

Surveillance of stroke: a global perspective

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For preventive strategies to be efficient, it is essential to have information on the pattern of disease and exposure to major risk factors that predict future diseases in the population. Basic epidemiological data such as mortality rates are reported for less than one-third of the world's population and are almost exclusively from developed countries. However, it is the developing countries, particularly those in rapid economic and demographic transition, which will experience a major rise in ageing-related diseases.

The World Health Organization is intensifying the development and implementation of simple, sustainable surveillance systems that can be used in many different settings around the world. Unlike heart disease and cancer, stroke is a clinically defined disease, which makes it possible to identify trends in different countries irrespective of access to technological equipment. A stepwise approach to increasing detail in the data to be collected for surveillance of stroke is suggested. This will allow countries with different levels of resources and capacity in their health systems to collect useful information for policy.

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In 1999 stroke was the cause of death in 5.54 million people worldwide, approximately 10% of all deaths.¹ Two-thirds of these deaths occurred in people living in developing countries.² In addition to it being the third leading cause of death, many survivors of stroke have to adjust to a life with varying degrees of disability. The Global Burden of Disease Study^{3,4} described a measure that integrates the sum of life-years lost due to premature mortality and years lived with disability adjusted for severity, the so-called disability-adjusted life years (DALY). In 1999 cerebrovascular disease accounted for 50 million DALY worldwide, representing 3.5% of all DALY.¹ Projections to year 2020 show that 61 million DALY are likely to be lost due to cerebrovascular disease each year, and of these 52 million (84%) will be in the developing countries.⁵

Life expectancy is increasing in most parts of the world, largely because of lower childhood mortality as a result of better control of previously lethal infectious diseases, but also because of a decline in mortality in adults. This trend will have a major impact on the demographic structure of populations in the near future. The global population aged over 65 years is increasing by 9 million a year. By 2025 there will be more than 800 million people over 65 years of age in the world;² two-thirds of them will be living in developing countries. In China alone, there will be more than 180 million people over the age of 65.⁶ Increases of up to 300% in the older population are expected in many developing countries within the next 30 years, especially in Latin America and Asia. With increasing age, the burden of non-communicable diseases such as heart disease, stroke and

cancer increases. One of the biggest public health challenges for many nations will be to prevent and postpone morbidity and disability due to chronic diseases and to maintain the health, independence and mobility of an ageing population.

While definitive diagnoses of heart disease and cancers rely on access to laboratories and trained specialists, stroke is a clinically defined disease, which makes it possible to identify trends in different countries irrespective of access to technological equipment. The World Health Organization (WHO) standard definition of stroke is 'a focal (or at times global) neurological impairment of sudden onset, and lasting more than 24 hours (or leading to death) and of presumed vascular origin'.⁷ The definition has been proved to be valid in many different settings and, despite increased use of neuro-imaging, the clinical diagnosis remains the foundation of epidemiological studies of stroke.

Along with many chronic diseases stroke can be prevented. For preventive strategies to be planned and evaluated, it is essential to have information on the pattern of disease and exposure to risk factors in the population. Basic epidemiological data such as mortality rates are reported for approximately 30% of the world's population, almost exclusively from developed countries. However, it is the developing countries, especially those in rapid demographic transition, which will experience a major rise in the burden of diseases of an ageing population. The WHO is recommending simple sustainable surveillance systems that can be used in sentinel surveillance sites in many different settings around the world to improve health planning and to measure the impact of preventive programmes. A stepwise approach with increasing demands related to the amount and detail of data is suggested in order that countries with different levels of resources and sophistication in their health systems can contribute with data on stroke and its risk factors.

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Surveillance

Surveillance, the ongoing systematic collection, analysis, interpretation and dissemination of health information, is essential in measuring the impact of efforts to prevent stroke. At the 21st World Health Assembly in 1968, the WHO held technical discussions on the national and global surveillance of communicable disease and identified three main features of surveillance: the systematic collection of pertinent data; the orderly consolidation and evaluation of these data; and the prompt dissemination of the results to those who need to know, particularly those who are in a position to take action.⁸ Subsequently, the applications of surveillance concepts have broadened to include a wider range of health data—risk factors, disability, and health practices—as well as diseases.⁹

The primary purpose of establishing and maintaining a system of surveillance is to provide health workers and policy makers with a reliable tool to plan cost-effective strategies to meet the demands for health care and prevention in the population. Surveillance should be focused on diseases that are or are likely to become public health problems.¹⁰ Also, surveillance programmes are more likely to be sustained if they address diseases for which effective control or prevention measures are available.

