I63.9)

Table 2. Reported number of carotid endarterectomies (CEA) and postoperative stroke and death in the Norwegian Registry for vascular diseases (NorKar) compared to the Norwegian Patient Register (NPR) for hospitals reporting to NorKar

Year	CEA in NorKar	CEA in NPR	Strokes in NorKar	Strokes in NPR	Deaths in NorKar	Deaths in NPR	Stroke/mortality rate in NorKar (%)	Stroke/mortality rate in NPR (%)
2000	164	226	3	4	1	1	2.4	2.2
2001	206	242	10	14	1	6*	5.3	7.0
2002	246	267	8	10	1†	1†	3.3	3.7
Total	616	735						

* Including three fatal strokes.

† Fatal stroke.

and unspecified angina pectoris (I20.9), indicating the possibility of a cerebral or cardiac cause of death, and the other died of unknown cause. Combining the figures from NorKar and NPR, there were altogether eight peri-operative deaths in connection with carotid endarterectomy during the years 2000–2002. Under-reporting of patients in NorKar compared to NPR usually happened when the patient was transferred to other departments or readmitted with stroke within 30 days. The under-reporting varied over time and was most pronounced in 2001, when altogether four strokes and two deaths were missing in NorKar compared to NPR data (Table 2). In 2002 the official statistics of NorKar seemed to be more in accordance with NPR. Nevertheless, two strokes after carotid endarterectomy were missing and one stroke after balloon angioplasty and stenting had been included falsely. Finally, there was double recording of one fatal stroke in the official NorKar statistics. For the entire study period, NorKar reported a combined stroke and mortality rate of 3.8%.⁹ According to NPR-data, there were 28 postoperative strokes, four of which were lethal, in addition to the two other deaths not reported to NorKar and two deaths within NorKar. This would have given a combined stroke and mortality rate of 4.4%.

Discussion

A significant proportion of patients (16%) undergoing surgery for carotid artery stenosis were missing from the National Vascular Registry, NorKar when compared with NPR data for NorKar member hospitals. This is similar to data from the Finnvasc and SWEDVASC registries, where the mean percentage of missing cases compared to hospital records were 19 and 16%, respectively.^{10,11} The present investigation indicates an under-reporting of operative procedures as well as stroke and mortality following carotid endarterectomy in the National Vascular Registry compared to the National Administrative Registry. This is a serious problem since stroke

and mortality are well-defined end-points of major importance for the definition of quality of carotid artery surgery. Usually less severe complications, like wound problems, are more likely to be omitted from registration.¹² Under-reporting is also more frequent for emergency procedures,¹⁰ but carotid endarterectomy in most cases is performed on an elective basis. The reporting to NPR is likely to be almost complete because reporting is compulsory for formal discharge of a patient from hospital, and subsequent reimbursement from the health authorities. In the National Vascular Registry there is no economic motivation or administrative demand for reporting to the registry. These facts may explain some of the discrepancy in numbers reported to the two registries for some of the member hospitals. Some of the departments did not report to the central NorKar registry every year. This impairs the quality of the registry and contributed heavily to the discrepancy between the two registers.

There is a theoretical possibility that the administrative registry could over-estimate the number of cases.⁴ One double entry was found in the NPR, probably because the hospital had reported the same procedure twice, but otherwise only admissions with both diagnosis-code and procedure-code relevant to carotid endarterectomy were counted. Furthermore, patients have a unique i.d. number and readmissions within the same calendar year are readily identified. Therefore, we think that over-reporting is unlikely to represent a problem.

In the NorKar registry the patient is supposed to be followed at the out-patient clinic 1 month and 1 year after surgery. Complications occurring during the interval from discharge until 30 days should be reported in the NorKar form. Under-reporting of three patients or more was seen in six different departments, indicating that there were no departments systematically under-reporting to NorKar. We suppose that the under-reporting to NorKar is due to lax reporting standards for this registry. For example, when patients are transferred to other units because of a complication, they may be treated by groups of personnel other than surgeons, who may be unaware

of the vascular registry.^{11,12} We also think that reporting of 1 month follow-up at the out-patient clinic was unsatisfactory. No matter the reason, early mortality and stroke rate following carotid surgery are crucial data and it is important to improve these results in our local vascular registry. Also in NPR, readmissions to the same institution are recorded, whereas admissions to other hospitals for a complication or an operation will not be identified. This could result in under-reporting of complications. Making the two registries patient identifiable can solve most of these problems.

During the study period the combined annual stroke-mortality rate varied. According to NPR the highest complication rate was seen in 2001 when the stroke-mortality rate was 7% compared to 2.2% in 2000 and 3.7% in 2002. We have no indications that there were changes in operative technique or indications for surgery during these 3 years and the discrepancy is probably due to chance. It is pertinent that four deaths after carotid endarterectomy, probably were caused by intracerebral haemorrhage. This is consistent with the high mortality rate observed for post-operative cerebral haemorrhage after carotid endarterectomy.¹³

The total number of carotid endarterectomies in Norway for the 3 year period was 822 according to NPR. Thus, our study of 735 patients includes 89% of these. This selection should be fairly representative of routine practice and results. However, we have not studied the reporting in NPR of the remaining 11% of the patients operated with carotid endarterectomy, since these represent procedures that were not reported to NorKar.

How can we improve the register?

We believe that clearer guidelines for coding and proper instructions for participating surgeons could make the registration easier to use, safer and more complete.³ Since, 2002 it has become compulsory to record specifically that there had been no post-operative cerebral complications after carotid endarterectomy in NorKar. Previously, a secondary diagnosis would not have given a clear indication of such complications since only 12 out of 22 patients with stroke after carotid endarterectomy had an adequate secondary diagnosis recorded. However, in 2002 there was still a certain amount of incorrect coding.

Medical registries are used increasingly for scientific work. However, we need a better strategy to get correct data from the NorKar registry. Matching of the two registries is one way of effecting quality control of

NorKar, but improved quality can also be obtained by an algorithm to ensure complete recording of primary and secondary diagnoses. The responsibility for correct reporting should be given to one particular surgeon, and data transfer should be done by trained staff. Direct data entry into the computer, with warning systems for logical errors or improbable values, could make this easier and safer.¹⁰ A validation of the registry should probably be done on a regular basis and random validation of a limited time span may be as effective as a more extensive comparison.¹⁴ A short period of validation, monitoring and feedback to participating centres also may improve the quality of a register.¹⁵

In conclusion we have shown an under-reporting of carotid endarterectomies when comparing the National Vascular Registry (NorKar) with the National Administrative Registry (NPR). Also early deaths and strokes were under-reported in NorKar. If NorKar data are to be used to establish a national standard and allow comparison between centres, there is a need for a better quality of the data in the NorKar registry.¹⁶ We suggest that both NorKar and NPR are made patient identifiable.

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