Validation of Patient Recall of Doctor-diagnosed Heart Attack and Stroke: A Postal Questionnaire and Record Review Comparison

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Few studies have assessed the accuracy of patient recall of doctor-diagnosed heart attack and stroke on postal questionnaire, yet such data are widely used in epidemiologic studies. In the national prospective British Regional Heart Study of 7,735 men aged 40–59 years, based in general practice and followed up for a mean 13.8 years, a mailed questionnaire was sent to all available survivors in 1992. Patient recall of doctor-diagnosed heart attack and stroke was compared with the 316 new general practice-reported heart attacks and 102 new general practice-reported strokes from the medical record reviews. Both study and general practice records were checked for all discordant findings, and corrections were made to the study database. Patients tended to overrecall major cardiovascular events more than they underrecalled them, 33% versus 6% for heart attacks and 25% versus 11% for strokes. Among overrecalled heart attacks, other circulatory problems were present in 78% of the subjects; transient ischemic attacks accounted for 57% of overrecalled strokes. In contrast, the general practice record review system tended to underreport events rather than to overreport them, 3% versus 0.3% for heart attacks and 23% versus 5% for strokes. Patient recall of doctor-diagnosed heart attack and stroke provides a useful method for estimating prevalence rates and resource needs, but the tendency to overestimation needs to be recognized. In etiologic studies when strict diagnostic case criteria are essential, patient recall should be used to complement rather than to supplant medical record data. Am J Epidemiol 1998;148:355-61.

cardiovascular diseases; medical records; questionnaires, recall

Compared with the rigorous standardization and validation of clinical measurements in epidemiologic field studies, there have been few attempts to evaluate information collected by administered or self-completed questionnaire. In particular, few studies have fully examined the validity of patient recall of doctor-diagnosed conditions such as major cardiovascular disease events, yet increasing use is being made of patient questionnaire information to establish both the prevalence and incidence of chronic diseases (1–3). In a review describing studies of patient questionnaire data compared with medical records (4), fewer than 30 suitable studies were found, of which only five (5–9) included data on cardiovascular disease. Since that review, four further studies have been published (10–13).

The British Regional Heart Study has collected incident cardiovascular disease morbidity data from two sources (patient recall on questionnaire and case finding from review of general practice records), which provide an opportunity to examine the validity of patient recall of doctor-diagnosed heart attack and stroke. After a focused reexamination of the study documentation and general practice records for all discordant reports, we were able to correct the study database for major nonfatal cardiovascular events and to quantify the inaccuracies from both sources.

MATERIALS AND METHODS

Study subjects

The British Regional Heart Study includes 7,735 men aged 40–59 years at recruitment, randomly selected from age-sex registers of a group general practice in each of 24 towns in England, Wales, and Scotland. Details of the town and practice selection, the recruitment, and examination of the men have previously been described (14). Men were included in the study sample whether or not they had a history of preexisting cardiovascular disease. The few exclusions made by the general practitioner (6–10 men per practice) were patients with severe mental or physical disability. Of the 9,971 men invited to attend, 7,735 (78 percent) presented for examination between 1978 and 1980.
Ascertainment of heart attack and stroke by patient recall

At the initial examination, a research nurse administered a questionnaire (Q1) that asked about recall of 12 medical conditions diagnosed by a doctor. In November 1992, these questions were asked again on a postal questionnaire (Q92) sent to all available surviving men (6,563) still living in Great Britain. A reminder was sent 1 month after the initial mailing and again after a further 4 weeks if a subject had still not replied. On each occasion the men were asked, “Has your doctor ever told you that you have, or have had: 1) heart attack (coronary thrombosis or myocardial infarction), 2) angina, 3) other heart trouble, 4) high blood pressure, 5) stroke, etc.?”

