Identification of stroke in the community: a comparison of three methods

J Mant, R J McManus, R Hare and P Mayer

SUMMARY

Background: *Evidence concerning secondary prevention of cerebrovascular disease is not optimally used in clinical practice. A necessary first step is to identify those eligible for treatment. In primary care, this equates to setting up a register of prevalent stroke.*

Aim: *To compare three different methods for identifying prevalent cases of cerebrovascular disease in the community: general practice-based computer systems; population surveys; and hospital-based routine information systems.*

Design of study: *Comparison of results of each method applied to a defined population and then assessed against reference criteria for cerebrovascular disease.*

Setting: *A total of 5801 people aged 65 years or over, resident in seven practices situated within the South Birmingham Primary Care Trust area.*

Method: *The sensitivity, specificity, and predictive value of each method of identification were calculated against reference criteria applied by two investigators independently of each other.*

Results: *The prevalence of reference criteria-validated cerebrovascular disease in patients aged 65 years or over was 8.2%. Overall, general practice-based computer systems had a sensitivity of 81.0%, a specificity of 97.2% and a positive predictive value (PPV) of 71.8%, but there was a wide range of sensitivity (33% to 90%) and PPV (42% to 92%) between practices. Patient survey and hospital information systems were less sensitive (75.7% and 28.4%, respectively) but had higher PPVs (77.5% and 89.2%, respectively). Thirty-nine per cent of patients with a history of cerebrovascular disease had not been admitted to hospital.*

Conclusion: *General practice-based computer systems can produce reasonably accurate prevalent stroke registers. In areas where these are poorly developed, patient survey is an alternative.*

Keywords: *cerebrovascular disease; secondary prevention; computerised medical records; prevalence survey; stroke registers.*

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Introduction

THERE is a strong evidence base for reducing the risk of stroke in people with pre-existing cerebrovascular disease. Effective treatments include blood pressure and cholesterol lowering,[1,2] using antiplatelet agents[3] or anticoagulants if there is co-existing atrial fibrillation,[4] and encouraging lifestyle modification in terms of diet and exercise.[5] However, uptake of these interventions remains patchy. In a survey in the United States, 61% of people with a history of stroke reported receiving advice on diet, and 64% advice on exercise.[6] In the United Kingdom (UK), analysis of primary care data between 1992 and 1996 suggested that only a minority of patients with cerebrovascular disease were on aspirin.[7] In contrast, the recent British National Sentinel Audit found that, six months after admission to hospital for stroke, 91% of people were on aspirin.[8] However, six months after stroke, only a minority of patients (37%) had been given lifestyle advice, and over a third of people who had high blood pressure were not on antihypertensive therapy.[8] The National Sentinel Audit reflects care of incident strokes, whereas the primary care data reflect care of prevalent stroke patients, some of whom will not have been admitted to hospital.

A necessary first step to ensuring that patients with cerebrovascular disease are receiving optimal therapy to prevent stroke is identifying who those patients are. Experience from setting up coronary heart disease registers suggests that this activity alone can lead to substantial improvements in follow-up and assessment of individuals.[9] There are two complementary ways to set up stroke registers — identify new cases as they occur (incident cases), or identify people who have had a stroke in the past (prevalent cases). The former is appropriate for hospital-oriented programmes of secondary prevention, whereas the latter is more relevant for community-based programmes, given that the point prevalence of stroke will be ten times higher than the annual incidence.[10] This has been recognised in national strategies. For example, in the UK, the National Service Framework for Older People requires that 'every general practice can identify people who have had a stroke' by 2004.[11] The aim of this study was to compare the accuracy of three different methods of identifying prevalent cases of cerebrovascular disease in the community: general practice-based registers; population surveys; and use of hospital-based routine information systems. Under the umbrella of cerebrovascular disease, we included both stroke and transient ischaemic attack (TIA), since both benefit from the same therapies to reduce stroke risk, and the distinction between the two is arbitrary, in that a proportion of patients who have a clinical TIA have evidence of cerebral infarction on a computed tomography scan.[12]

HOW THIS FITS IN

What do we know?

