

The impact of stroke

Charles D A Wolfe

Department of Public Health Sciences, Guy's, King's and St Thomas' Hospitals School of Medicine, London, UK

The socio-economic impact of stroke is considerable world-wide. Stroke is assuming an increasing impact in terms of media attention, patient and carer knowledge, service developments and research.

It is estimated that there are 4.5 million deaths a year from stroke in the world and over 9 million stroke survivors. Almost one in four men and nearly one in five women aged 45 years can expect to have a stroke if they live to their 85th year. The overall incidence rate of stroke is around 2–2.5 per thousand population. The risk of recurrence over 5 years is 15–40%. It is estimated that by 2023 there will be an absolute increase in the number of patients experiencing a first ever stroke of about 30% compared with 1983. There is a total prevalence rate of around 5 per thousand population. One year after a stroke, 65% of survivors are functionally independent, stroke comprising the major cause of adult disability.

The socio-economic impact of stroke is considerable world-wide, both in industrialised and non-industrialised countries. Stroke is assuming an increasing impact in terms of media attention, patient and carer knowledge, service developments and research. However, it still remains a 'Cinderella' specialty and is not apportioned relevant resources to allow effective services to be delivered equitably. This is despite considerable advancements in the evidence base to reduce the impact of stroke both in terms of prevention and treatment. Governments around the world have set conservative targets to reduce mortality from stroke, particularly in younger people, and the stroke physicians of Europe have set targets to reduce the impact of stroke over the next 10 years^{1,2}.

The impact of stroke can be considered from several perspectives which are often overlapping: patients, their families and carers, primary care, acute hospitals and purchasers of healthcare along with policy makers. This chapter will provide an up-date on the impact of stroke focussing on areas that still require considerable attention. A useful description of how to assess the needs of a population for stroke by Wade³ has been drawn on for this chapter, as have the English inter-collegiate guidelines for stroke⁴.

*Correspondence to:
Dr Charles D A Wolfe,
Department of Public
Health Sciences,
Guy's Hospital,
42 Weston Street,
London SE1 3QD, UK*

The disease

The definition of stroke used in assessing its impact will be that used by the World Health Organization: 'a syndrome of rapidly developing clinical signs of focal (or global) disturbance of cerebral function, with symptoms lasting 24 hours or longer or leading to death, with no apparent cause other than of vascular origin'.

This includes subarachnoid haemorrhage but excludes transient ischaemic attack (TIA), subdural haematoma, and haemorrhage or infarction caused by infection or tumour. It also excludes silent cerebral infarcts. It would appear that studies are likely to underestimate the total burden of cerebrovascular disease, the data discussed being mainly based on symptomatic stroke.

There are a number of classifications of stroke, none of which are ideal. Routine National Health Service data utilise the International Classification of Disease (ICD)⁵. A useful clinically-based classification has been developed by Bamford and colleagues in which prognosis is related to subtype of stroke, although this classification does not adequately describe the risk factors associated with the subtypes, which is important for secondary prevention⁶.

Mortality

Mortality data are readily available, reasonably accurate with regard to stroke and used both to assess the overall need for stroke care and, increasingly, by policy makers as outcome measures of health services. When interpreting mortality data, it would be useful to have information on case-severity and incidence of stroke, both of which influence the mortality rate.

The World Health Organization data (1996) indicate that deaths from circulatory diseases are among the world's commonest diseases killing more people than any other disease, and accounting for at least 15 million deaths, or 30% of the annual total, every year⁷. Stroke accounts for 4.5 million of these. In the past, such diseases were thought of as affecting exclusively industrialised nations. However, as non-industrialised countries modernise, cardiovascular diseases are assuming importance, accounting for at least 25% of deaths, *i.e.* 10 million a year. Two-thirds of the stroke deaths occur in non-industrialised countries. There are an estimated 9 million stroke patients world-wide.