Follow-up procedures

After the initial examination, the general practice medical record of each man was stamped for follow-up for four specific cardiovascular conditions (heart attack, angina, stroke, transient ischemic attack), plus death or removal from the original practice to a new general practice. A card was inserted into each set of notes, both as a prompt and as a report card for the four specific cardiovascular disease events as they occurred during the first 8 years. Details of this procedure have been described (15). In addition, every 2 years the practice coordinator reviewed the medical records of all the British Regional Heart Study subjects in that practice, using a computer listing supplied by the study center. All new cardiovascular disease events, deaths, and removals from the practice were recorded with the date of occurrence. At the eighth anniversary of each man’s entry to the study, a full 8-year retrospective record review was carried out to confirm all incident cases to that date. At this point the British Regional Heart Study card was withdrawn from the notes and returned to the study center, but the record reviews occurring every 2 years continued.

Removal to a new general practice

All men who moved and registered with a new general practitioner were followed through the routine registration procedures at Family Health Service authorities and, when necessary, the National Health Service central registers at Southport and Edinburgh. All new general practices were requested to provide information similar to that supplied by the original group practices by completing a brief inquiry form every 2 years (Appendix). In 1992, they were also asked to provide the patient’s current address to enable a questionnaire to be mailed directly to the subject. All but two of the 1,057 new general practices provided this information.

Case criteria

All reports of a myocardial infarction were followed for evidence of World Health Organization case criteria in which two of the following conditions had to be present: severe chest pain lasting at least half an hour, electrocardiographic evidence of a myocardial infarction, and raised cardiac enzyme levels. If the information was not available from hospital discharge summaries in the general practice records, a letter was sent to the hospital consultant with a brief inquiry form seeking this information.

Angina was defined as typical effort- or stress-related chest pain (16). A reported stroke was required to have acute symptoms of cerebral dysfunction of vascular origin lasting 24 hours or more. A diagnosis of transient ischemic attack was made if disturbance of cerebral function of vascular origin lasted under 24 hours and left no residual deficit. Clinical evidence for these three conditions was not sought following reports from the record reviews.

Cross-checking of discordant data

Those men who already had a diagnosis of heart attack recalled at Q1 (n = 147) or stroke (n = 27) were excluded from the validation analyses, leaving 5,787 and 5,907 men, respectively. Cross-tabulation of patient recall (yes/no) with general practice report (yes/no) for heart attack and stroke identified all discordant reports. The study records (both patient questionnaires and general practice reports) of these patients were retrieved and reexamined to see what other cardiovascular or noncardiovascular conditions had been recalled and what had been recorded in other parts of the questionnaire that might explain the discordance. In particular, questions relating to medication, referral, hospitalization, and disability were checked and, where there was clinical inconsistency, a specific inquiry form was sent to the general practice coordinator for confirmation or rejection of the patient-recalled event. Reports from the general practice record reviews of possible cardiovascular events that did not meet our case criteria were accepted as an explanation of the recalled event without further inquiry.

Statistical methods

The kappa statistic was used to assess the strength of agreement (yes/no) between patient recall and general practice report, corrected for chance (17). The false positive rate of recall is equal to the false positive recall divided by the total positive recall \((b/a + b)\). The false negative rate of recall is equal to the false negative recall divided by the total positive general
practice reports \((c/a + c)\). These summary measures, also used in the Leisure World Study (11), were chosen as they describe the discordance being assessed more appropriately than the usual measures of test validity (sensitivity and positive predictive value).

**RESULTS**

From the initial recruitment of 7,735 men in 1978–1980, 5,787 and 5,907 subjects aged 52–74 years in 1992 were eligible for inclusion in the analyses (table 1).

**New heart attacks occurring in survivors between entry (Q1) and Q92**

Among the 5,787 available subjects with no initial history of a heart attack, comparison of patient recall of a doctor-diagnosed heart attack with reported events from general practice record reviews identified 296 agreed cases of myocardial infarction, 5,311 agreed negative subjects, and 180 discordant reports (Kappa statistic = 0.74), indicating a high level of consistency between the two measures (table 2).

Of the 20 general practice reports of heart attack not recalled by the patient, the validation inquiry found one to be a reporting error (due to a father and son with the same name and address). Thus, one subject was added to the true negative cell (table 2). Of the remaining 19 general practice-reported heart attacks not recalled by the patient, the study records indicated that presentation was atypical, that is, without severe chest pain in 13 of these subjects. On the postal questionnaire, 11 of these 19 patients had recalled “angina,” and two had recalled “other heart problems,” again leaving six cases without any suitable explanation.

