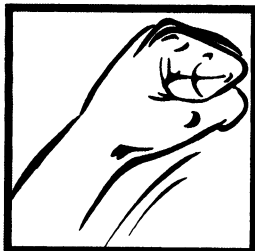


## Is stroke better managed in the community?

### Community care allows patients to reach their full potential

John Young



This is the tenth in a series of articles examining some of the difficult decisions that arise in medicine

Hospital based care currently dominates the management of stroke in Britain. This has been an insidious and unplanned process, and it is concerning that this acute care model may become regarded as the solution to stroke. I do not believe that hospital care should be replaced by community services but that a more appropriate balance needs to be achieved: one which recognises the limitations of hospitals and the pressing community (home) needs of stroke patients and their families.

Up to 70% of people who have a stroke are admitted to hospital, where they account for 12% of general medical and 25% of geriatric bed days. However, these widely cited statistics disguise considerable variations between districts, and it has become apparent that most stroke patients do not require hospital admission for medical reasons. Rather, the hospital is used as a form of rapid access sanctuary. It is a refuge for stroke patients who are socially disadvantaged (most commonly those living alone) and provides terminal or palliative care for those most severely affected.<sup>1</sup> But while hospitals remain the default service for stroke, progress in community care initiatives will be stifled. Stroke, with its rapid response and complex needs, should be regarded as a key index condition by which the success of community services is judged. The now conclusive demonstration of the effectiveness of stroke units, although a major triumph for international rehabilitation research, may be a further stimulus to distort the play of resources between hospital and community services and further reinforce the view of stroke as a hospital disease. Our rush to establish a stroke unit in each acute trust must be tempered by a larger vision for stroke management: one which embraces the community—that is, the home, as the main focus of service and research activity.

Our understanding of stroke care expanded greatly in the 1980s. Increasingly comprehensive observational studies left no doubt about the daily struggle for people with stroke and their families. These studies, however, have also exposed the inherent weaknesses and limitations of hospital based care. Three inter-related themes have emerged as the stroke research and development challenges for the 1990s. All three themes indicate unequivocally that the community should become the real battleground for stroke care.

#### Longer term perspective

It is now recognised that stroke rehabilitation requires a longer term perspective: probably at least three to five years after the initial stroke.<sup>2</sup> This may not seem a particularly awe inspiring notion, but it does represent a crucially different way of considering stroke care—one that clashes with the contemporary “short termism” of hospital practice. There are obvious parallels with other chronic disease such as rheumatoid arthritis where long term systematic follow up with multiprofessional interventions tailored to the individual have resulted in improved and more consistent outcome.

Blaxter followed the course of patients with a new disability (including stroke) after hospital discharge.<sup>3</sup>

The practical difficulties, the intense frustrations, and the hardships were plainly laid out. Two decades later, this experience is little changed despite advances in hospital care for stroke.<sup>2</sup> Blaxter came to recognise the continuous nature of this struggle and suggested the term “a career in disability” (which we could now redefine as “a career in stroke”) as an appropriate way to capture the lifestyle changes she observed.

Do hospital staff usually consider stroke in these terms? I think not. Hospital staff are entrapped by a short term view with a dominating focus on discharge from hospital as the end point of rehabilitation. Even in stroke units a good start is rapidly dissipated because we hand over the rehabilitation process to a near vacuum of community care.<sup>4</sup> The pressing challenge is to develop a community care rehabilitation process based on the proved principles of the stroke unit but which is capable of fulfilling the longer term perspective required by stroke patients and their families.

#### Minimising handicap

There is an important distinction between stroke related disability and handicap. Disability is usually readily apparent in stroke—for example, difficulty in standing or walking. But handicap—the manner in which a disability impinges on the particular circumstances of the person—may be less apparent. It is especially opaque in hospital, where there are limited opportunities to discover the handicap dimension since patients are necessarily separated from their home and social context. Hospital staff therefore tend to focus on a standard repertoire of abilities, and patients may not achieve their potential within their home.<sup>5</sup> Home delivery of physiotherapy for stroke is more effective, considerably more efficient, and more cost effective than hospital based care.<sup>6</sup> This supports the notion that home treatment addresses problems in a way that is more relevant to the patient.

#### Neglect of psychosocial needs

A special consequence of hospitals' short term outlook is that current rehabilitation programmes overemphasise physical recovery from stroke and do not address adequately the competing needs of education, psychological support, and enhancing social opportunities for patients and families. The dominance of hospital based physical rehabilitation is evidenced in the inverse therapy rule: that patients with the severest strokes and least potential for recovery receive most therapy. Conversely, many patients with good physical recovery remain housebound and socially impoverished, resulting in unnecessary additional burdens for their carers.