Interventions, such as blood pressure-lowering, lipid-lowering, and aspirin therapy, are highly effective for secondary prevention of stroke, but several studies, including the recent British National Sentinel Stroke Audit, have demonstrated that such therapies are not being optimally used. A necessary first step to improve population coverage of secondary prevention is to identify who has had a stroke.

What does this paper add?

Some general practices can identify most (up to 90%) of their patients with cerebrovascular disease from their computer system, but others can only identify a minority in this way. Linkage with hospital systems may not lead to significant improvement, since many patients with cerebrovascular disease are not admitted or referred (in the case of transient ischaemic attack). Patient survey can identify 70% of cases of cerebrovascular disease, so may have a role in supplementing practice computer systems.

Method

Seven practices were recruited from within the South Birmingham Primary Care Trust (PCT) who were also members of the Midlands Research Practices Consortium (MidReC). This PCT comprises 68 practices with a total population of 368 000. Its mortality from stroke (2.36 per 10 000 aged under 75 years)[13] is similar to the national rate (2.56 per 10 000).[14] The seven practices have a total population of 36 946, and were selected to represent both small and large practices (range of size from 2215 to 7572) and areas of low and high deprivation (range of index of multiple deprivation score from 18.97 to 46.31 with a mean of 32.40, as compared with the South Birmingham PCT mean of 33.03).

The study population comprised patients registered with the participating practices in January 2002 who were aged 65 years or over. Patients who might have suffered a stroke were identified in three ways. First, a simple validated questionnaire was sent, asking whether the responder had ever had a stroke.[15] The wording was designed to identify both stroke and TIA. A single reminder was sent to non-responders. Secondly, the general practice computer systems were searched for relevant diagnosis and symptom codes for stroke and TIA (Table 1). Thirdly, the information system covering all hospital trusts (acute and community) in the South Birmingham area were searched for hospital admissions in the previous five years with a relevant diagnosis code (ICD-9 430-438 and ICD-10 I60-I69 and G45) for patients registered with the participating practices. Where there were discrepancies between the three data sources, the general practice records were reviewed (including hospital letters and discharge summaries) to ascertain what evidence there was to corroborate the diagnosis of stroke or TIA.

Two of the authors (JM and RM) independently applied a set of reference criteria, to judge whether each patient had a previous stroke or TIA (Table 2). Unsubstantiated stroke or TIA was counted as negative. Where disagreements occurred, a final decision was reached through discussion. The sensitivity, specificity, and predictive value of each of the three methods of stroke identification in the community were calculated against these criteria. The South Birmingham Local Research Ethics Committee approved the study.

Results

There were 5801 people aged 65 years or over in the participating practices. Of these, 296 (5.1%) were identified from the general practice computers as having had a stroke, and 524 (9.0%) as having had a stroke or TIA. Five thousand and forty-four people responded to the postal questionnaire, a response rate of 87%. Of these, 462 patients reported that they had had a stroke, representing 8% of the total and 9.2% of the responders. One hundred and forty-eight (2.6%) of the current practice patients were identified from the local hospital information systems as having had a stroke during the previous five years.

The overlap between the different sources of information is shown in Figure 1. One hundred and seventy-one (2.9%) patients reported a stroke that had not been identified from the general practice or hospital information systems. For 55 (32%) of these, there was uncoded evidence (free text or letter) in the general practice records of a stroke, and for a further 24 (14%) there was evidence of a TIA. In the remainder (92 [54%]), there was no corroborative evidence of any cerebrovascular event. Two hundred and eighteen cases were identified by the general practice computer system alone. Over half of these (118) had a diagnosis of TIA, but only in 34 (29%) of these was there evidence of confirmation of the diagnosis by a specialist.

