Improving long-term rehabilitation

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The long-term problems of stroke are both physical and mental. Rehabilitation (active promotion of recovery), maintenance (active prevention of deterioration), and care (support for those with disabilities) are intertwined elements of service provision aimed at reducing these problems. Over time, the prevention of deterioration becomes dominant.

Currently there is interest in 'intermediate care' — services aiming to provide choices other than inadequate care at home, inappropriate care in hospital, or expensive care in long-term institutions. There is also interest in stroke coordinators to manage community services. These developments have exposed problems of inequity (e.g. minority groups) and service provision (e.g. a shortage of trained staff). This had led to experiments in novel approaches such as generic workers and co-workers.

There is interest too in examining ways in which the social and built environment can be altered to increase the participation of disabled people in society.

Follow-up studies of stroke units show that half of all stroke patients are dead by 5 years\(^1\)\(^-\)\(^3\) and only 10–20% are alive after 10 years\(^4\). These studies also show that the survival benefits of stroke units persist for these periods of time. Better still, improved survival does not seem to be at the expense of increased disability.

But long-term stroke survivors have long-term problems. About 10% of survivors will have severe disability (Barthel score < 10/20) and many of these will live in institutional care\(^5\). But even in those that make a good physical recovery, there is a poor quality of life\(^6\)\(^,\)\(^7\). Niemi and colleagues followed up 46 stroke patients under the age of 65 years over a 4 year period and found leisure activities and family relationships were severely affected\(^6\). Problems with long-term quality of life were particularly associated with depressive symptoms. Many non-specific symptoms are prominent in long-term stroke survivors, including tiredness, irritability, intolerance of hustle, increased need for sleep, forgetfulness, mental slowness, poor concentration, inability to do two things simultaneously, crying more readily and loss of initiative\(^6\)\(^,\)\(^7\).

In its strict sense, rehabilitation is the active promotion of recovery. It is a labour intensive process and such activity is not generally applicable in the longer term. However, rehabilitation services in practice do more than...
provide rehabilitation in its strict sense. For example, they provide care or support, whilst disability is being overcome, and they arrange for long-term care needs to be met. They also deal greatly with the prevention of deterioration, for example by attempting to prevent painful shoulders, pressure sores, malnutrition and contractures. They also provide curative treatment for complications, e.g. depression or urinary sepsis. They are also involved in medical secondary prevention of stroke, e.g. the use of antiplatelet drugs, and in the primary prevention of other vascular diseases in helping to stop smoking and modify life-style. In the early phase after a stroke, while a patient is in hospital, all these activities are provided by a rehabilitation service. Once the patient leaves hospital, the scope for recovery is more limited, and services aimed at promoting recovery tend to be used less. As time goes by and services withdraw, the long-term outcome of the patient depends upon the residual problems left after the stroke, and the ability of the patient and his/her support and care mechanism to resist decline.

There is evidence that 'late' rehabilitation interventions (in the strict sense of the word) can produce measurable benefits, at 9 months, 1 year or even several years after a stroke. In a randomised cross over study in Nottingham, Walker and Drummond showed that focused dressing therapy about 9 months after a stroke could improve performance. Tangeman and colleagues in Oregon showed that intensive intervention at one year could improve performance. This was a non-random study, but the size of the benefits appeared to be much greater than would have been expected without the intervention. Collen and colleagues' randomised study in Oxford showed that gait speed could be improved even after up to 5 years post-stroke.

Whilst these studies attest to the efficacy of rehabilitation interventions, they do not offer a great solution to the long-term problems of stroke survivors. All three studies did not aim to treat the neuropsychiatric problems after stroke. In the Oxford study, the benefits of intervention were quickly lost. The intensity of treatment given in the Oregon study was greater than would be possible in the UK, and would be hard to justify on cost-effectiveness grounds.

There has been too great an attention on the narrow focus of the word rehabilitation, and too little attention to some of the other important functions performed by rehabilitation services. Little is known about the sorts of services that can be used after a spell in hospital to protect against poor long-term outcome, nor about models of care in the community or about the role of the social and built environment in maximising quality of life.

**Service delivery – intermediate care**

One of the most important adverse long-term outcomes of stroke is institutionalisation. In a study in Nottingham, we found that a quarter of
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survivors of acute stroke admitted to hospital went into institutional care on discharge, at a mean time of less than 3 months after the stroke. This study was conducted in the late 1980s when the availability of private nursing homes was rising exponentially, and without any major development in community care. In the late 1990s, attention was been brought to bear on this problem by the Audit Commission’s report *Coming of Age*. It describes a vicious cycle, wherein the majority of the budget designated for community care actually pays for institutional care, thereby allowing no funding for community alternatives. Attention has focused on these community alternatives for two reasons. The first is that older people, whether disabled by stroke or other conditions, do not want to end their days in an institution. The other is that if they avoid institutionalisation, they may reduce long-term care costs. These community alternatives go under the title ‘intermediate care’ and include the following.

**Community hospitals**

These are typically small hospitals, often supervised primarily by GPs, suitable for temporary care, either rehabilitation or convalescence. They often provide a range of services. They may provide a community safety net for unstable patients, who might otherwise go into institutional care. They have been closing around the UK on economic grounds, but their effectiveness in this role is unknown.

