

CHAPTER ONE

Stroke: An introduction to the problem

Every year, in a typical Western population of 100 000 people, about 200 suffer a stroke and come into medical care. Most of these people are admitted to hospital but the proportion varies, depending, in part, upon whether the patient lives in town or country. Stroke is the most important single cause of hospital use after mental disorders; altogether, care of stroke patients may absorb about 6% of hospital running costs and nearly 5% of all National Health Service costs (Carstairs, 1976). As a report from the Royal College of Physicians (1990) underlines, stroke is a major cause of chronic disability and the source of a heavy burden on patients' relatives and friends, as well as consuming a great deal of the resources of the health and welfare services.

About a quarter of the people who suffer a stroke die in the first month, but more than half survive for a year or more (Aho *et al.*, 1980; Warlow *et al.*, 1987). Most stroke survivors, probably about two-thirds, are rated as independent in daily activities by 1 year after the stroke (Weddell and Beresford, 1979; Wade *et al.*, 1985*b*; Warlow *et al.*, 1987), although this does not mean that they have returned to levels of activity or performance that they had before the stroke. Altogether, in a population of 100 000 people there are roughly 750 survivors of stroke, most of them living in the community with, or near to, family, and with varying levels of disability (Warlow *et al.*, 1987).

On the basis of existing research it is possible to describe quite well the characteristics of the people who suffer a stroke; which of them survive, and for how long; the ways in which they are dependent on others; which patients make improvements in physical functioning; and which of them return home. These themes – the factors that influence medical management and rehabilitation – reflect the principal concerns of most investigators. A broader perspective, including social aspects of stroke and follow-up over time in the community, is given in some recent studies

(esp. Wade, 1984). However, the effects of stroke on family relationships, housing, money, social life and general attitudes to life has been relatively neglected. Even less so, has research considered the perspectives – the views, attitudes and preferences – of patients and their family supporters, either alone or in relation to each other. Little is known about how patients and supporters feel about the care and support they receive; about how they want to be helped and what information they require; about which problems distress them most; or about how they view the main effects of stroke on their lives.

The experience of a chronic illness such as stroke, and its implications for practice, cannot be reduced to the rise and fall of performance in activities of daily living. There is a need to make policies and services relevant to the everyday lives of people living in the community. The effects of stroke on everyday life can be considered within the framework developed by Wood (1980) and discussed as handicaps (see Bury, 1987); while disability refers to loss of the ability to perform an activity, handicap refers to the disadvantage that accrues from being unable to fulfil a role that is normal for that individual. Thus the nature of disadvantage will depend upon social values and culture, but people will generally be disadvantaged if they are unable to orient themselves, move around, manage their body's physical needs, occupy time with work or recreation, maintain social relationships and be economically self-sufficient. These accomplishments constitute the core dimensions of handicap (Wood, 1980) and provide the framework for the discussion of the experience of stroke presented here.

The dimensions of handicap can be considered just as readily for family carers as for patients, and that is also done here. When stroke is dealt with as a 'family illness' the permutations of 'successful' recovery increase in number; there has been almost no research into the influence of the perspectives and perceptions of patients and their carers on the process of recovery from the stroke. Assessments of outcome have typically been made in terms relevant to the goals of the many professions involved; apart from the biographies of strong-willed and resourceful individuals there is no systematic information on the meaning of the stroke for patients and their carers. Yet if services are to support patients and their carers there is a need for greater awareness of the experiences and views of the main parties involved.

This book reports a study of the experience of a stroke as seen from the perspectives of patients and their main supporters. It looks at who provided what help, and what happened to whom, but it is mainly concerned with changes in the daily lives and attitudes of patients and supporters

over the first 18 months after a stroke. When patients survive the first weeks after a stroke they and their families embark upon a complex process of change and accommodation. This may lead to major changes in lifestyle, not only in patterns of social activities, housing, family relationships and financial circumstances but also in values, expectations and priorities. The perception and meaning of life may be altered. The chapters that follow aim to increase awareness and understanding of this process of change following stroke.

