

EDITORIAL

Rehabilitation for disability

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Introduction

It seems self-evident that the effectiveness of rehabilitation services requires well-organized, co-ordinated, multidisciplinary services, if only because no one discipline has the range of skills needed for rehabilitation. For one major service, at least, a problem-oriented approach has been shown to be effective.¹

Rehabilitation has recently seen many innovations and interventions, but the major advances in rehabilitation have been theoretical rather than practical. Firstly, the model used has moved from a medical one to one in which sociocultural aspects are equally important. Secondly, the need for highly specialist rehabilitation for specific problems is being recognized.

Definition of disability

The International Classification of Impairments, Disabilities, and Handicaps (ICIDH) was developed under the auspices of the World Health Organisation and was first published in 1980.² The development of this classification model and its worldwide acceptance is arguably the greatest single advance in the field of rehabilitation. There are many other models of disability and illness, but most are similar to the ICIDH model.

The ICIDH was revised in 1992, and renamed the International Classification of Functioning, Disability and Health.³ In the new version, the emphasis on the personal, social, and physical context was expanded and the emphasis on disability was overtaken by an emphasis on functioning, which underlines that many 'healthy' people have a limitation in function of one sort or another. It emphasizes the idea that there is not a group of 'normal' people and another group of 'disabled' people, but

a continuum across all of these boundaries. Some of the major terms have been changed to reflect the need for more neutral, less medically-biased terminology: 'disability' has become 'activity', and 'handicap' has become 'participation'.

The acceptance of this model has fostered more consistent communication among professionals from different disciplines. The model is useful for understanding and analyzing patients' problems, and it encourages a more systematic analysis of rehabilitation interventions. It also brings structure and order to research. Most importantly, it has facilitated the change of emphasis within rehabilitation from a mechanistic, medically-driven process of 'physical medicine' to a comprehensive, more socially-driven form of rehabilitation. Finally, it has helped workers in rehabilitation to argue more coherently for an equitable share of health resources, though it is arguable if such a change has actually come about. The nearest that government and think-tanks have come to such ideas is in a new emphasis on 'chronic disease management'.

The model has some weaknesses, especially a failure to consider explicitly quality of life and to allow for a patients' subjective experiences. The model makes explicit, however, that quality of life is probably on a separate axis or forms a separate domain.⁴

The use of the ICIDH model has also fostered discussion of the nature of rehabilitation. Although a definition of rehabilitation has still not been universally agreed, it is now recognized that definitions may refer to structure (the operational characteristics of a rehabilitation service), process (how rehabilitation services work), and outcome (the aims of rehabilitation services). The core skills associated with rehabilitation are probably goal-setting⁵ and teamwork.

Many people, in particular those with a disability, are concerned about the 'medicalization' of disability.⁶ One important consequence of adopting the revised model is that these concerns are

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acknowledged. The model emphasizes the relation between disease and disability and sets the rehabilitation agenda clearly in a social context, while still recognizing that disease has an important influence on patients' levels of physical activity and social participation, and on the process of rehabilitation.

The model shows that services and agencies must work together for rehabilitation to be effective. It also extends the boundaries of rehabilitation – from the few conditions where recovery is expected, to any condition in which someone experiences disability or handicap secondary to (or as part of) illness. For example, people with multiple sclerosis, motor neurone disease, or rheumatoid arthritis are all potential clients of rehabilitation services.

Changes in prevalence of disability over time

The National Health Service (NHS) was set up in 1948. At a macro level we cannot say that it did or did not have any impact on disability. Data on disability over this period are very difficult to find. Incapacity for work data have been available since the 1950s and show that incapacity has steadily increased while mortality has been decreasing. The picture is not clear here, for there are a large number of people who are marginally incapacitated. As a result, when unemployment rises they tend to be thrown out of the labour market more rapidly than able-bodied people. Changes in incapacity rates may therefore reflect unemployment rather than any NHS effect. Other issues swamp any effect that the NHS may have.

Having said this, people who were working in the NHS at the time remarked upon the huge influx of people with long-term problems that they had never been able to have fixed because of the cost. This backlog caused the successive governments of the day considerable heartache, but within a short time the NHS was so popular that no government would dare to revoke the Act.

In reality it is unlikely that the NHS or any other health service in developed countries will have a great effect on death or disability in relation to the amount of money expended. The vast majority of the money and the effort expended within the NHS, for example, is to treat people who have self-limiting problems or who are at a late stage of diseases which can be only slightly modified in terms of their future disability.

While life expectancy has increased, research here and abroad on trends over the past 15–

20 years suggests that these extra years of life have not been years of severe disability, but of mild-to-moderate health problems. NHS spending per head on elderly people has risen no faster than spending on all age groups. There is continuing debate about future trends in morbidity and their implications for the demand for care, but it would be wrong to assume unmanageable pressures.

Survey data point to an increase in the amount of time elderly people can expect to live without disability. The countries where disability among older people appears to be declining include France, Belgium, Taiwan, Italy, Netherlands and Switzerland. In countries where no substantial decline is apparent there is no consistent evidence that disability rates are rising. These include Australia, Canada, and Britain.