Above all, a surveillance system should include not only a capacity for collection and analysis of data, and dissemination of information, but also direct links to public health programmes. An example where this has been done successfully is in California, US, where public campaigns against tobacco have been associated with decreasing mortality rates of lung cancer.¹¹

The challenge of stroke surveillance

Stroke meets many of the criteria that warrant the establishment of a surveillance system: it is a major public health problem, it is largely preventable and it is a disease that has a major impact in all countries. Reports of incidence rates for stroke mostly come from communities in developed countries and, even there, in communities with well-established epidemiological traditions, there is a shortage of studies that are able to provide data on temporal trends in the incidence of stroke.¹² Different methodological approaches hamper the comparison of rates over time and between populations. The WHO MONICA Project (MONItoring trends and determinants in CARDiovascular disease), initiated in the early-1980s, was an attempt to overcome some of these difficulties and to understand the reasons for the trends in cardiovascular mortality.¹³ It has yielded substantial information about the burden of ischaemic heart disease and stroke in the communities of the participating centres, although many only included subjects aged up to 65 years and the remainder only those aged up to 75 years, thereby omitting the age groups where the burden of stroke is greatest.^{14–16} Strict definitions and tight control of the quality of the data collection have permitted detailed analyses of trends over time and comparisons between the populations studied.^{17,18} Such a system is, nevertheless, not appropriate in countries with limited resources, including those that have no access to information about cause of death. WHO has recognised that if ongoing surveillance of stroke is to become a reality, there is a need to develop simple, sustainable systems that can be used

widely to provide further within-country comparisons as well as allow a measure of between-country differences.

The framework for a stroke surveillance system

A stroke surveillance system includes many different aspects of stroke in the community. Measures of incidence, case-fatality, and mortality are essential for the planning and evaluation of preventive strategies and allocation of health resources. More elaborate information includes mode of treatment, functional level before and after stroke, and subtype of stroke (ischaemic stroke, primary intracerebral haemorrhage, or subarachnoid haemorrhage).

For this reason, a stepwise approach to surveillance of stroke is suggested (Figure 1). There are three different groups of stroke patients: those admitted to hospital (or other health facilities), fatal events occurring out of hospital, and non-fatal events managed outside of a hospital facility. Stroke patients in hospital are the easiest to identify, and non-fatal non-hospitalized cases the most difficult to identify. It is through the completion of each of the three steps that the system provides basic epidemiological estimates. Step 1 gives frequency of hospital admission due to stroke, inclusion of step 2 would enable calculation of mortality rates, whereas completion of step 3 would provide incidence rates and the case-fatality.

Stroke patients admitted to hospital

Within the framework of surveillance, data on patients admitted to hospital include age, sex, identification of whether it is a first-time or recurrent stroke, and vital status (dead or alive) at discharge from hospital, the *core* data. Although patients with stroke admitted to hospital may constitute a highly selected group of all cases in the community, the information will nevertheless give basic estimates of costs, need for rehabilitation programmes, and severity of stroke for a given community. It will also act as a marker at a local level for increases in stroke burden if admission practices are taken into consideration.

Case-fatality is often expressed according to vital status 28 days after stroke onset, but this usually requires follow-up after discharge and may be difficult to accomplish in countries where the infra-structure and the communication technologies are only scarcely developed. A shorter observation period of 10 days is therefore suggested for the core data set as it is easier to ensure completeness of data collection.