Three hundred and eighty-nine (6.7%) of the study population had had strokes according to the reference criteria in Table 2. There were a further 75 (1.3%) who had had TIAs, giving an overall prevalence of cerebrovascular disease of 8.0%. If unsubstantiated cases (126 TIA; 18 stroke) are included, the prevalence rises to 10.5%.

The performance of each of the three methods of identifying stroke against these reference criteria is shown in Table 3. General practice computer systems were the most sensitive method of identifying cerebrovascular disease, but there was only a 71.8% chance that a positive diagnosis would be correct. Conversely, hospital information systems only identified 28% of strokes, but had the highest PPV. The postal questionnaire missed 30% of people with cerebrovascular disease. Seventy-eight (56%) of these 139 cases were missed because there was no response to the questionnaire. Out of 325 patients who correctly stated that they had cerebrovascular disease, 128 (39%) reported that they were not admitted to hospital.

Table 4 shows the accuracy of the general practice computer systems by practice, ranked in order of decreasing sensitivity for cerebrovascular disease diagnosis. There was wide variation between practices in both sensitivity (33% to 90%) and PPV (42% to 92%). Practices achieving higher sensitivities tended to record consultations exclusively on computer. The two smallest practices achieved the lowest sensitivities.

Table 1. Read codes used in the general practice computer searches to identify possible cerebrovascular disease.

Description	Read code (5-byte)[a]
Cerebrovascular disease	G6
[X]Cerebrovascular diseases	Gyu6
Phlebitis and thrombophlebitis of intracranial sinuses	F05
Hemiparesis/Hemiplegia	F22
H/O codes for cerebrovascular disease	14ab,14af,14ak,14a7,1477,14a
O/E — paralysis	2833
Subacute confusional state, of cerebrovascular origin	E03
Stroke monitoring	662m
Stroke in the puerperium	L440
TIA	G65
H/O TIA	14ab
[x] Other cerebral TIAs and related syndromes	Fyu55
Cerebrovascular disease not TIA	G6 exclude G65
H/O subarachnoid haemorrhage	14af
H/O stroke in last year	14ak
H/O stroke/CVE	14A7
Hemiplegia codes	F22

[a]In each case, subcodes below the stated code in the Read hierarchy were also searched. H/O = history of; O/E = on examination; CVE = cerebrovascular event; TIA – transient ischaemic attack.

Discussion

The prevalence of cerebrovascular disease in patients aged 65 years or over was found to be 8.0% — a finding consistent with other UK surveys.[16,17] Computer-based general practice registers identified 81% of these cases, but there was wide variation between practices. The patient survey identified 70%, and hospital information systems 28% of these cases. Thirty-nine per cent of cases had not been admitted to hospital and the majority of patients with a general practitioner (GP) diagnosis of TIA had not been reviewed by a specialist.

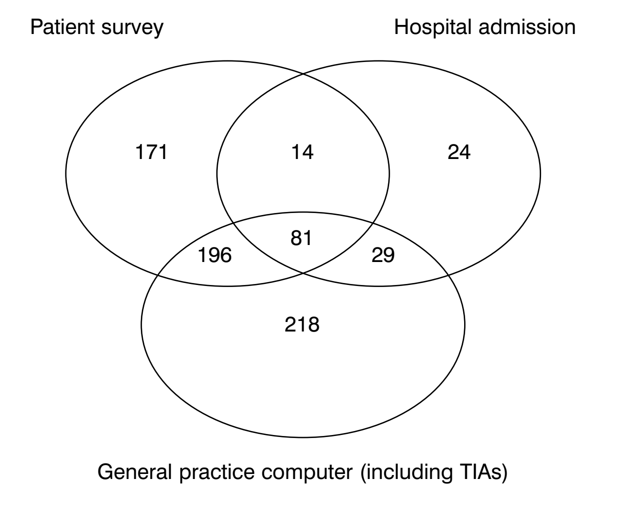

Figure 1. Possible cerebrovascular disease (stroke or TIA) by method of identification.