Of the 160 “false positive” recalls by patients, further examination of the general practice records found an additional 11 cases of heart attack. In the 149 remaining subjects (table 2), 117 men (78 percent) were found to have some record of cardiovascular problems. These included possible myocardial infarction \((n = 14)\), angina \((n = 61)\), coronary artery bypass graft \((n = 18)\), angioplasty \((n = 4)\), stroke \((n = 4)\), and other circulatory problems \((n = 16)\), for example, deep vein thrombosis, pulmonary embolus, and miscellaneous conditions, leaving 32 unexplained patient-recalled heart attacks.

**Corrected database for heart attacks**

After the addition of the 11 newly identified heart attacks from the general practice records and the removal of the one erroneous report, the new database total of 326 events was used to calculate the false reporting rates. Against this best available information, the false positive patient recall rate was 33 percent \((149/456)\), and the false negative recall rate was 6 percent \((19/326\) from table 2), compared with false positive general practice reporting of 0.3 percent \((1/316)\) and a false negative rate of 3 percent \((11/326\) from table 2).

**New strokes between entry (Q1) and Q92**

Similarly in the 5,907 subjects with no previous history of stroke, a comparison of patient recall of a doctor-diagnosed stroke with reports from general practice record reviews identified 83 agreed cases.
5,687 men free from a diagnosis of stroke, and 137 (118 + 19) discordant reports (table 3) (kappa = 0.54, moderate agreement).

Of the 19 general practice reports of stroke not recalled by the patient, five were subsequently found to be documentation errors due to poor record legibility, clerical transcription, and data entry. In the 14 remaining men with general practice-reported strokes, which they did not recall, multiple conditions including other cardiovascular disease were present in all subjects. Among the 118 men who recalled a stroke for which there was no supporting general practice report, reexamination of the general practice records identified 29 additional strokes. A further 51 men were recorded in the general practice records as having had a transient ischemic attack, although these men were probably told by their general practitioner that they had had “a small stroke.” In the remaining 38 subjects (table 3), confusion with other diagnoses, such as facial palsy and multiple problems not apparently associated with cardiovascular disease, was identified in six cases; otherwise no explanation was found.

Corrected database for strokes

The new information from the general practice records added 29 new stroke reports to the database and removed five incorrect reports, a net increase of 24 strokes (table 3). The 51 men with patient-recalled strokes that were matched with transient ischemic attack reports from general practice records were transferred to the stroke-free cell for the purpose of this analysis. Thus, 38 false positive recalls of stroke remained, giving a false positive recall rate of 25 percent (38/150) (compared with 59 percent before correction) and a false negative recall rate of 11 percent (14/126) (19 percent uncorrected). The false positive rate of general practice reports was 5 percent (5/102), and the false negative rate was 23 percent (29/126).

DISCUSSION

The primary purpose of this analysis was to examine the validity (correctness and completeness) of patient recall of two specific diagnoses (heart attack and stroke), given by a doctor within a defined time period (1978–1992) and reported by them on questionnaire in December 1992. The measure used to evaluate patient recall was the information recorded in the British Regional Heart Study database from general practice reports during this time period, obtained from the standard British Regional Heart Study report card and from record review procedures occurring every 2 years that were introduced into the collaborating general practices in 1978–1980. By 1986–1988, many new partners had joined the original 24 practices, and 1,057 men had moved to new general practices throughout Great Britain. These doctors were unfamiliar with the study procedures and, for this reason, the British Regional Heart Study card, which required proactive reporting, was withdrawn and a thorough 8-year retrospective review was carried out on 7,084 records (99.2 percent of survivors in 1986–1988), to ensure that all major cardiovascular disease events had been recorded on the study database. The retrospective record reviews occurring every 2 years continued regularly from 1980 to 1992.