Countries with greater resources might prefer to expand measures to include vital status at 28 days, some measure of functional level, information on prevalence of risk factors, and medical treatment given during the stay in hospital and prescribed at discharge; this constitutes the *expanded* version of the hospital data (Figure 1). The information obtained at this level is thus more complex than the 'core' data. Until this point of the stepwise approach, access to expensive technological facilities is not required. Classification of the stroke as either ischaemic or haemorrhagic requires advanced technical equipment, and constitutes the most sophisticated level of data collection, the *comprehensive* hospital data. Such information is of interest as the proportions of haemorrhagic and ischaemic strokes vary considerably between countries and may have an impact on strategies for prevention and management. Technical

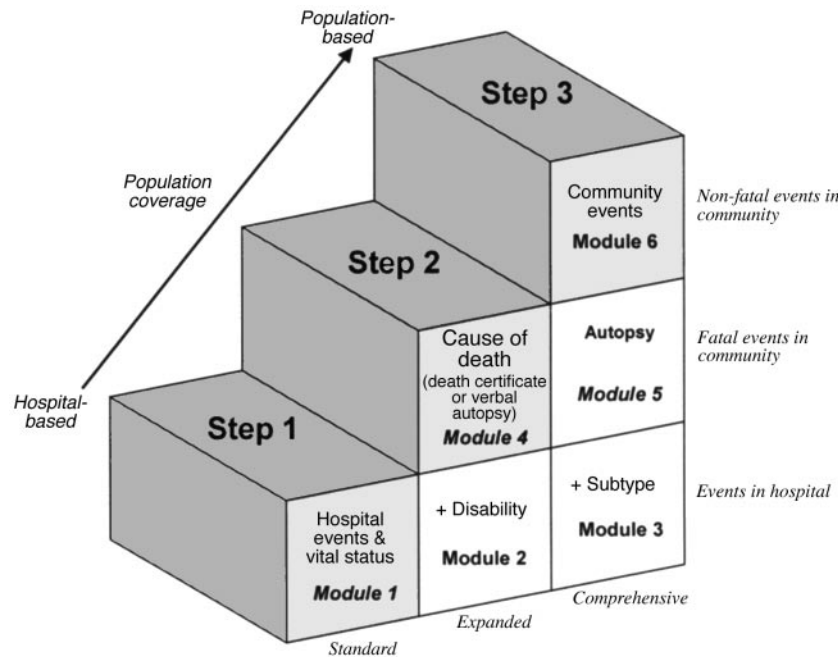


Figure 1 A step-wise approach to stroke surveillance

investigations also provide information on the prevalence of other conditions, for example infectious diseases, that may mimic a stroke.¹⁹

Fatal stroke events in the community

Fatal events that occur in the community, that is without contact with a hospital, or clinic, constitute the next element in the stepwise approach to stroke surveillance. Expanding case ascertainment to include fatal stroke events is warranted to define the numerator for calculating the mortality rate in the community. Two methods can be used, namely case identification from death certificates or verbal autopsy.

Reports from developed countries indicate that a large proportion of fatal stroke events occur without admission to health facilities.¹⁶ In these settings access to a registry of death certificates can be a key method for ascertaining fatal cases. In many developed countries physicians are responsible for issuing death certificates, and although there are differences between coding practices between regions, death registrations are the major source of routine data and have been shown to be useful for measuring trends in mortality. The quality may be further increased by scrutinizing patient files, records, and interviews with carers in order to ensure that the symptoms before death were consistent with the definition of stroke. While this source of information should be used whenever possible, in many countries death certificates are either not routinely issued or their validity is doubtful.

Verbal autopsies are increasingly being used to monitor the distribution of death by cause in places where medical certification of cause of death is uncommon. The method involves interviewing close relatives or caretakers of the deceased and classifying causes of death on the basis of the interview.²⁰ To date most studies employing verbal autopsies have described infant and maternal causes of mortality but the method has

recently been extended to a study of mortality from stroke in a developing country²¹ (Reddy KS—personal communication). Validation studies, using hospital events as the reference category, have demonstrated that verbal autopsy could be an important way to obtain information on adult cause of death²² until better systems can be established.

Information on cause of death is also available through necropsy reports. However, in many countries the necropsy rates are decreasing, and in several places they are not done because of traditional, religious or other reasons. It is therefore insufficient to base an estimate of mortality on this fraction of stroke deaths alone, but the information should be added where it is available.