Table 2. Reference criteria for determining whether a cerebrovascular event has taken place.

Diagnosis	Criteria
No CVE	No positive identification of a CVE from any of the three methods OR CVE reported by patient, but no corroboration from other sources (including review of patient record)
Unsubstantiated TIA	TIA recorded in general practice records without corroboration from a specialist
TIA	TIA recorded in general practice records with corroboration from a specialist
Unsubstantiated stroke	Stroke identified from an electronic source (general practice or hospital) with no corroboration from other sources
Stroke	Stroke identified from at least two sources OR CVE identified from one source with evidence of stroke in review of patient record

CVE = cerebrovascular event; TIA = transient ischaemic attack.

Strengths and limitations of this study

This is the first study to compare the accuracy of these different possible methods of identifying prevalent cases of stroke in the community. There are five limitations that need to be considered. First, there is the risk of incorporation bias, in that the reference criteria take account of the results of the different methods that were being evaluated. The effect of this would be to artificially improve the performance of the methods being evaluated. However, this applies to all three methods, so comparisons of the relative accuracy of the different methods are still valid. The overall effect is likely to be small, since to count as a ‘true positive’, a case needed to be corroborated by at least one of the other methods, or be verified in case note review. Secondly, the reference criteria may have missed some strokes, so the ‘true’ prevalence may have been higher than observed. The effect of this would be to overestimate the sensitivity of each of the methods. Again, this applies to all three methods, so comparisons of relative sensitivity remain valid. Thirdly, uncorroborated events were counted as ‘false-positives’, and it is conceivable that some of these were true cerebrovascular events, in which case this study will have underestimated the predictive value of the individual methods of identification. Fourthly, the practices were drawn from a single area of the UK, and incorporated practices where the performance of the general practice computer systems may be anticipated to be above average (see below). Finally, only patients aged 65 years or over have been included. This was a pragmatic decision, as the majority of strokes occur in people over the age of 65[10] and it would have been impractical to

Table 3: accuracy of three methods of identifying prevalent stroke in the community.

	Sensitivity (%)	Specificity (%)	Positive predictive value (%)
General practice computer	376/464 (81.0)	5189/5337 (97.2)	376/524 (71.8)
Hospital information system	132/464 (28.4)	5321/5337 (99.7)	132/148 (89.2)
Patient survey	325/464 (70.0)	5200/5337 (97.4)	325/462 (70.3)

Table 4. Accuracy of general practice information systems by practice, ranked in order of sensitivity.

Practice rank	Characteristics of computer diagnosis coding[a]	List size (multiple deprivation score)	Sensitivity (%)	Positive predictive value (%)
1	Computerised summaries and paperless consulting	6235 (31)	77/86 (89.5)	77/114 (67.5)
2	Computerised summaries and paperless consulting	5731 (39)	75/86 (87.2)	75/95 (78.9)
3	Computerised summaries for new patients only; paperless consulting	7572 (23)	80/94 (85.1)	80/87 (92.0)
4	Computerised summaries; dual-entry consulting	4558 (46)	51/61 (83.6)	51/66 (77.3)
5	Computerised summaries; paperless consulting	7250 (37)	67/81 (82.7)	67/111 (60.4)
6	Computerised summaries; dual-entry consulting	3385 (31)	16/26 (61.5)	16/38 (42.1)
7	Computerised summaries; paper records for consulting	2215 (19)	10/30 (33.3)	10/13 (76.9)

[a]Computerised summaries: patient records have been summarised and entered on computer. Paperless consulting: computers used exclusively to record consultations. Dual entry consulting: combination of computer and paper records used to record consultations. Paper records for consulting: paper records used exclusively for consulting.

survey the whole practice population.

