

Uses of coronary heart attack registers¹

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SUMMARY By studying all coronary heart attacks presenting within defined communities it should be possible to avoid the distortions and omissions inherent in hospital-based case series. In practice the technique presents several problems. Measures of frequency and outcome are very sensitive to the diagnostic criteria used. Data of varying quality are mixed and specific attack rates can be calculated only for items for which the census provides a denominator. Patients presenting to different medical services have different outcomes, but probably less because of treatment than because the severity of the attack affects behaviour in it. Despite these problems, some such intelligence system is of value in any comprehensive strategy for coronary heart disease.

In May 1968, the World Health Organisation Regional Office for Europe convened an international working group to discuss the establishment of pilot coronary heart attack, or as they called them, Ischaemic Heart Disease Registers (World Health Organization, 1968). The working group eventually sponsored a project involving 19 centres in 17 countries. Now that the collaborative report has appeared (World Health Organization, 1976) it seems a good time to attempt an assessment of the uses and limitations of this technique and its potential for the future.

A disease register is a medical information system or in 1984 'double think', a health information system (Brooke, 1974). Its use can be compared with that of military intelligence. Coronary heart disease is the biggest single killer in economically advanced countries, the major determinant of national and regional differences in death rates, the major component of excess mortality in men compared with women, and the chief cause of death before retirement; and yet there has until recently been no comprehensive intelligence on the disposition, time, place, number of attacks, and damage produced by this formidable adversary. Each aspect of the disease has been studied using the groups of subjects and the definitions most convenient and accessible to the investigator—treatment was studied in specialised units, mortality rates without reference to treatment services, and morbidity in employed persons. The result was a jigsaw

puzzle whose pieces failed to interlock. Medical services had to be planned without knowledge of the numbers of victims or their potential needs. A fuller picture might conceivably be built up by scanning the records of all the medical and social institutions involved, employment, general practice, hospital, and forensic medicine. However, these records are not usually designed for analysis; the same person's records would appear in several different places and might be incomplete through failure of follow-up. Different case definitions and different populations would be involved. Something more than case records is needed.

An answer is the community register. A study population is chosen, one for which social and demographic data are available from the Census and, in order to be able to feed back results into medical planning, one which constitutes a unit of medical administration such as a Health District. (In Britain, the London Borough of Tower Hamlets was used as the register centre for the collaborative study (Tunstall Pedoe *et al.*, 1975).) Basic to the idea of disease registration is that standardised information on victims of diseases satisfying predefined diagnostic criteria is collected centrally, and that their progress is followed and statistical analyses made. Some of the potential benefits of such a register were forecast by the 1968 Working Group report (World Health Organization, 1968). 'Registers would facilitate the study of aetiology, pathogenesis and it was hoped prevention of attacks. They would provide information on the occurrence of coronary disease in the community and its human, social and economic costs . . . provide measures of how existing services matched needs . . .

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provide a basis for the evaluation of new and old methods of management by comparing the experience of groups in the population managed in different ways . . . would highlight areas where treatment was inadequate and would be invaluable in research by providing representative cases for study and a sampling frame for clinical trials.'

These were the expectations in 1968. What are the factors that determine their success?

Problems of case definition and recognition

One of the objectives of disease registration is to measure the frequency and case fatality of the disease. It is of interest to consider how sensitive these are to the diagnostic criteria. In the World Health Organisation study notified cases were classified at 28 days from the attack as definite, possible, or not (Tunstall Pedoe *et al.*, 1975), the first category being those with confirmatory investigations. Fig. 1 shows in three dimensions the numbers and percentages of non-fatal 'definite' attacks in men which satisfied the different combinations of diagnostic evidence for a 'definite' attack. Of 348 men 86 per cent had typical chest pain, 87 per cent raised cardiac enzymes, and 73 per cent unequivocal serial electrocardiographic changes. Had the WHO criteria demanded that all three be positive to make the diagnosis then the

frequency of 'definite attacks' would have been reduced to one half. Table 1 shows how sensitive the case fatality rate is to the diagnostic criteria used. Historically myocardial infarction was a pathological term associated with the postmortem room and 100 per cent fatality. On the other hand the serial development of electrocardiographic changes or a rise in blood enzyme levels depends on survival, at least for a few hours. The case fatality is correspondingly low as most fatal attacks have been excluded. Combinations of criteria embrace more cases and give intermediate fatality rates.