Holbrook has described a useful scheme for charting stroke recovery in which patients move from a stage of crisis, through a treatment stage and a realisation stage, to a final stage of adjustment: a stage at which a new validating role is discovered with a return of self esteem and dignity.<sup>7</sup> Our current emphasis on hospital based physical rehabilitation leaves too many patients stranded at the treatment stage. I have argued

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BMJ 1994;309:1356-8

previously for a more comprehensive rehabilitation approach with greater emphasis on psychosocial functioning.<sup>8</sup> This might be started in hospital, but its full realisation requires a community orientation.

### Conclusion

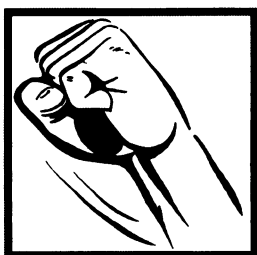
Hospital based care creates insoluble difficulties in addressing the key patient issues of long term treatment, handicap, and psychosocial functioning. Even in the best hospital centres, with patients carefully selected for the best recovery potential, the outcome in the medium term is poor.<sup>9</sup> Few districts currently provide stroke services that respond to the umbrella term "career in stroke disability." The shortfall is

large, and although community rehabilitation is in its infancy, it has the best potential to fill this gap.

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## Only hospitals can provide the required skills

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No effective treatment exists for acute stroke.<sup>1</sup> The only consistent evidence derived from randomised controlled trials is that management on a specialist stroke unit reduces both mortality and morbidity.<sup>2</sup> The key feature of these trials is that coordinated multidisciplinary care is better than disorganised care. The question to be debated is whether such coordinated multidisciplinary care is better provided in the community.

### Coordination is a problem

Unfortunately both experience and formal clinical studies have taught us that coordinated rehabilitation is lacking in the community. This is confirmed by the nature of requests for information and support made to the Stroke Association.<sup>3</sup> Coordinated care is possible in the community but difficult in practice. The professions concerned have different employers, patterns of referral, and work bases. Community nursing services offer significant input but tend to concentrate on the more disabled and those least likely to change. They provide a care service but not rehabilitation. Domiciliary physiotherapy is attractive, but the service is provided in only a few areas. Therapists have to deal with a varied caseload and many lack specialist expertise. Studies of the benefits of domiciliary physiotherapy and its cost effectiveness have produced conflicting results.<sup>4</sup> Occupational therapy is available more often but consists of providing aids and adaptations rather than therapy.<sup>5</sup> Even when a community rehabilitation service was provided it did not reduce admissions to hospital.<sup>6</sup>

Surveys of care after hospital discharge indicate lack of coordination, underreferral to support services, and no review of progress.<sup>7</sup> Effective coordination requires general practitioners to play a central part, but most have neither the training nor the time to take on the burden of yet another specialist service. They would be required to request, deploy, and maintain continued contact with other professionals over weeks or months. Whereas, at present many patients do not have contact with their general practitioner after discharge from hospital.<sup>7</sup> If the coordination of care is the crucial element to the effectiveness of rehabilitation, stroke is not better managed in the community.

patients who are admitted to specialised units.<sup>2</sup> Indredavik *et al* attributed improved outcome in the acute phase to the standardised programme for diagnostic evaluation, acute treatment, and early intensive rehabilitation.<sup>8</sup> The programme consisted of standardised systematic observation, and most patients had a computed tomography. Those with embolic infarction were treated with anticoagulants. Whether antithrombotic therapy is likely to have contributed to the difference in outcome will be clarified when the results of the international stroke trial become available. Most patients are admitted to hospital for nursing care, but diagnosis can be a contributory factor.<sup>9</sup> These functions can be served most effectively by a specialist unit.

Indredavik *et al* also proposed that early intensive rehabilitation contributed to the better outcome of patients in stroke units.<sup>8</sup> This rehabilitation usually consists of positioning patients to prevent the development of spasticity and mobilisation to facilitate long term recovery. These are specialist skills and not in the domain of community nursing services. Community physiotherapy services do not provide early intensive treatment. Further skills available in hospital include the multidisciplinary assessment of swallowing problems, identification of cognitive deficits, appraisal of mood disorders, and initiating secondary prevention strategies.

Other studies have shown the benefit of transferring patients to a specialised unit for rehabilitation alone. Kalra *et al* compared patients randomised to a stroke unit with those on general medical wards.<sup>10</sup> Patients on the stroke unit had a better functional outcome with reduced hospital stay without increasing therapy time. This suggests the content of the rehabilitation programme is important rather than the quantity. Early medical treatments, specialist rehabilitation, coordinated care after discharge, and secondary prevention require admission to hospital. It seems unlikely these could be achieved in the community.

### Evaluation of new treatments

Community services should be improved, but it is important that this is done within the context of randomised controlled trials so that the costs and benefits are known. If coordinated multidisciplinary care by specialists is the key to effective management and it is available in some hospitals, it seems better to capitalise on what we have and to develop the stroke units. Such multidisciplinary units act as a central

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### Stroke units work

In contrast, it is apparent from controlled trials that morbidity and mortality are reduced in those stroke