Stroke: Social and Emotional Outcome

MARGARET HOLBROOK, SRN, CQSW

Research Social Worker, Neurological/Stroke Rehabilitation Unit, Frenchay Hospital, Bristol.

Stroke is a family matter. It disrupts family life, work patterns, financial status and general life-style. It imposes a heavy workload on hospital and community care services. Papers on its social consequences[1-3] indicate that life after a stroke can be a miserable affair for the majority of sufferers who are left with residual disability, and recommend that they should be kept in their own community, that greater use be made of voluntary services, more information given about financial benefits and services for disabled people, and that social workers should be more deeply involved. Our experience in the Stroke Unit in Bristol indicated that, even with a greater social work input, better information and more voluntary services, there is still a residue of misery and maladjustment that it is difficult to alleviate.

The Stroke Unit

The Stroke Unit at Frenchay Hospital, Bristol, accepted both in- and out-patients for rehabilitation and as there were no beds attached to the Unit, in-patients stayed under the care of their consultant-in-charge. Patients were treated in the Unit by a multi-disciplinary team of physiotherapists, occupational therapists, speech therapists, nursing staff and a social worker, led by a doctor. Out-patients were given all their rehabilitation in the Unit; in-patients continued to come for treatment after they had left hospital if they lived in, or near, the Frenchay Health District, or had their own transport.

During the period of rehabilitation, patients and relatives were encouraged to become actively involved in the aims and techniques of rehabilitation. Relatives' groups met every fortnight and all relatives were invited. The groups gave relatives information on stroke (Chest, Heart and Stroke Association Handbooks)[4], services and benefits, advice on rehabilitation problems, a chance to compare problems with other relatives, and a chance to gain comfort and encouragement from experiencing and overcoming similar problems.

After discharge from active rehabilitation a range of services, both statutory and voluntary, is available, including day centres, speech groups, craft centres, and our own more specialised voluntary service which grew up in response to the needs of stroke patients that could not be met elsewhere[5]. It provides individual as well as group help. The groups include a weekly meeting for men of working age who need to get away from their womenfolk, chat over a pint, play cards if they want to, or arrange outings for themselves. Two skittles groups meet every fortnight in a local pub, a ladies' group meets every two weeks for social activities, and there is a garden for the disabled where volunteers have devised ways of teaching our patients one-handed gardening skills. In addition, an individual service is offered to patients. Volunteers work at increasing social skills, on defined projects suggested by the therapists, and on the more generally recognised volunteers' tasks such as sitting in or taking the family out. Although these services would seem to meet all needs, there are many patients who do not wish to join groups or who feel patronised by the offer of voluntary services.

Patients

The study of our patients is based mainly on a follow-up of new stroke cases, i.e., those referred within 90 days of stroke, who were assessed and treated in the Stroke Unit, and who were followed up at six-monthly intervals until their final assessment two to three years after stroke, in 1980. There is also reference to an earlier follow-up study on patients from a population study in 1970-73 who were seen in 1975, two to five years after stroke (Table 1).

Table 1. Findings of two studies of stroke. First Study 1975—follow-up of a population study. Second Study—Stroke Unit patients seen in 1980.

	First Study 1975	Second Study 1980
No. of Strokes	264	162
Survivors followed-up	88	92
Male <65	28	20
>65	19	25
Female <65	16	12
>65	25	35
Disability—		
*Moderate (R3-4)	30 (34%)	—
*Mild (R1-2)	58 (66%)	—
**Severe (– 40)	—	6 (7%)
**Moderate (41-59)	—	12 (13%)
**Mild (60 +)	—	74 (80%)

*Rankin Grade
**Barthel Scale

Disability scores by Rankin's[6] grades or Barthel's[7] scores have been included with some reluctance, as they do not appear to have a great deal of relevance when considering what happened to this population. There were more people with minimal residual disability in the first study than in the second, but this is not reflected in the scores. This information gives an inaccurate picture of the 'perceived disability' of these patients.

Results

Employment (Table 2)

Table 2. Employment. Second Study 1980.

Patients (92)
- 30 working before stroke
- 22 did not return to work
  - 8 returned to work, of whom 3 later left work for health reasons
  - 5 in work at 2/3 years

Spouse or main carer (59)
- 26 working
- 16 returned to same work
  - 2 to part-time work
  - 8 did not return to work

Time off work—2 to 13 weeks.