Not only can the interpretation of tests influence the final diagnostic category but the frequency and immediacy of the tests may also do so. Table 2 shows the mean frequency of investigations for each attack in the different Tower Hamlets hos-

Table 1 Frequency and 28-day fatality using different diagnostic criteria in men

Criterion	No. accepted	Fatality %
Necropsy infarction or thrombosis	157	100
Necropsy coronary heart disease	205	100
Typical chest pain	508	23
Electrocardiographic progression	277	8
Raised enzymes	351	9
Definite by WHO criteria	534	35
Coronary heart attack	707	38
(definite or possible by WHO criteria)		

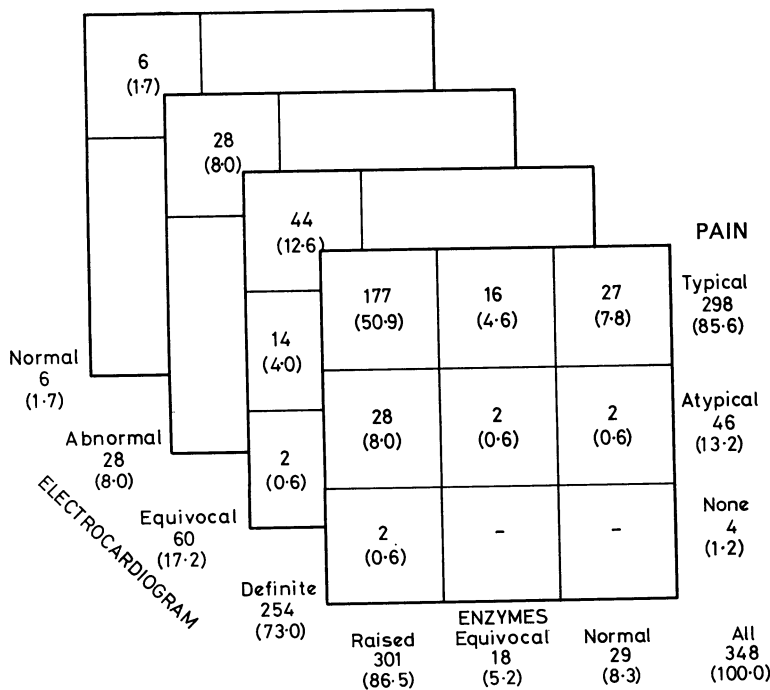


Fig. 1 Diagnostic evidence in 348 non-fatal attacks in men classified as 'definite' by WHO criteria. Percentages are given in parentheses.

Table 2 Mean frequency of investigations per coronary heart attack

	Electrocardiogram	Enzymes
London Hospital (Whitechapel)	5.2	3.4
London Hospital (Mile End)	4.5	3.7
London Chest Hospital	4.9	3.1
Bethnal Green Hospital	4.5	2.7
Mildmay Mission Hospital	3.8	3.0
St. Andrew's Hospital	3.4	1.3
Poplar Hospital	3.3	1.1
London Jewish Hospital	2.5	2.0

pitals. Both the number of electrocardiograms and the number of enzyme estimations varied by more than two to one. The number of times these tests were done on those cases where other diagnoses were made would be of even greater interest.

How important are these theoretical objections to the use of the register for measuring attack and fatality rates? In the WHO study case fatalities were similar in different centres and attack rates correlated well with national mortality rates. Any biases in recording must, therefore, have applied equally to the recognition of fatal and non-fatal attacks. This is not true of the three British studies. Kinlen, in his pioneer study in the Oxford region (Kinlen, 1969, 1973) found a lower overall attack rate than was reported from Edinburgh (Armstrong *et al.*, 1972) and Tower Hamlets (Tunstall Pedoe *et al.*, 1975). However, the Oxford case fatality was high suggesting that, if there were any underrecording, it must have been among survivors. The Oxford study included rural areas and the region has a lower ratio of acute medical beds to population than many others (Department of Health and Social Security, 1974). Those resident at a distance from Oxford's coronary care unit are admitted less often than local residents but suffer a higher fatality rate in hospital (Acheson and Sanderson, 1977). Though Kinlen's study included cases diagnosed out of hospital, registers cannot record unrecognised cases. We may have here a medical example of Parkinson's law—that the proportion of cases of non-fatal heart attack that are recognised will expand with the diagnostic and therapeutic services locally available. Registers record what is being diagnosed, not what might be.

Table 3 Annual Attack Rate per 1000 men

Age (y)	20-39	40-44	45-49	50-54	55-59	60-64	20-64 Unstandardised (The Times, 1974; Osman, 1975)	20-64 Age standardised (World Health Organization, 1976)
London	0.6	4.0	4.8	8.0	11.4	15.2	5.2	4.3
Dublin	0.4	1.9	6.9	10.9	13.8	15.5	4.6	4.7
Tampere (Finland)	0.2	4.4	6.8	13.3	16.2	25.4	5.3	6.2

Better diagnosis may lead to more cases, a bigger work load, and a fall in fatality rate, with no real change in numbers of deaths (Rose, 1975).