The meaning of stroke and the response to disability depend upon access to different elements in the 'armoury of resources' (Croog and Levine, 1977) – systems of personal, informal, community and institutional support. Evidently these resources are not distributed equally among people (with or without chronic illness) but may vary with sex, social class and age (Locker, 1983). These three characteristics will be investigated throughout the report as core variables influencing response to stroke and disability. Among the social resources for patients and their families, the health and social services are major supports upon which people may draw. Their contribution is considered in terms of their availability, the attitudes of patients and their supporters, and the effects of services on changes in the lives of patients and their supporters. In the context of viewing the stroke as a family illness with diverse and long-term consequences for the lives of patients and their supporters, it is important to identify gaps in service provision. There is currently widespread discussion of services which are relevant to the whole person, which improve quality of life, and which support the supporters. What is offered here is an opportunity to locate the rhetoric in the reality of life after a stroke.

Any attempt to review and assimilate the existing research literature is fraught with difficulties, the principal one being that much of the research with stroke patients is neither comparable nor cumulative. Studies of stroke patients are often conducted with small, convenient groups, and the sample populations vary in characteristics such as the definition of stroke used, age, degree of initial disability, management in home, hospital or rehabilitation centre, time since onset of the stroke, and measures of outcome or recovery. Major studies with which authors often compare their own results have included men only (Baker *et al.*, 1968), hospital patients only (Marquardsen, 1969), hemiplegic patients only (Adams and Merrett, 1961) or those with hemiparesis (Brocklehurst *et al.*, 1978a), and those suffering transient ischaemic attacks (Wolf *et al.*, 1977). These constraints on comparisons are often not acknowledged, to say nothing of differences between studies in their methods (for example, the definition and validation of the diagnosis of stroke).

In part, the problem with definitions of stroke is that the term ‘stroke’ refers to a description of symptoms and signs rather than to a single underlying pathology. However, most of the more recent epidemiological studies in England and Wales (Chin *et al.*, 1980; Stevens and Ambler, 1982; Oxfordshire Community Stroke Project (OCSP), 1983; Wade and Langton-Hewer, 1985) have used the definition of stroke recommended by the World Health Organization (WHO); this was also used in the study reported here.

Incidence of stroke

European studies using prospective stroke registers have produced incidence rates of about 200 new cases of stroke every year in a population of 100 000 (Radic *et al.*, 1977; Herman *et al.*, 1980; OCSP, 1983). All studies show that stroke happens overwhelmingly to older people: in the studies from areas in England (OCSP, 1983; Wade *et al.*, 1985a; Stevens and Ambler, 1982) between 75% and 86% of stroke patients were aged 65 and over. In these prospective studies, between 55% and 60% of the initial sample of stroke patients have been women. This is not surprising given the relationship between age and incidence. However, there is some indication that, at least in certain age groups, men are more likely to have a stroke: in the studies from Carlisle (Chin *et al.*, 1980), Dover (Stevens and Ambler, 1982) and Farnham (Weddell and Beresford, 1979) there is a higher incidence among men aged 55 to 75; in Oxfordshire the greatest excess was among men aged 45 to 65, and the overall excess of risk of stroke among men was 30% (Warlow *et al.*, 1987) – a figure also estimated by Haberman and colleagues (1981) from a worldwide review of community and hospital-based studies.

There appears to be no published information on the relationship between social class or socio-economic status and the incidence of stroke; in the Farnham district study no link was found (J. Weddell, personal communication). The analysis of ‘standard consulting ratios’ in general practice reveals no social class trends – for men at least; the data are not presented for all women (Royal College of General Practitioners, 1982). Lack of a relationship between stroke incidence and social class would be surprising, given that in England and Wales there is a clear pattern of increasing mortality due to stroke with increasing social class (Evans, 1979). However, the nature of the relationship between stroke incidence and social or economic conditions has attracted little specific research.