Case ascertainment

The information gained from this validation inquiry of patient recall identified a small number of errors in the general practice record review/reporting system, despite all the efforts made. It also highlighted the patients’ confusion with terminology between various cardiovascular conditions. Combining information from the two data sources improved the database, more for strokes than for heart attacks, as illustrated by the corrected estimates. This is likely to be due to the greater attention given to the confirmation criteria of a heart attack in the general practice-reporting protocol. Compared with the corrected database, patientrecall tended to overreport rather than underreport for both stroke and heart attack. General practice reports from record reviews, not surprisingly, produced more false negative (omissions) than false positive (incorrectly documented) reports.

TABLE 3. Stroke by patient recall compared with initial database and corrected study database and by initial general practice (GP) reports compared with corrected study database, British Regional Heart Study, 1978–1992

<table>
<thead>
<tr>
<th></th>
<th>Positive</th>
<th>Negative</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Patient recall</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Positive</td>
<td>83 (a)*</td>
<td>118 (b)</td>
<td>201</td>
</tr>
<tr>
<td>Negative</td>
<td>19 (c)</td>
<td>5,687 (d)</td>
<td>5,706</td>
</tr>
<tr>
<td>Total</td>
<td>102</td>
<td>5,805</td>
<td>5,907</td>
</tr>
<tr>
<td><strong>Corrected database after supplementary record review</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient recall</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Positive</td>
<td>112</td>
<td>38</td>
<td>150</td>
</tr>
<tr>
<td>Negative</td>
<td>14</td>
<td>5,743</td>
<td>5,757</td>
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<tr>
<td>Total</td>
<td>126</td>
<td>5,781</td>
<td>5,907</td>
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<tr>
<td>Initial GP reports</td>
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<td></td>
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</tr>
<tr>
<td>Positive</td>
<td>97</td>
<td>5</td>
<td>102</td>
</tr>
<tr>
<td>Negative</td>
<td>29</td>
<td>5,776</td>
<td>5,805</td>
</tr>
<tr>
<td>Total</td>
<td>126</td>
<td>5,781</td>
<td>5,907</td>
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* Italic letters in parentheses: a, true positive; b, false negative recall; c, false positive; d, true negative recall.
Over- and underreporting

Heart attack. Overrecall of heart attacks by the man was largely due to the presence of other cardiovascular conditions. Unstable angina and chest pain leading to a hospital admission that did not culminate in a diagnosis of definite heart attack were also identified as contributory factors by two other studies (10, 12). Patient recall of a heart attack appears to be influenced strongly by the subject's experience of pain and anxiety rather than by the information given by the doctor when a suspected diagnosis is not confirmed (12, 18). The term coronary thrombosis, offered on the questionnaire as an alternative diagnosis for heart attack, can provoke inappropriate responses from men who have had other forms of thrombosis. Underreporting appears to occur in those patients who did not experience severe chest pain but who presented with atypical symptoms and subsequently received a diagnosis confirmed by electrocardiogram and enzyme levels.

Stroke. Overrecall of stroke was largely due to the doctor's recording a transient ischemic attack in the general practice records, while telling the patient that he had probably had a "small stroke." In addition, some confusion was caused by patients experiencing impairment from other conditions such as facial palsy and physical disability, which they attributed to a stroke. Few men who had a stroke failed to report it, but for those in whom it was one of many serious illnesses, it was lost from recall.

Results from previous studies

Patient recall of doctor-diagnosed conditions is frequently used either as a baseline for establishing pre-existing disease in prospective studies (6, 12, 14), or as a method of estimating prevalence and health care needs in populations (1-3). Criteria for validity tend to vary according to the purpose of the data collection. In studies investigating etiology and risk factor interactions, a high case specificity is the preferred quality (correctness over completeness) (19), whereas for population prevalence and needs assessment the completeness of the data is generally considered more appropriate. The positive predictive value and sensitivity of recall are the usual measures used for test validity, but these imply that an independent gold standard is available for comparison. Many studies make the assumption that the medical record is the gold standard (5, 6, 10, 12). Only in the present study and two others (11, 13) has it been acknowledged that incomplete medical records or inadequate extraction of medical data could adversely affect the validity of patient recall. Furthermore, the extent of false negative recall was adequately assessed in only three of the previous studies (5, 11, 13). In one of these (13), however, designed specifically to validate questionnaire assessment of stroke prevalence, the case criteria for stroke categorically excluded transient ischemic attack, yet the questionnaire requested inclusion of transient ischemic attack in its response and found a 10 percent prevalence. The investigators concluded that further questions are required to discriminate transient ischemic attacks from strokes, which defeated the stated aim of the study.