Interpretation of findings in the context of previous research

The observed variations in the completeness and accuracy of practice computer-based cerebrovascular disease registers are similar to those that have been reported for coronary heart disease.[18] The wide variation in sensitivity between practices reflects the extent to which diagnoses have been coded onto computer through note summarising and/or ongoing data entry during consultations. The high sensitivity observed in some practices demonstrates that these processes can lead to reasonably complete cerebrovascular disease morbidity registers. The practices in this study were all research active and five were involved in GP training or undergraduate teaching. As such, the standards of computer diagnosis coding in these practices will be above average (summarising of notes is a prerequisite for training practice status and is required locally for those practices with extensive undergraduate teaching input). The wide variation in PPV between practices reflects the extent to which there was verification of a diagnosis of cerebrovascular disease, which will reflect GP referral patterns. The main reason for false-positives was GP diagnoses of TIA that had not been substantiated by specialist opinion. It is likely that many of these diagnoses will be incorrect. For example, in a review of 332 patients referred to a regional neurovascular clinic, in only 60% of cases did the neurologist agree with the diagnosis.[19] Current guidance recommends that patients with suspected TIA are referred to a specialist neurovascular clinic within two weeks and PCTs are required to have protocols in place by April 2004 for referral to such services,[5,11] so these false-positive errors may become less common.

The simple patient questionnaire asking about stroke achieved a high response rate — a finding consistent with other studies.[15-17] However, this approach will be less efficient in people aged less than 65 years, in whom the prevalence of cerebrovascular disease is low. We found a sensitivity of 70% for the patient survey, which is lower than the 95% sensitivity reported in Newcastle.[15] Our analysis included non-responders, and counted TIA in the 'reference standard'. While non-response explains a proportion of those missed, 61 patients who had evidence from the general practice record of cerebrovascular disease reported that they had never had a stroke or TIA. Conversely, we could find no evidence of cerebrovascular disease in the records of 92 patients who reported that they had had a stroke. The positive predictive value (PPV) of 77.5% for patient-reported cerebrovascular disease was very similar to the Newcastle results (PPV = 79% if TIAs included), where the diagnosis was validated by a home visit and review of medical records.[15] The discrepancies between patient self-reporting and the 'reference standard' perhaps highlight differences between lay and professional understanding of what is meant by a stroke.

Hospital information systems, while highly specific for cerebrovascular disease, only identified a quarter of the prevalent cases of cerebrovascular disease. At least 128 (28% of the total number of confirmed cases) will have been missed because the patient was not admitted to hospital. Other explanations for the low sensitivity are that the stroke may have occurred over five years ago, or the patient may have been admitted to a hospital outside south Birmingham. The high specificity of the hospital information system is consistent with a study of incident stroke in Oxford, which found that the main reason for false-positives was that previous stroke was coded as current stroke, which is not a problem if prevalent stroke is being sought.[20] While it is difficult to generalise on the accuracy of hospital information based on one area — for example, in other areas it may be possible to link to admissions in other hospitals, or search over the previous five years — a major limitation of hospital systems identified in this study is that a significant proportion of prevalent stroke patients were never admitted. This finding is consistent with previous incidence studies: the Oxford Community Stroke Project (1981–1985) found that only 55% of patients with stroke were admitted to hospital,[21] while more recent studies have found higher hospitalisation rates: 70% in East Lancashire and 84% in South London.[22,23] A prevalent population of cerebrovascular disease patients contains a higher proportion of people with minor stroke or TIA than an incident population, which will be a factor towards explaining the low admission rate in this study.

Implications for clinical practice

In order to optimise secondary prevention of cerebrovascular disease, it is important to be able to identify which people have had a stroke or TIA in the past. This study suggests that the method with the best potential for identifying cerebrovascular disease in the community is the use of general practice computer systems. However, considerable effort will be required in some practices to develop such cerebrovascular disease registers, since drug codes cannot be used as a proxy for diagnosis codes.[24] Hospital information systems offer an unsatisfactory alternative, since many patients with cerebrovascular disease will never have been admitted. In areas with poorly developed general practice registers, patient survey may offer an alternative interim measure to identify people who might benefit from secondary prevention.

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