Survival after stroke

The natural history of stroke involves a fairly high level of deaths soon after the stroke, followed by a lower but relatively continuous fatality over succeeding years. The aggregated data from the WHO study (Aho *et al.*, 1980), in which there were no significant differences in survival rates between centres, showed 23% dying within 7 days, 31% within 3 weeks and 48% before the end of the first year after a stroke. The figures are similar in reports of other studies, suggesting that, on average, half or more of all stroke patients survive beyond 1 year. Survival in two English studies, which were also organised along the lines of the WHO study, appear rather worse than average: preliminary results from Carlisle (Chin *et al.*, 1980) show 54% of patients died in the first month, while in Farnham (Weddell and Beresford, 1979) 54% of patients died in the first 3 months. However, results from the Oxfordshire study, which appears to have good coverage of milder cases of stroke, indicate that the overall 1-year case fatality rate is between 30% and 40% (Warlow *et al.*, 1987).

Most studies report that survival is more likely among younger patients (Ford and Katz, 1966; Aho *et al.*, 1980; Warlow *et al.*, 1987). However, a conspicuous feature of many different studies is the lack of any consistent relationship between sex and survival. There are few reports which consider other social characteristics of patients in relation to survival. In their study Abu-Zeid and colleagues (1978) found that, after adjusting for age, married patients were more likely to survive the stroke than single people. The same authors reported no association between stroke survival and socio-economic group, but Sussman (1965) refers to work, now more than 25 years old, showing that stroke patients with higher levels of economic dependence deteriorated more rapidly in their functioning and died sooner than less economically dependent patients.

In general, it appears that 'Irrespective of treatment, about a third of all stroke patients die of the condition, and the majority of these deaths occur very early' (Wright and Robson, 1980, p. 250). Among those who survive the acute stroke, subsequent mortality is almost certainly higher than in the general population of the same age and sex (Abu-Zeid *et al.*, 1978; Sacco *et al.*, 1982). About a quarter of survivors at 3 weeks may die before the end of the first year; thereafter deaths appear to progress at a rate of about 15% of the at-risk population every year. This is broadly compatible with the results from Farnham, where about 40% survived for between 3 weeks to 4 years after the stroke (Weddell and Beresford, 1979). There is a lack of detailed data on the longer-term survival of stroke patients, and the factors influencing this survival.

Consequences of stroke

In a limited sense, and subject to caveats about whether it is possible to generalise the results of different studies, there is a good deal of information about some consequences of the illness for both patients and their supporters.

Neurological impairment

The main symptoms of stroke vary, but frequently involve some period of unconsciousness, which may last for moments, hours or days. On recovering consciousness the patient commonly has one or more of the following difficulties: paralysis of one side of the body (hemiplegia); slighter loss of strength in one arm and one leg (hemiparesis); loss of feeling in, or loss of awareness of, the affected side of the body; weakness on one side of the face; difficulty in seeing out of one side of each eye; difficulty in understanding what is said and in speaking to others; difficulty in coughing or swallowing; and incontinence of bowel or bladder. Some of these deficits are associated with each other, due to the site or nature of the neurological lesion. Thus patients with weakness or paralysis on the left side of their body (left hemiplegia) more often have visuo-spatial and perceptual difficulties; patients with right hemiplegia are more likely to suffer from impairments in communication, particularly speech (dysphasia) (Adams, 1974; Brocklehurst *et al.*, 1978a).

Some evidence of weakness or paralysis has been found in between two-thirds (Stevens and Ambler, 1982) and five-sixths (Weddell and Beresford, 1979) of patients soon after the stroke. However, the proportion of survivors with limb weakness or paralysis declines through death and recovery, so that, for example, more than half of the survivors in the WHO multicentre study (Aho *et al.*, 1980) were free of hemiplegia or hemiparesis at 1 year after the stroke. It is against this general background that the consequent 'disability' or 'handicap' (Wood, 1980; Bury, 1987) can be described.

Disability and handicap

The patient's physical disability and dependence have been investigated more extensively than other consequences of stroke, although the meaning of disability in terms of disadvantage is seldom explicit. The ability to perform activities of daily living, often described as 'independence', does not necessarily mean 'back to normal'; patients may be able

to walk 50 metres outdoors but be unable to reach the shops, to carry the shopping or work out how much the shopping cost.