These validation studies of patient-recalled heart attacks and strokes (5, 6, 10-13), carried out both before and after the review in 1989 (4), produced a wide range of results suggesting a lack of generalizability between studies (table 4). False positive recall rates for heart attack ranged between 19 and 45 percent and, for stroke, between 25 and 37 percent. The small amount of information available on false negative (missed) recall ranged from zero to 48 percent for heart attack and from 5 to 66 percent for stroke. It is likely that the different sampling frames, the age of the subjects, and the various periods of recall used in the questionnaires all contributed to the variability of these results. In the present study, the results are at the lower end of these error ranges and were improved by the rechecking of medical records against discordant patient information. These results have also provided estimates on the reliability of a systematic case-finding strategy using general practice records.

Three studies reporting on the broader definition of "heart disease" recall (7-9), rather than the specific endpoints of heart attack and stroke, found wide-ranging estimates of accuracy very similar to those for heart attack (e.g., false positive coronary heart disease recall, 16-44 percent, and false negative coronary heart disease recall, 21-48 percent), suggesting that there is no advantage in reducing the precision of the condition being recalled. In a study of disease recall by retired couples (18), it was also concluded that milder, less specific conditions are generally less well confirmed.

It is perhaps surprising that, in the Nurses Cohort Study (6), the recall is no more accurate in a group of health professionals than it is in other groups studied. On the other hand, some of the remaining discrepancy may still be due to medical record or reporting omissions rather than to overreporting by the patient.

Ascertainment of cardiovascular outcomes in epidemiologic studies

The best approach to obtaining accurate data is the use of more than one source of information. As this is not always possible, the limitations of each single data
source should be recognized and taken into account. For prevalence estimates in large populations, patient recall of a doctor-diagnosed condition offers a simple and sensitive method. However, interpretation of the findings requires caution due to the lack of specificity for major cardiovascular events and subsequent overestimation of their prevalence rates. To establish the presence of preexisting disease in subjects recruited into large prospective cohorts, patient recall is a useful first line of inquiry, after which medical record checks can be made on those with recall. For case ascertainment in etiologic studies when clear and specific criteria are essential, the medical record review remains the best single approach, but it can be usefully complemented by patient recall data to rectify omissions occurring in the reporting system.

Conclusions

Patients tend to overrecall heart attacks and strokes more than they fail to recall these events, because of poor discrimination between different types of cardiovascular episodes. Patient recall plays a useful role in population prevalence estimates and in identifying preexisting disease in prospective cohorts, but it does not adequately replace medical record reviews for etiologic studies.

ACKNOWLEDGMENTS

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REFERENCES

APPENDIX

Study no. ..............................................................
Mr. ..............................................................
Date of birth..................................................
National Health Service no.............................

These questions relate to the last two years (1990 and 1991).

1. Is the above patient still registered with you?
2. Has he consulted you between 1 Jan. 1990 and 31 Dec. 1991?
3. Was any consultation for a new episode of:
   (i) Myocardial infarction Date..........................
   (ii) Stroke Date...........................................
   (iii) Other cardiovascular disease problems (state)...........

4. Has he been referred or admitted to hospital for any cardiovascular problem during 1990 or 1991?
   If yes, diagnosis and date:..................................
   Name of hospital:.........................................

Questions 5 and 6 relate to PREVIOUS HISTORY

5. Has he EVER been diagnosed as diabetic?
   If yes, please give year of diagnosis

6. Has he EVER had a coronary artery bypass graft, angioplasty, pacemaker, or cardiac catheterization?
   Procedure............................................... Year..................................

7. If the patient has left your practice, to which Family Health Service Authority has he transferred?

8. May we have this patient’s current address, so that we can send him a questionnaire similar to that used in 1985?
   Current address:...........................................
   ..........................................................

General practitioner’s signature........................ Date..............................