Defining the study population

A register collects information on diseased persons from routine medical and medico-legal services but makes no direct comparisons with the healthy. Information on those at risk is obtained from other sources, notably the decennial population census. In theory any enumerated population could be used, but in practice there are problems. Over a 10 year period there may be major changes in the size, age, and sex structure. Administrative boundaries may be changed. Populations defined by domicile may be mobile by day and seek medical attention elsewhere, so that local medical services may fail to treat some residents but also may be used by those resident elsewhere. The more fragmented and incoordinated the medical services, the more necessary a comprehensive overview becomes, but the more difficult it is to achieve because of multiple sources of incomplete data. Registration and follow-up would be most easy in isolated communities with completely centralised medical services.

Even where the study populations have been well defined, comparisons between centres can be hazardous. The World Health Organisation released figures for the attack rates in men aged 20 to 64 for different centres in the international study in advance of the detailed report, and these were widely publicised as showing an attack rate in London as high as that in Tampere, Finland, and higher than that in Dublin (*The Times*, 1974; Osman, 1975). When the *age-specific* rates are compared (Table 3) the rates between ages 45 and 64 in London men are seen to be lower (World Health Organization, 1976). The apparent excess was caused by a larger proportion of middle-aged men in Tower Hamlets, who were therefore over-represented in the all-ages attack rate, which had not been age standardised.

The decennial census records demographic rather than medical information. The register can,

therefore, be used to measure risk in relation to age and sex and place of birth, but not in relation to items of aetiological interest that are not recorded at Census. A previous history of diabetes or smoking may be elicited from coronary heart attack victims, but the prevalence in the population is not known, so that the relative risk associated with these characteristics cannot be measured as it would be in a formal longitudinal incidence study. Incidence itself cannot be measured in the strict sense of the attack rate in the previously healthy, as the total population includes those already affected, so the denominator is unknown. However, use of data on place of birth for attack victims in Tower Hamlets and census data for the resident population showed that the relative attack rate for Southern Irish male immigrants standardised for age was about 100 per cent, of Asian immigrants 130 per cent, and West Indians 8 per cent of that for all male residents (Tunstall Pedoe *et al.*, 1975). By registration of attacks and relating them to defined and measured populations it was possible to confirm and quantify what would otherwise have remained a clinical suspicion.

To summarise, therefore, not only should a register be based on a circumscribed community, but the better this population is known in terms of factors of interest, then the more worth while will be the study of these factors in the attack victims who form the numerator.

Internal comparisons

Registered cases may be related to the population at risk or broken up into subgroups for internal comparisons, for example men and women, fatal and non-fatal attacks, those treated in different ways. One of the problems here is that a comprehensive survey must include cases on which information varies in completeness. Survivors reaching hospital will be better documented than others, but the survey cannot exclude out-of-hospital cases for that reason. A parallel problem is shown in Table 4 showing the previous medical history

Table 4 *Medical history before registered coronary heart attack*

	Men 707	Women 171
Previous coronary heart attack	36	35
Angina pectoris	40	37
Any coronary heart disease	51	52
Stroke	7	8
Intermittent claudication	12	14
Diabetes	7	12
Hypertension	15	30

of male and female attack victims. Though women appear to have hypertension and diabetes more commonly before the attack, these conditions cannot be diagnosed other than by medical examination, and middle-aged women are known to consult more frequently than men. Though the difference is probably genuine, it is not as well substantiated as it would be in a longitudinal study involving screening before the onset of the disease.

It is of interest to compare the fate of those using the medical services in different ways. Table 5 shows the case fatality at 28 days in relation to the means of seeking medical help and Table 6 does likewise for the means of transport to hospital.

Table 5 *Case fatality at 28 days by first medical contact in attack*

Contact	Proportion of cases % n = 878	Case fatality %
Home visit	26	23
Surgery visit	15	12
Direct to casualty	25	27
No contact	19	98
Others	8	30
(Not known)	7	64

Table 6 *Case fatality at 28 days by means of transport to hospital*

Transport	Proportion of cases % n = 878	Case fatality %
Ambulance	56	47
Driven by car	9	14
Self drive	3	} 0.8
Taxi	4	
Walked	9	
Bus	2	
(Never and not known)	16	73

The results appear to show that the orthodox emergency services are summoned for high risk patients and, in the case of ambulances, those who are already dead. Patients who go round to their own doctor's surgery or walk to hospital seem to do well—not, presumably, because emergency treatment is lethal but because the severity of the attack determines the behaviour in it. While the survey reveals the variety of reactions to an attack it cannot specify what should be done, which could be determined only by experiment. The apparently grave consequences of not consulting a doctor in an attack shown in Table 5 could be used as an argument for the benefits of such a consultation. In fact the data are censored in two ways—most of those who died did not have time to call a doctor and those who lived and did not consult could not be diagnosed and registered with the study.