In 1997, there were 57,747 deaths in England and Wales from stroke, with 2525 from subarachnoid haemorrhage⁵. Stroke is the third most

common cause of death in the UK after myocardial infarction and cancer and is consequently a focus for the UK Government¹. The target is to reduce deaths from stroke in the under 75-year-olds by two-fifths by 2010 and the White Paper outlines strategies to reduce impact, which include prevention and therapeutic interventions, often without supporting evidence.

There are noticeable differences in the standardised mortality ratios (SMR) for stroke (*i.e.* mortality rates adjusted for age and sex differences in populations) between regions of Europe and in the UK specifically, ranging from 132 in Northumberland to 75 in NW Hertfordshire (national SMR =100)⁸. This implies certain areas would have more difficulty in achieving mortality reduction targets and local knowledge of incidence and case-severity will need to be addressed.

In terms of years of life lost as a result of stroke, in England and Wales in 1993–1994, an average of 28 years of life were lost per 10,000 population and this varied from 21.6 in the South and West region to 34.9 in the North West region⁸.

There would appear to be inequities in mortality from stroke between social classes. Kunst *et al* showed that in all countries for men, manual classes had higher stroke mortality rates than non-manual classes, this inequity being relatively large in the UK, Ireland, Finland and small in Sweden, Norway, Denmark, Italy and Spain. These differences probably represent differences in the prevalence of risk factors and access to health services in the different groups⁹.

Incidence

The incidence of stroke is defined as the number of first in a life-time strokes occurring per unit time. It is a sensitive measure of the need for stroke services, but is difficult to estimate without considerable resource. The incidence of all acute strokes (first and recurrent) is in the region of 20–30% higher than the first in a life-time. Bonita has estimated that the risk of a person 45 years of age having a stroke within 20 years is very low (about 1 in 30)¹⁰. However, almost one in four men and nearly one in five women aged 45 years can expect to have a stroke if they live to their 85th year. Although the life-time risk of having an acute stroke is higher in men than women, the converse is true for the life-time risk of dying of a stroke. Thus about 16% of all women are likely to die of a stroke compared with 8% of men; this difference is largely attributable to the higher mean age at stroke onset in women, and to their greater life expectancy.

Sociodemographic influences on incidence

The incidence of stroke doubles with each successive decade over the age of 55 years, with an overall rate 0.2/1000 in those aged 45–54 years and 10/1000 in those aged over 85 years. Men have a 25–30% increased chance of having a stroke. African-Caribbean and African men and women have approximately double the risk of stroke compared to the Caucasian population. People in the lowest social class have a 60% increased chance of having a stroke compared to those in the highest social class¹¹.

Subarachnoid haemorrhage

The incidence is about 9–14 per 100,000 per year³. Other published estimates are as high as 33 per 100,000 per year for men and 25 per 100,000 per year in women.

Cerebral infarction

There have been many population-based studies of stroke, most having had significant methodological flaws¹². Although the Oxford Community Stroke Project is the gold standard for incidence studies in the UK, it commenced in the mid-1980s when mortality rates were higher and the study area was predominantly in rural Oxfordshire with no ethnic minority groups. The overall crude incidence of first in a life-time stroke was 2.4 per 1000 per year³. A south London register reported an overall crude incidence rate of 1.3 per 1000 population (1.28 male, 1.33 female) with a 2.2-fold increased risk in the Black population in 1995¹³. Studies published or presented at conferences covering the years 1995–1997 indicate the incidence rates to be between 119–203 per 100,000 adjusted to the European population, but with significant differences between and within countries.

Incidences of subtypes of cerebral infarction

Intracerebral haemorrhage (excluding SAH) accounts for just over 10% of all stroke, the remainder being cerebral infarction. Using the Bamford classification, the following proportions of first strokes can be expected: cerebral infarction 76% (partial anterior circulation 56%, lacunar 20%, total anterior circulation 15%, posterior circulation 8%, unclassified 1%), primary intracerebral haemorrhage 10%, subarachnoid haemorrhage 4%, not known 10%⁶.

Recurrence

The cumulative risk of recurrence over 5 years is high, ranging from 15–42% in community studies and the pathological subtype of recurrence is the same as the index stroke in 88% of cases¹⁴.