Non-fatal stroke events in the community

The final level in the surveillance system includes stroke patients who are cared for entirely within the community. Identifying these cases is often difficult but is important as they may constitute a large fraction of relevant events.²³ For example, the proportion of non-fatal stroke cases diagnosed and treated out of the hospital was up to 16% in the MONICA study.¹⁶ Furthermore, it is only when these cases are included that the incidence rate and case-fatality for stroke can be calculated accurately.

Three different methods are suggested for obtaining these data. The first involves contact with general practitioners, a well-known approach already used in several community-based stroke studies in developed countries.^{23,24} If all general practitioners in the study area cannot be included, a random sample can be used.²⁵ It is then possible to derive an estimate of how many affected patients have not been admitted to hospital once allowance is made for the sampling and response fractions. This approach is valid, although it requires that the study population has easy access to medical practitioners or primary care practitioners, which may not be the case in developing countries.

Alternative methods for obtaining information on the number of non-fatal events treated out of health facilities are therefore required, and the capture-recapture method may be a suitable approach.²⁶ Participants in a population survey would be asked a screening question about recent medical diagnoses of stroke, and the corresponding register of cases managed in hospital during the same period is then checked. The final estimate for non-fatal cases occurring in the whole population is derived by adjusting for the mismatch and allowing for the response fraction in the population survey. This method is feasible when integrated with other survey activities, for example, a population census or a risk factor survey, to decrease the expense of administering the questionnaire. While this technique is promising, only a few investigators have used the capture-recapture technique for stroke,²⁷ and there remain uncertainties about independence of data sources and correct identification of events.²⁸

A third approach to determine the number of patients with stroke managed in the community is to estimate the number of people with hemiplegia/hemiparesis and the time since the onset. Sudden onset of hemiplegia or hemiparesis in adults is, to a great extent, limited to stroke and head injury and these are easily distinguished. Studies from different developing countries have already provided information on the prevalence of hemiplegia following stroke.²⁹⁻³¹ If the incidence of residual hemiplegia following stroke and the time course of survival of affected patients are constant within a given community, trends in the prevalence of hemiplegia will reflect trends in the incidence of stroke. It should be noted that the rates are likely to be an underestimate as some minor strokes are likely to be missed. Nevertheless, when combined with the rest of the stroke surveillance system, it will provide data to improve estimates of the incidence rate.

Reference population

Calculations of epidemiological estimates are based on the number of events occurring in the study population, but this may be difficult to obtain if a reliable estimate of the source population (the denominator) is not available. It should be noted that in communities where it is not possible to get information on the size of the population, the hospital step of the stroke surveillance system may still be used. However, the remaining two steps assume the availability of an estimate of the size of the source population.

One of the first issues in setting up surveillance studies is therefore to specify and describe the population in which the study is to take place. The selection criteria are of paramount importance as the data and interpretation of the results will depend on what part of the population is included. To provide a reliable estimate of the occurrence of stroke, community-based programmes are recommended. Inclusion of the entire population in a country is usually not possible, and it may therefore be better to identify different regions in the country for the survey. Often there are differences between urban and rural districts with respect to exposure to risk factors, treatment of predisposing diseases, for example hypertension, and access to health facilities. An ideal surveillance programme therefore should include a random, representative sample of the total population, including both urban and rural areas.

The precision of the calculated rates and proportions is inversely related to the size of the study population, and the number of events. In contrast, expenses of the study are positively correlated to the total size of the source population in which the surveillance is to take place. It is feasible to restrict the programme to age groups where stroke starts to occur. Strokes occur in developing countries at a much earlier age than in developed countries.²¹ Even so, most strokes happen in people aged more than 45 years, and this may be set as the lower age limit. Elderly people often have multiple co-morbidities, which increase the uncertainty of assigning one specific disease as the primary cause of death.³² It may therefore be feasible to set the upper age limit to 85 years.