The community perspective

So far discussion of the uses of coronary heart attack registers has been largely one of urging caution and sophistication in the interpretation of their findings, but this should not discourage their use. One of the major potential uses is in putting treated cases into an overall perspective. Table 7 shows the place of apparent onset of fatal attacks in relation to place of apparent death. There are problems in defining both of these terms (World Health Organization, 1971; Maclean, 1975) but the conclusion appears to be that nearly half of all fatal attacks begin and end at home and less than one-third of victims are moved in an attack. The reason for this is seen in Fig. 2 which shows cumulative fatality rate against time. Circumstantial evidence had to be used to estimate survival in many cases where death was not witnessed. Exclusion of these cases would have distorted the graph as long-term survivors would have been preferentially included. The result suggests that the majority of deaths in coronary heart attacks are very rapid and that the dividend from even an improbable speeding up of medical services might be small in percentage terms, however valuable in individual cases. Halving the time from onset anticipates only an additional 4 to 5 per cent of deaths (Tunstall Pedoe, 1975).

Table 7 Place of apparent onset and death in 348 attacks where death occurred within 28 days (%)

	All	Place of onset				
		Home	Work	Other	Hospital	
Place of death	All	100	61	13	20	6
	Home	47	44	1	1	—
	Work	7	—	7	—	—
	Other	14	1	1	12	—
	Hospital	32	15	3	7	6

No change 69

Table 8 Hospital and community views of coronary heart attacks (percentages based on 707 male cases)

	Hospital ward view	Community view
2 cases managed at home excluded	70 formal admissions	100 cases
26 deaths outside hospital excluded (17 brought dead to hospital)	32 to coronary care unit (1 resuscitation 5 deaths)	38 deaths
1 sudden death in casualty not included	38 to acute medical ward (1 resuscitation 5 deaths)	2 resuscitations
1 sudden death of hospital patient under care for another condition not included	Case fatality 14.5% successful resuscitation in 16% of cardiac arrests	Case fatality 38% successful resuscitation in 5% of cardiac arrests

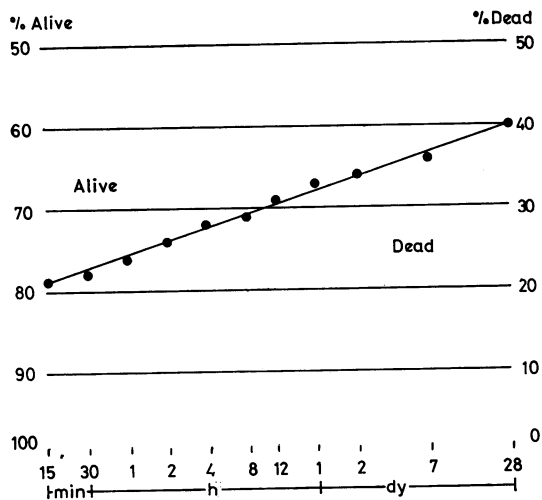


Fig. 2 Cumulative fatality rate against time in 878 coronary heart attacks in men and women.

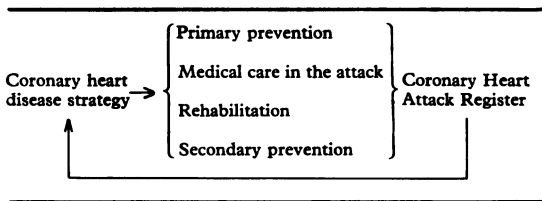
Table 8 shows the overall disposal and fate of men with coronary heart attacks in Tower Hamlets compared with the hospital view which is based on patients formally admitted to the wards. The limitations of traditional statistics as against a community perspective are all too apparent.

Conclusions

What then are the uses of the coronary heart attack register? The main function of the pilot registers has been educational. In the future their use must depend on our strategy for coronary heart disease, whether it is primary prevention, acute care of the attack, or secondary prevention in those affected, or a combination. Whatever the plan an appropriate information system such as registration or community surveillance (Rhoads *et al.*, 1975)

would be of value in monitoring the effects of treatment and in seeing that it was reaching those who needed it (Table 9). The collection of information for its own sake is of doubtful value unless it is acted on. Community registers should not become the medical equivalent of village war memorials.

Table 9



If there is no strategy, no manoeuvring, but simply hand-to-hand combat using any weapon available at any point with no questions asked about the results, then no intelligence system is needed.

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