Those patients whose strokes were slight, leaving them with minimal residual disability, and whose employers wanted them back, went back to work. The three who went back to work and then gave it up, did so because one had another stroke, and the other two found they could not cope. Those who had more severe residual disability—which included motor function, or communication problems, visual problems or cognitive problems—did not get back to work. Although there is a Hospital Resettlement Officer, no stroke patient managed to get employment in two Remploy factories in Bristol.

Spouses also have work problems. If patient and spouse have to give up work, inevitably the financial loss is considerable. Although there are allowances to be claimed if the couple are of working age, these benefits are payable only as long as the disability is severe and the patient stays alive. Consider a man who gives up his job to look after his wife, who also previously worked. After six months they receive benefits totalling over £70 a week, some tax-free, and the income from their savings. After three years of devoted care and a series of further strokes, the wife dies. In one week the man loses his wife and his main income, and finds that he is not employable. If his savings total over £2,000, he does not qualify for Supplementary Benefit. Had he refused to have his wife at home, or to care for her, he would have cost the Health Service a considerable amount of money and would still be in employment.

Financial Benefits

These are available to all who know about them, who qualify for them under the DHSS's terms of eligibility, and who apply for them. The most valuable source of information on who qualifies for what is a book, published annually, called *The Disability Rights Handbook*[8]. The highest number of benefits go to men and women of working age, although Mobility Allowance can continue to be paid until the age of 75, and Attendance Allowance is available to those over the age of two years who are eligible. Thirty-nine per cent (36) of our study patients qualified for benefits; two more were advised to apply at final assessment, as they had become less able. Someone needs to keep a careful watch on people with increasing disability, as failure to claim an allowance could result in considerable financial loss. For example, Mobility Allowance can be claimed only up to the 66th birthday; a late claim could result in the loss of £7,000 over the next nine years, at the 1981 rates of payment.

Housing (Table 3)

Table 3. Housing. Second Study 1980 (92 patients).

Unchanged	70
Changed to—	
Sheltered housing	4
Part 3 accommodation	4
Flat	5
Other	4
Institution	5
Living—	
Alone	19
With spouse, relative or friend	59
In institution (hospital, nursing home, Part 3)	14

Of the patients, 59 were living with relative, spouse or friend, 19 were living alone, and 14 in some sort of institution. Of the 22 who changed housing, all but one were quite severely disabled and could not have stayed on in their previous housing. Of the remaining 70, there were many for whom a change in housing would have been desirable, but the difficulties of moving house have to be considered, especially if the house is owner-occupied. In addition to the upheaval and the general costliness of a move, there may be the loss of supportive friends, neighbours and relatives. Thirteen of our patients were still using a commode at the end of the study period, but very few were still sleeping downstairs.

Mobility Outdoors (Table 4)

Table 4. Mobility outdoors, Second Study 1980. (92 patients.)

	No.	%
Walking		
Did not go out	13	14
Rarely went out	9	10
Total unable to walk outdoors	38	41
Driving		
Drove before stroke	26	28
Drove after stroke	5	5
Driven by spouses or main carers	24	26
Had regular use of car after stroke	29	31

Mobility indoors is reflected in the Rankin and Barthel scores. Mobility outdoors indicates the degree of handicap experienced by people in their own environments: for instance, 41 per cent could not walk outdoors, and 22 (24 per cent) including the 14 in institutions, either did not go out or only rarely did so. There is a very small percentage of people who did not get out at all. Few people used buses. It is encouraging to see that so many people got to the local shops by themselves.

Stroke certainly cuts down the mobility of any family, especially if the spouse does not drive. Table 4 shows that only about one-third of our families are mobile. Surprisingly, 35 patients still used wheelchairs. Nevertheless, most patients did manage to get out at least once a week, going to day centres and groups, being taken out by volunteers or relatives, or getting out under their own steam.

Use of Social and Community Services

The Social Services Department is responsible for providing a wide range of services for disabled people. The most widely used, and available, are Meals-on-Wheels, home helps, provision of aids and adaptations through domiciliary occupational therapists, personal social work services, day centres, and accommodation in elderly persons' homes (Part 3 accommodation). The amount of use made of Meals-on-Wheels and home helps depends on the quality of the former and the availability of the latter. Men have learned to cook in later life rather than eat pre-packaged meals. (One of our volunteers helped teach a husband to cook his wife's favourite dish.) Nevertheless, without these services, many stroke patients would not be able to manage at home at all.