Case fatality

Case fatality measures the proportion of people who die within a specified period after the stroke; comparisons are based on the first-ever stroke in a life-time since recurrent strokes have a higher case fatality. One month case fatality rates are dependent on the age structure and health status of the populations studied and vary from 17–49% amongst men in the MONICA studies and 18–57% in women with an average of about 24% from the literature¹⁵. In the UK, the Oxford 28-day case fatality was 19% overall, that for cerebral infarction being 10%, primary intracerebral haemorrhage 50%, and subarachnoid haemorrhage 46%³. Studies reporting rates in the 1990s estimate one month case-fatality of 19–28% and one year case-fatality as 34–41%¹¹.

Trends in stroke incidence and case fatality

Incidence

There have been few stroke incidence registers that have been maintained over long enough periods of time to document a change in incidence and the results are contradictory. Since stroke rates increase greatly with age and the number of elderly people is increasing worldwide, the burden of stroke on individual families, and the health services is unlikely to fall rapidly. Malmgren *et al* estimated that between 1983 and 2023 there will be an absolute increase in the number of patients experiencing a first ever stroke of about 30%¹⁶. There will be an increase in the number of deaths from stroke of about 40%, but there will only be an increase of 4–8% in the number of disabled long-term survivors. One can, therefore, anticipate an increase in the need for acute care and early rehabilitation services over this time period, but not an increase in longer term care.

Case fatality

There has been a significant decrease in mortality from stroke over time and in the western world which started in the early 1900s and has

accelerated during the past 30 years; this has been attributed by some to better control of hypertension, although this is far from clear¹.

Data on trends in case-fatality rates based on epidemiological studies are scarce and contradictory. Peltonen and colleagues demonstrated marked improvements in short and long-term survival since 1985 in Sweden, equating to a 30% reduction in death rates which they attribute to improved management¹⁷.

Prevalence of stroke

The prevalence is the number of stroke sufferers in the population. There have been very few prevalence surveys of stroke, the prevalence rates being estimated using the incidence and survival data from stroke registers. O'Mahony *et al* validated a simple self-completed questionnaire to screen for cases of stroke in the community and estimated that 10% of respondents reported a history of stroke. The question 'have you ever had a stroke?' had a sensitivity of 95% and a specificity of 96%¹⁸.

Geddes *et al*, in a study in the north of England, estimated the prevalence of stroke to be 46.8 per 10,000 (95% CI 42.5, 51.6). Cognitive impairment (33%), problems with lower limbs (30%) and speech difficulties (27%) were the most common residual impairments¹⁹.

Impairment, disability and handicap

The World Health Organization definitions are used to classify the impact of stroke longer term. The classification is being revised to introduce the concept of 'contextual factors' which impact upon the manifestation of all diseases (social, physical, personal). The revised classification refers to 'activities' and 'participation' rather than 'disability' and 'handicap'⁴.

Impairment

Impairment refers to abnormalities arising at the level of the organism. Impairments are usually the external manifestations of the pathology: the symptom and signs. Impairments are 'objective' and cover a wide range of states which carry no personal meaning to the patient: hemianopia, sensory loss, muscle weakness, spasticity, pain, *etc* (Tables 1 & 2).

Disability

Disability refers to changes in the interactions between the patient and the environment. It is the behavioural consequences, which manifest

Table 1 Acute (0–7 days), three week and six month impairment/disability rates

Phenomenon	Acute (%)	3 weeks (%)	6 months (%)
Impairments			
Initial loss/depression of consciousness	5	–	–
Not oriented (or unable to talk)	55	36	27
Marked communication problems (aphasia)	52	29	15
Motor loss (partial or complete)	80	70	53
Disabilities			
Incontinent of faeces	31	13	7
Incontinent of urine	44	24	11
Needs help grooming (teeth, face, hair)	56	27	13
Needs help with toilet/commode	68	39	20
Needs help with feeding	68	38	33
Needs help moving from bed to chair	70	42	19
Unable to walk independently indoors	73	40	15
Needs help dressing	79	51	31
Needs help bathing	86	65	49
Very severely dependent	38	13	4
Severely dependent	20	13	5
Moderately dependent	15	15	12
Mildly dependent	12	28	32
Physically independent	12	31	47

The 'acute' figures are of limited accuracy as many patients were not assessed within the first week, many of these were very ill and probably very dependent. Consequently, the figures relating to acute disability are minimum estimates.