Evaluation of preventive interventions

Many non-communicable diseases, including stroke, are the end result of exposure to risk factors that may have been present for several decades. However, in contrast to the long latency period (time from exposure to development of disease), there may be a relatively rapid reverse in incidence once exposure to risk factors is reduced. Several clinical trials and numerous epidemiological studies have shown that stroke is, to a large extent, preventable.³³ Level of blood pressure, diabetes and smoking have been associated with the lifestyle of developed countries, but these risk factors already have an immense impact on health in developing countries.^{34,35} Epidemiological studies have demonstrated that the risk of stroke decreases rapidly in smokers who quit smoking.^{36,37} Blood pressure is another important risk factor for stroke that is amenable to control and where adequate intervention is known to reduce the incidence of stroke.³⁸ Changes in the exposure of these risk factors are therefore likely to be reflected in changes in the stroke occurrence rate. This suggests that a surveillance system for stroke can become a valuable tool in evaluating preventive interventions aimed at tobacco and blood pressure.³⁹

Surveillance of risk factors for stroke

While information from a disease register indicates the magnitude of the problem at present and provides data for health policy makers, the prevalence and extent of exposure to risk factors in the population is the strongest indicator of the future burden of disease. Therefore, wherever possible the development of a stroke surveillance system should be accompanied by the creation of a similar system for measuring key risk factors in the same population.

As the level of economic development, and hence available financial and human resources varies between countries, a system that can be adapted to local needs and resources is necessary. Surveillance of major risk factors for stroke, like that of stroke itself, can be approached in a stepwise fashion. The recommended surveillance measures are categorized according to the degree of difficulty in obtaining them; self-reported or verbal responses provide the core level, followed by physical examinations requiring basic field studies, and finally, inclusion of measures that require access to laboratories.

Many risk factors for non-communicable diseases have been described. The focus in the risk factor surveillance system should be on those that are modifiable and which are known to result

in changes in the occurrence of the disease. The basic package of measures should include demographic data, smoking, physical activity, alcohol consumption, simple questions on nutrition based on self-report. However, many countries will be able to incorporate physical examination which can be accomplished at the next step of the stepwise approach of risk factor surveillance. At this level, information on demographic data, smoking, physical activity, alcohol consumption and nutrition would be repeated and in addition weight and height are estimated using a balance beam and tape or stadiometer. Furthermore, data on girth and blood pressure are measured. The final step would include estimates based on laboratory examinations. At this level of surveillance data on demography, smoking, physical activity, alcohol, nutrition, weight, girth, and blood pressure may be identical to that collected for the physical examination level. However, more sophisticated measures may also be included such as high density lipoprotein (HDL) cholesterol and serum triglycerides, together with more elaborate measures of smoking, alcohol consumption, blood cholesterol and blood glucose as options.

Data quality

One of the goals with both surveillance systems is to enable comparisons within and between regions. It is known from the MONICA study that the quality of data varies between countries,¹⁶ and a system that is to be set up in developed as well as developing countries is likely to face the same problem. In the stroke surveillance system the validity of the diagnosis may differ. In some countries infectious diseases such as HIV/AIDS, syphilis and tuberculosis may be relatively common causes of neurological symptoms that mimic those of cerebrovascular disease.⁴⁰ Patients admitted to a hospital with signs of stroke are likely to undergo clinical and paraclinical examinations which will increase the accuracy of the data, whereas only few patients managed in the community may be thoroughly examined. For the risk factor surveillance system, differences between the surveillance sites are also likely to occur, including variations related to response rates and in obtaining the physical measurements, as well as differences between laboratories. For both systems, when data become more complex the accuracy is likely to decrease. This is a flaw that will be important to keep in mind when interpreting the results. International quality control of the data, as was undertaken in the MONICA study, is beyond the scope of many countries. Instead, efforts should be directed at improving the quality of data collected locally.

Conclusion

With many countries experiencing an ageing population, especially those in rapid economic transition, prevention of non-communicable diseases such as stroke is of paramount importance. Primary prevention is central as an efficient and inexpensive way to reduce the disease burden, but this relies on epidemiological data to identify prevention priorities. Surveillance systems are useful tools for obtaining this information and adherence to standards enables national and international comparisons. However, differences in capacity would exclude many less wealthy countries from participation if the system is unable to adjust to local needs. The WHO surveillance systems

for stroke and its risk factors are designed so that they are flexible and can be used in different settings.

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