Progress in performing activities of daily living slows after the first month, and appears to be virtually complete by about 6 months after the stroke (Brocklehurst *et al.*, 1978a). After 3 months nearly three-quarters of the survivors in Farnham were classified as independent in ability to get in or out of a chair; 1 in 30 was totally dependent. The ability of survivors 4 years after the stroke was similar (Weddell and Beresford, 1979). However, another survey, of the spouses of young (under age 65) survivors at least 3 years after the stroke, found that two-thirds of the patients were described by their family as having problems with self-care (Coughlan and Humphrey, 1982). This points to the difference between measurement of dependency and the experience or perception of difficulties by patients and their families.

The problem of communication between the patient and others may also be underestimated if conclusions are based solely on tests for dysphasia (i.e. capacity for interpretation and formulation of the symbols of communication). There is little doubt that impairment of the abilities to read, write, speak and understand are often found after a stroke; the frequency with which these disorders are reported depends upon the methods of assessment, the characteristics of the patients and the time since onset of the stroke at which assessments are made (Wade *et al.*, 1986b).

The spouses and chief carers of the stroke patients may identify problems in communication even though the patient has not been assessed as dysphasic (Artes and Hoops, 1976). At 1 month after the stroke, 39% of chief carers reported difficulties understanding the patient's speech in one study (Brocklehurst *et al.*, 1978a) while, in the longer-term, 1 in 4 spouses continued to report communication difficulties (Coughlan and Humphrey, 1982). Clearly, the experience of difficulties in communication is made up from more elements than ratings of clarity of expression or comprehension.

For patients, the experience of loss of the ability to communicate effectively means more than an inability to read or make clear requests: it is a cause of significant distress. Hurwitz and Adams (1972) note how frustrating dysphasia can be: 'being regarded as brainless, being subjected to the indignity of having things done for them which they could well do for themselves, and ... not doing for them those things they cannot possibly be expected to do' (p. 94). Anxiety and depression, even a sense of hopelessness, are found among a large number of all stroke victims, but 'The failure to be able to remember, to use language, to solve familiar

problems, to think clearly, or to control feelings could be more devastating to the individual than the physical infirmities associated with stroke' (Levine and Zigler, 1975, p. 752). However, the evidence that patients with dysphasia are more depressed, for example, than other stroke patients, is not conclusive (Brocklehurst *et al.*, 1978a).

In the first weeks after stroke many patients must struggle to adjust to sudden changes in themselves and in their relationship to their environment. Assumed and unquestioned abilities may disappear – to drink a cup of tea, to visit the toilet alone; expectations of the future may be shattered and prospects for the future uncertain; the present may appear to contain only the humiliation of being fed and bathed and feelings of total dependence upon others. The term 'depression' is commonly used by patients, researchers and doctors to describe a variety of mood disorders following stroke. Different approaches to assessing the phenomenon of depression (Robinson and Price, 1982; Feibel and Springer, 1982; Wade, 1984) indicate that this is a common and persistent problem, affecting nearly one-third of patients over the first year after the stroke.

The longer-term outlook for many stroke survivors appears unpromising. Of patients discharged from an Australian hospital and followed-up 3 years later only one-quarter were optimistic about the future (Lawrence and Christie, 1979). In a 2–3-year follow-up study from Frenchay Hospital in Bristol, Holbrook (1982) reports that one-third of patients said they had not adjusted to the effects of the stroke, and many felt they never would. Isaacs and colleagues (1976) followed for 3 years 29 stroke patients who were discharged home. Although most remained physically fit, many became depressed and frustrated. Only 4 of these 29 survivors were described as adjusting successfully to the stroke; others had gone through changes in their personality towards aggression, frustration and a reluctance to co-operate or participate in normal living. One-quarter of the spouses of younger stroke survivors reported a marked personality change among patients discharged from a London rehabilitation centre (Coughlan and Humphrey, 1982); these included irritability, loss of self-control, impatience, lowered tolerance, frustration, emotional lability and reduced initiative. Spouses described life for 41% of patients as much less enjoyable than before the stroke, and 31% of the spouses said that they themselves now enjoyed life much less.

The impact of stroke on social and family life has been relatively neglected. Yet various studies (Hyman, 1971; Folstein *et al.*, 1977) suggest that the social reintegration of stroke patients is possibly the most problematic aspect of rehabilitation.