Day centres, whether statutory or voluntarily run, have a valuable place in the care and entertainment of disabled people. Nevertheless, many stroke patients feel that to use these centres is further confirmation of their disability and uselessness. The acceptance of day centre places was low in both our studies; 9 per cent of the first study and 18 per cent of the second. Our voluntary service groups attracted 33 per cent of the patients in the second study. Those who were able to get back to the clubs and groups they belonged to before stroke were encouraged to do so, the main problems being the suitability of premises, the availability of ground floor toilet facilities, and transport. My own feeling about day centres is that there is a time in the period of disability when they may be acceptable, but that if people are pushed into a world of disabled people before they have come to terms with their own disability, they are likely to feel that there is no hope for them. Moreover, most day centres encourage craft skills. These can be very difficult for someone with a hemiplegic arm, or with visual, perceptual or comprehensional problems. The relatives often gain more from a day off than do the patients from a day out.

Emotional Outcome

We have our own ideas about the sequence of reactions that people go through in the process of adjustment to a trauma which results in disability. There is an accepted pattern of grieving after loss which has been described [9-11] as denial, mourning, depression and disorganisation, followed by acceptance or adjustment. This may not be semantically accurate but it covers the main stages. Others[12-14] describe the stages of adjustment to disability as being shock, expectancy of recovery, mourning, defence and adjustment. This is near to our own model, which has evolved during six years of work with stricken families and is divided into four stages; crisis, treatment, realisation of disability, and finally, for those who make it, adjustment (Table 5). The second and third stages coincide with discharge from hospital and discharge from active rehabilitation[15]. It should be emphasised that not all families go through these identical stages at these particular times, but it is a generally observed pattern. Work is being done in the Bristol Domiciliary Study to see if adjustment is better when treatment is based at home.

Table 5. Reaction of stroke families.

FIRST STAGE
- *Crisis*
- Shock
- Confusion
- High anxiety

SECOND STAGE
- *Treatment Stage*
- High expectations of recovery
- Denial that disability is permanent
- Periods of grieving
- Fears for future—
  - Job
  - Mobility
  - Life-style
  - About coping

THIRD STAGE
- *Realisation of Disability*
- Anger
- Feelings of rejection
- Despair
- Frustration
- Depression

FINAL STAGE
- *Adjustment*

Interruptions to the accepted pattern of adjustment are more likely not to occur if the role changes experienced by the family are those that can be taken on without trauma, for it must be remembered that a spouse who has always assumed the dominant role in the marriage will find it very difficult to change from being breadwinner, driver and maker of executive decisions to a more subservient role, and to being dependent upon spouse and children for most activities. Similarly, a dependent spouse may find that taking over the executive role in the household, dealing with all business and finances, is so worrying that she may need considerable help over a long period of time, for she has also to love and encourage her unhappy spouse.

Adjustment and Residual Problems

Patients (Table 6)

Patients were asked, in a joint interview with their spouse or main carer, whether they had adjusted or come to terms with what had happened to them. They were asked about relationships with their families, their spouses, and whether they felt that the stroke had altered their sex life. They were asked whether they worried about their mobility, their health, or their finances.

Table 6. Adjustment and residual problems in 92 patients in Second Study 1980.

	No.	%
Time to Adjust		
< 6 months	18	20
<12 months	20	22
<18 months	7	7
<2/3 years	4	4
Not known	10	11
Not adjusted	33	36
Adverse effect on		
Relationship with family	23	25
Relationship with spouse	17	18
Sex life	17	18
Specific concern (79 patients only)		
Mobility	57	72
Health	32	40
Finance	6	8

The main health problem was fear of further stroke, a common fear among our first group. Other problems described, mostly with anger, were change in life-style, depression, frustration, extra work for the spouse, communication problems, loss of confidence, loss of concentration, loss of independence, lack of progress, other people's reactions, feeling useless, loneliness, and having to stay in hospital.

It is interesting to note that adjustment did not necessarily take place if disability was slight, although most of those who felt they had not adjusted were substantially handicapped, and many of them had had further strokes or complications.

Relatives or Main Carers (Table 7)

Table 7. Adjustment and residual problems in 50 spouses or main carers. Second Study 1980.

	No.	%
Time to Adjust		
< 6 months	16	32
<12 months	9	18
<18 months	5	10
< 2 years	4	8
Not adjusted	16	32
Adverse effect on		
Finances	27	54
Social mobility	38	76
Social life	36	72
Relationships	22	44
Sex life	19	38
Working life	14	28
Health	27	54

Relatives were asked similar but more specific questions. Although reactions were similar in proportion to those of the patients, it did not follow that if the patients had adjusted, the relative had also done so. It is also worth pointing out that main carers usually felt less emotionally involved than spouses.