These data relate only to survivors and are summarised from Wade³

within the patient's environment, or the personally meaningful functions or activities which are no longer executed, or are altered. Altered behaviours stretch from continence and turning over in bed to dressing and bathing and gardening, interacting with other people and specific work skills. In practical terms, especially in relation to health and social services, disability manifests itself as an increasing dependence upon people and/or environmental adaptations.

Some representative data of disability for the acute phase and 6 months are shown in Tables 1 and 2. The Oxford study estimated that, at 1 year, 65% of survivors were functionally independent.

Handicap

Handicap is the most difficult level to define and measure and is the change in social position which arises from illness; it also refers to the social, societal and personal consequences of the disease. It is the roles and expectations which are performed less readily, if at all.

Table 2 Epidemiology of stroke: the figures are per 100,000 population per year, where relevant

General - SAH, TIAs, stroke - diagnosed	
Cases SAH per year	14
New cases TIA per year	42
- carotid territory TIAs	34
First strokes per year	200
All acute strokes per year	240
Stroke survivors alive in community	600
Presenting for diagnosis	Not known
Impairment/disability presentation (i.e. need acute care), all stroke	
With reduced consciousness	84
Severely dependent	140
Incontinent of urine	106
Disoriented/unable to communicate	132
Unable to get out of bed unaided	168
Impairment/disability at 3 weeks (i.e. need rehabilitation), all stroke	
Needs help dressing	86
Needs help walking	67
Needs help with toilet	66
Communication problems	49
Impairment/disability at 6 months (i.e. needing long-term support)	
Needs help bathing	71
Needs help walking	22
Needs help dressing	45
Difficulty communicating (aphasia)	22
Confused/demented (or severe aphasia)	39
Severely disabled (Barthel < 10/20)	13
Services at 6 months	
Needs long-term institutional care	23
Possibly needs speech therapy	24

This assumes (i) all stroke, first and recurrent (2.4 per 1000 per year), (ii) 30% die by 3 weeks, (iii) 40% die by 6 months, and (iv) minimal contribution from SAH to care and rehabilitation needs. From Wade³

In a population-based survey in south London, the vast majority of stroke survivors, 5 years after their stroke, lived in private accommodation, and the most disabled were only likely to be in private accommodation if they had an identified carer²⁰. One-third of survivors were severely or moderately disabled and two-fifths of survivors were more disabled than they had been at 3 months after their stroke. Respite care was only received by a few people. Nearly 75% had an adaptation to the environment and 75% were prescribed treatments aimed at preventing further vascular events. Some 23% were depressed and a further 14% had borderline depression scores. The assessment of quality of life, using the SF36 score and Nottingham Health Profile, suggested that the patients' scores on the various scales were related to their residual disability²⁰.

Quality of life after stroke is increasingly being measured but published assessments report widely different findings. These differences can be attributed to different methodologies, including the specific quality of life measure and time of investigation.

Needs of families and carers

In recent years, there has been an increasing, but unproven, emphasis on the need for stroke services managed in the community. The strategists and health service planners have not considered the considerable proportion of care undertaken by carers and families. As a result of the pressures, carers suffer from depression and anxiety and family tensions and financial problems are common. Four main areas of concern to carers can be identified through the literature. Carers want information, skills training, emotional support and regular respite. However, these have been highlighted as areas of major deficiency in informal carers' interactions with professionals. Carers frequently mentioned a failure of agencies to supply promised aids or services, a general lack of information and advice and the provision of irrelevant help. These points obviously have great implications for the type of help offered to carers. The nursing literature does suggest the importance of nurses in information giving and counselling: 'the support of informal carers must be seen as a legitimate and important focus for nursing interventions'. Yet the literature also highlights the fact that, on the whole, this has not been happening. The literature also cites the benefits of intervention such as support groups for patients and their carers. However, it has also been shown that these may only benefit certain people and there is a lack of proper evaluation of such groups²¹.