Survivors may become socially isolated not only because they lack the

opportunity or inclination to visit friends or travel to social events, but also because there is a lack of appropriate facilities, such as day centres and restaurants, which are able to accommodate disabled people, and because old friends, colleagues and social contacts do not visit (Isaacs *et al.*, 1976). The stroke survivor may be a changed person, difficult to communicate with, distressing to meet, and with whom it seems embarrassing to discuss past occasions or future plans. Many patients will acquire the status of 'disabled', which is likely to attract a multitude of negative evaluations, extending into different spheres of life including work (Seifert, 1979).

Although less than a quarter of stroke victims are people of working age, this group survives better than older patients; thus, for example, in the sample of Weddell and Beresford (1979) one-third of the males alive at 3 months after stroke were of working age. Of the males in this study who had previously been employed full-time less than one-third had returned to full employment 3 months after the stroke. (In all age groups, nearly half the housewives said that they were working at the same level as before by 3 months after the stroke.)

The loss of employment may mean a reduction in income and financial difficulties for many patients, at a time when additional money may be necessary to cover new transport or housing costs, and when the ability to buy aids and appliances may be useful. M. Smith and colleagues (1981) note that extra expense was incurred by patients who bought aids for themselves, either because they found they needed them urgently, did not want to join a waiting list, or were unaware that aids could be obtained on loan.

A quarter of the younger (work-age) patients in the study of Mackay and Nias (1979) felt they had sustained a financial loss because of the stroke; and this figure is likely to be an underestimate for problems over the course of a year since interviews were held about 6 months after the stroke, and, in England, the obligation of employers to pay employees on sick leave ends after 6 months. Blaxter (1976), in a general study of physically disabled people, found that 'financial problems were likely to begin some 6 or 7 months after the illness episode'. A study of members of a stroke club in Seattle, at least 1 year after being discharged from a hospital treatment programme (Belcher *et al.*, 1978), revealed that the mean income of single stroke survivors was only one-third of the mean income for married stroke survivors. None of the single people were working, but 7% of the married stroke patients and 38% of their spouses were working. Clearly, single people recovering from stroke are less likely to have readily available support of many types than are their married

counterparts. The financial consequences of stroke should be considered with regard to the entire household unit and not only the stroke patient.

Carers: their contribution and some consequences for their lives

Stroke is a 'family' illness; it presents challenges and dilemmas to those who live with or support patients. For stroke patients, and the chronically ill generally, the family is the main source of emotional, social and practical support (Henwood 1990). Since most stroke patients are elderly, it is important to establish their expectations about who should help when they are ill. Shanas (1979) reports that: 'Old people turn first to their families for help, then to neighbours, and finally, to the bureaucratic replacements for families – social workers, ministers, community agencies, and others – because they expect families to help in the case of need' (p. 174).

Changes in the attitudes and preferences of disabled people for different sources of support have received little attention; much more has been made of demographic changes – such as the growing numbers of dependent older people, rising rates of divorce, and the increasing proportion of women employed outside the home – and statements about the increasing reluctance of family members to care, as indications of an impending decline in the availability of family support. Firm evidence about changes in attitudes to caring is lacking, nor has a reduction in support given by the family been adequately documented (Allen *et al.*, 1987). In the Farnham study (Weddell and Beresford, 1979) nine-tenths of patients living with others at home 3 months after the stroke were receiving help from someone in the household; a quarter of all the survivors were being helped by members of the extended family. Among 67 survivors 4 years after the stroke, 9 received no help at all (either from their own families or anyone else), 45 had help in one or more ways from members of their own households, 7 had help from neighbours, and 14 from their extended family. There has clearly been growing awareness, if not appropriate recognition (Anderson, 1987), of the non-professional caring resource of family, neighbours, mutual aid and voluntary organisations. Both government and service providers acknowledge that family carers constitute the backbone of caring in the community, but they may be hesitant or uncertain about how to support the carers effectively (Twigg *et al.*, 1990). Many of the general needs of carers are well known (Anderson, 1987), but response to these needs will not be helped by the growing constraints on public expenditure, nor by long-established problems of co-ordinating care (Royal College of Physicians, 1986). A major focus of the chapters