The more specific questions show that stroke disrupts almost all aspects of life. Many feared that they, too, would have a stroke or a coronary, brought on by worry. Of those whose spouses died, two had strokes and two had coronaries. Additional problems, described with great feeling, included change in life-style, fear of another stroke, depression, frustration, stress, tension, tiredness, coping, tackling tasks previously done by spouse, keeping family harmony and remaining loving despite great provocation.

Conclusions

1. Stroke affects families; they may need considerable support, not just during the crisis stages, but for many years afterwards.
2. Adjustment, if achieved, can take a long time.
3. Voluntary services, tailored to meet changing need, can offer a good service to supplement those supplied by the Social Services Department. Because they can be more flexible, they can extend rehabilitation beyond the active therapeutic input and can provide supportive help for families in time of difficulty.
4. The provision of better services does not mean that the problems of coping with an unacceptable illness disappear. Better services can mean a wider range of interests which lead to a better quality of life, but they are not a substitute for a whole mind and body.
5. Stricken families need continuity of care. They need to know to whom to turn for help when further problems crop up. The most likely source of help is the team that first became involved with them, and knows about their problems.
6. There are many scales of disability, based on activities of daily living, i.e., transferring, toileting, washing, dressing, feeding, bathing, etc. It is recognised that people can do things in hospital that they cannot do at home[16], sometimes because they lack the motivation, sometimes because they are stuck in a rut of depression, sometimes because relatives find it easier to do them themselves. No scales of disability include cognitive problems, nor are there scales that include the patient's perception of himself as able or disabled. For doctors and therapists, success means ability to perform self-care activities independently. For a stroke patient, a successful rehabilitation is perceived as getting back to a formerly enjoyed way of life.

This article is based on a paper read at the Conference on Assessment and Management of Complex Disability held at the Royal College of Physicians in November 1981.

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Book Review

British National Formulary 1981, No. 1. The British Medical Association and the Pharmaceutical Society of Great Britain, 1981. 400 pages. Price £3.80.

Hearty congratulations to the team who have compiled the new BNF. It shows a remarkable departure from the adverse features of its predecessors because they have put day-to-day usefulness before the official image. For various reasons the format has been changed from hard-back to strong fabric cover, allowing more content for less weight and making it more expendable. It will fit most white coat pockets, but the corners might have been rounded with advantage.

The old BNF always seemed out of date and out of step with the drug industry because it was hard to find novel drugs in current use and their brand name equivalents. The new book is relevant and up to date. One wonders how often it will be revised; the clear 'Number 1' on the cover seems to be a declaration of good intent—may it be so.

Excellent features include the placing of brand names under each approved name heading; the sections are intelligently arranged and immediately accessible through a very clear indexing system. The entries include sensible advice confined largely to comment about the drug in use rather than about the clinical field in which it is used; this is exactly as things should be in a formulary. There is an index of manufacturers and their telephone numbers, a most practical advance. There are useful specialist sections, including a Dental Practitioners' formulary list, each of which seems to be cast in a form that will help both specialists and general physicians who wish to use it. As was the case with previous editions, the preliminary information is excellent and includes what one needs to know in a hurry about cases of poisoning. The abbreviations are few and sensible, being confined to those in general use.

Two very valuable new additions are the cost classification of remedies, conspicuously but simply given, and the inverted black triangle which has hitherto only been available in MIMS. These additions should help doctors greatly in economy and in the assessment of adverse reactions.

There are a few critical comments. The section on interactions, though a very useful addition to the Formulary, seems to miss some of the main messages this Formulary would have enabled the authors to provide. For example, the provision of comprehensive lists of brand names under each approved name makes it possible for doctors to educate themselves to think of drugs in chemical classes with closely similar properties. This habit is particularly helpful with interactions, the majority of which occur with either oral anticoagulant drugs or with amines that occupy the active transport systems into neurones, or with the carrier sites for weak acids in the gut and kidney. Once these straightforward basic points have been remembered it is possible to anticipate interactions rather than just try to remember lists, an impossible task for most people. Similarly, the brief discussion on what to do when an adverse reaction is suspected does not really convey the simple practical message of how the various sources of information may be located and used, and how to get the most out of the yellow card system. Another weak point is an inadequate discussion of the prescription of drugs of misuse in registered dependent persons who happen to be under treatment for intercurrent disease. Nevertheless, these small points will prove troublesome only if readers make the very understandable mistake of thinking that this small book says everything; it is so good that it would be easy to do that because almost any useful detail seems to be there, even down to a table of units with their reverse conversions.

In summary, a remarkably useful book which for the first time should be able to take premier place among the reference works consulted by busy doctors.

D. W. VERE