**Community care centres**

These are like community hospitals, but tend to have been created more recently, and do not aim to duplicate hospital services. They are often nurse-led. They may use health or social services facilities. Evaluation is limited.

**Hospital at home**

These may be schemes to avoid admission to hospital or an institution, or expedite discharge. They are essentially augmented domiciliary rehabilitation and care services, to be targeted at short-term needs. Evaluations to date suggest that they can reduce the use of hospital care, but it is not known if they influence the rate of long term institutionalisation.

There is currently much experiment in these sorts of services, and it seems likely that some version of them will, increasingly, be part of the
pattern of service delivery in the future, as hospitals become more and more sophisticated high technology centres with shorter lengths of stay. Careful use of these services may break the vicious circle, and avoid diverting frail or vulnerable people unnecessarily into institutions, thereby improving their longer term outcome.

**Service delivery – stroke co-ordinators**

If such services are developed, they will augment the existing community rehabilitation and care services, which are patchy and vary from region to region. Patients in the community need a wide range of services, including the traditional rehabilitation services of physiotherapy, occupational therapy and speech therapy. But they also need chiropodists, dentists, dieticians, GPs, orthotists, social workers, nurses, and so on. In hospital, the stroke unit provides the organisational focus to allow these services to be brought together and focused upon the patients. In the community, the role of ‘stroke co-ordinator’ has been invented, with the objective of bringing the appropriate services to bear upon properly identified needs. Little is known about what sort of training stroke co-ordinators should have, nor the degree to which the services they co-ordinate should be specific for stroke. More importantly, little is known about whether stroke co-ordination in the community produces the benefits of organised stroke care in hospital. After all, organised in-patient stroke care saves lives and there is no reason why organised out-patient care might do likewise.

Little is written about what stroke co-ordinators do, but it is my observation that there is a great deal of experimentation. For example, the national shortage of trained therapists has prompted the development of generic workers – members of staff from one discipline who learn and are authorised to act in other professional roles. Community working has identified groups of patients from ethnic minorities who are often not well served by the hospital service. The lack of a range of trained professionals who speak the language of each of these minorities has meant that the idea of the ‘bilingual co-worker’ has needed to be invented. These are often bilingual people who receive a simple training allowing them to interface between a professionally trained person and a patient from an ethnic minority. As in much of this field, there is much experiment, but little research.

Just as one can expect that the primary/secondary care interface will be populated by intermediate care schemes, so longer term community stroke care will be populated by new breeds of health care professionals, managing increasingly complicated services.
Environment

Short-term rehabilitation interventions seem to produce measurable benefits, but these appear to be lost over time. Furthermore, the benefits that are seen are often in terms of improved ADL ability or gait speed. But, in the longer term, the objective is to reduce handicap, or increase participation (as new terminology has it). Another ambition is to reduce the number of psychological symptoms and complaints that longer term stroke survivors report. There seems to be a need to find ways to achieve rehabilitation gains that are resistant to decline and which are ultimately satisfying to the patient. This is where the social and built environment comes in.

Stroke patients report a sense of abandonment after discharge from hospital, and this indicates that the rehabilitation was incomplete because it failed to achieve re-integration into society. Yet integration to society may also be the key step to sustainability of function. For example, in some cases, patients are left house-bound because of the lack of ramps, or wheelchairs. In other cases they live too far away from bus-stops, or the bus service is infrequent, or the buses do not go where the patient needs to go. Public transport does not easily accommodate wheelchair users. If the environment were more carefully designed to meet the needs of all its potential users (the able-bodied and the disabled), then perhaps the effect on life-style of a particular disability would be less. In a modern population there are large numbers of people with disabilities, from stroke, arthritis, blindness, dementia, and so on. Many of the structural changes to the environment would help all of them, and most changes would make it easier for the ‘able-bodied’ too (e.g. access to buses for mothers carrying shopping and pushing buggies).

Aiming to re-integrate people back into society after an illness may require some radical thought. For example, perhaps rehabilitation should take place in ordinary community settings, e.g. shopping centres or leisure centres, rather than in hospitals or in patients’ homes. It would then be a much smaller leap from therapeutic activity to ordinary activity. ‘Patients’ having rehabilitation could more easily become ‘shoppers’ or ‘leisure centre clients’ on discharge instead of becoming lonely, house-bound, excluded individuals. Clearly, if rehabilitation did take place in such settings, there would be much more emphasis on getting access to transport and in making these settings more suitable for users with disabilities, whereas at present the containment of these people in hospital settings does not.

All this sort of activity will have a financial cost. But on the other hand, if it sustains the more frail and vulnerable members of society outside of institutions, then there is the opportunity for savings. Unfortunately, the evaluation of the cost-efficacy of such environmental
changes is not easy to do. It is a challenge for health and social scientists and policy makers alike.

Conclusions

Good long-term outcome for stroke patients requires organised acute and hospital management. It also requires careful attention to the more disabled survivors who are at risk of institutionalisation and, in the near future, this is likely to require the judicious use of intermediate care services. Community rehabilitation services themselves will need greater organisation, especially as the range of community services develops, and the benefits of so doing could be considerable. Re-integration into society is a particular goal of community rehabilitation in that it might ensure that rehabilitation achievements are sustained in the long-term.

References

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