Current service provision for stroke

It is estimated that stroke services accounted for at least 4–6% of the NHS budget in the UK, but these figures do not take into account social service and carer costs.

Primary care

The morbidity survey in general practice in the UK estimates that circulatory diseases account for 9% of consultations, 36% of which are 'serious' with the most common reason being essential hypertension²².

Overall, cerebrovascular disease prevalence was estimated at 5–8 per 1000 individuals. Nearly all patients who consulted for cerebrovascular disease did so for transient cerebral ischaemia or for acute but ill-defined cerebrovascular disease. Comparison of prevalence rates for 1971/2 and 1991/2 shows an overall 64% increase in consultation rates. The number of contacts for follow-up of a stroke would appear from the statistics to be low. These data will vary from country to country depending on the role of primary care in stroke management. Specific stroke surveys in the UK over the last 15 years indicate poor follow-up of patients once discharged. Under half of patients were followed-up by their GPs, less than a third by community nurses and less than 20% had access to other services.

Secondary care

Secondary care services for stroke management span many specialties. The patterns of care vary considerably between and within countries, depending on a variety of local influences such as historic patterns of care, priority of purchasers and providers to modify traditional service provision, and local enthusiasm and expertise in the management of stroke patients^{23–25}.

Although stroke care usually involves hospitalisation, wide variations have been reported between English districts in the proportion of stroke cases that is admitted to in-patient care (55–90%)³. It is estimated that, in terms of acute stroke services, patients consume the following resources: 20% of acute beds, and 25% of all long-term beds, including nursing home places³. In a Stroke Association survey in the UK in 1998, consultants responsible for care of stroke patients were questioned. The findings are summarised to illustrate the inequity in impact on health services in the UK of stroke patients²⁴: over three-quarters of consultants had access to organised stroke services, yet only half of stroke patients go to them; there was geographical inequity in the provision of organised stroke services; social work support was inadequate; access to neuroradiology remained difficult; stroke consultants are rare; better information and management tools are required.

In a sentinel audit of stroke care in the UK in 1999, Rudd and colleagues re-inforced the survey findings of the Stroke Association but actual practice appeared even more sub-optimal than the consultant survey²⁵. Only 18% of patients spent over half their stay in a stroke unit. If care is to be more effective, the changes in stroke service provision will have to be considerable, which will impact on the health services but to the advantage of the patient and their families.

Key points for clinical practice

Table 3 outlines some of the relevant data presented in this chapter that are considered useful information for both patients, families and health care professionals. Stroke has a significant impact on our society and we are only just beginning to be able to quantify it. With increasing opportunities to reduce this impact, it is important that there are reliable baseline figures on the needs of stroke patients and robust tools for monitoring improvements in outcome.

Table 3 Key points for clinical practice

Incidence	<p>1 in 4 men and 1 in 5 women will have a stroke if they live to 85 years</p> <p>Incidence rate of cerebral infarction 1.2–2 per 1000</p> <p>Incidence rate of subarachnoid haemorrhage 9–33 per 100,000</p> <p>Recurrence 20–40%</p> <p>30% increase in acute strokes between 1983 and 2023</p>
Prevalence	<p>9 million stroke patients world-wide</p> <p>Prevalence rate 5 per 1000</p>
Survival/mortality	<p>4.5 million deaths a year world-wide</p> <p>Third most common cause of death</p> <p>28 day case fatality 20–28%</p> <p>1 year case fatality 34–41%</p>
Health service provision	<p>4–6% health service budget</p> <p>9% primary care consultations are for 'circulatory' disorders</p> <p>55–90% admission rates to hospital</p> <p>20% acute beds, 25% long-term beds used for stroke</p> <p>Inequity in provision of effective stroke services</p>

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