The average person surviving past age 80 is now documented to be in better health and incurs lower health care costs than the average person dying in his 60s.^{7,8} Much new evidence suggests that health at late ages has been improving for a long time, probably beginning, at least in the United States and Britain, for the generation born in the 1840s.⁹

Routine measurement of disability

Disability in patients attending NHS services is not measured routinely. This despite suggestions from a number of groups, including the British Geriatrics Society, that this would be a useful addition to the routine data collected on patients admitted to hospital and seen as outpatients. The common measures used on a research basis have mostly attempted to quantify physical disability sometimes with a little bit of mental disability thrown in for good measure. The SF36 and its subsets are examples of this approach, though for measuring quality-of-life years the EuroQual-5D seems to be preferred. The SF36 has the benefit of having received the Department of Health seal of approval, though most measures show a close correlation with one another.^{10,11}

Prevention of disability

Approaches that are likely to be most effective are in carefully chosen screening programmes, the prevention of smoking and high immunization rates. The hard part will be having the courage to say no to extensions of the traditional approaches in order to divert, say 10% of the NHS budget, to effective but less glamorous areas of work.

Some of this is outside the NHS altogether. The commonest causes of disability in young and middle-aged people are work-related accidents. The NHS may have to face the ultimate degree of altruism, to allow a proportion of its budget to be used to improve the standards of safety in industry.

Immunization of children has obviously and remarkably had an impact on a number of diseases, most obviously the prevalence of paralytic poliomyelitis in the Western world. Other disabling diseases, such as whooping cough, have been reduced in prevalence and severity. The coverage of immunization has improved markedly since the responsibility for providing it was moved to general practitioners from the community health services. The detection of diseases in utero and subsequent abortion of babies who are badly affected has had an impact on the prevalence of Down's syndrome and spina bifida. For older age groups, the most disabling diseases are the arthritis family and chronic diseases.

Legislation

The Disability Discrimination Act, 1995 gave disabled people rights in the areas of:

- Employment
- Access to goods, facilities and services
- Buying or renting land or property

The Disability Rights Commission (DRC) oversees its implementation. The Act defines a disabled person as someone with 'a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities'.

The Act requires schools, colleges and universities to provide information for disabled people and allows the Government to set minimum access standards for new taxis, trains and buses. The duties relating to further and higher education were implemented in July 1996, after consultation. The employment provisions and the initial rights of access to goods, facilities, services and premises were implemented in December 1996. Statutory Codes of Practice have been laid before Parliament covering employment and access to goods, facilities, services and premises provisions. A code of practice was published by the government in July 1996.

The first duties of providers of services to the disabled are:-

- Not to refuse service
- Not to provide services of a worse standard or in a worse manner
- Not to provide service on less favourable terms

Since October 1999, service providers have to take reasonable steps to change practices, policies or procedures which make it impossible or unreasonably difficult for disabled people to use a service. They are also required to provide auxiliary aids or services that would enable disabled people to use a service and overcome physical barriers by providing a service by a reasonable alternative method.

From 2004, service providers will have to take reasonable steps to remove, alter, or provide reasonable means of avoiding, physical features that make it impossible or unreasonably difficult for disabled people to use a service.

A second important advance in disability medicine has been the growth in high-quality research. The National Clinical Guidelines on stroke cite 80 or more randomized controlled trials focused specifically on stroke rehabilitation. Associated with this growth, the number of specialist rehabilitation journals has increased, and a Cochrane collaboration review group covering rehabilitation and disability has produced a number of useful systematic reviews.

Rehabilitation, however, is a complex and multidisciplinary process. It is difficult to define the specific nature of interventions and to isolate the effect of specific interventions from other factors. When outcome is measured at the participation (handicap) level, factors such as employment status, housing, and social relationships are likely to be influential. Moreover, the measurement of participation is still a problem, especially as the nature and operational definition of participation is still debated.¹² Handicap scales assess participation from an outsider's perspective; the need to assess participation and autonomy has been recognized and is being addressed.¹³

Evidence of effective rehabilitation

A Cochrane Review of rehabilitation for older people looked at alternative care environments, for example care-home environments, for rehabilitation.¹⁴ However they found that there appears to be limited evidence on which to base decisions. They compared the effects of care-home

environments (e.g. nursing home, residential care-home and nursing facilities) versus hospital environments and own-home environments in the rehabilitation of older people. They found that there was insufficient evidence to compare the effects of care-home environments, hospital environments and own home environments on older persons' rehabilitation outcomes. As a result, the comparability between intervention and control groups was weak. For example, there were differences in the services provided in the intervention and control arms.

Another general review of rehabilitation in older people found 108 good quality trials on the subject.¹⁵ In terms of the best evidence, they concluded that a number of topics stood out: thus frail elderly patients with hip fracture should receive geriatric rehabilitation.¹⁶ They should also be screened for nutrition, cognition, and depression. In addition they found that older persons should receive nutritional supplementation when malnourished. In severe dysphagia, in patients with a stroke, gastrostomy tube feeding is superior to nasogastric tube feeding.

This team also found that the evidence supported the idea that frail elderly patients should be screened for rehabilitation potential.¹⁷ It recommended standardized tools to aid diagnosis, assessment, and outcome measurement and made the point that the team approach to geriatric rehabilitation should be interdisciplinary and use a comprehensive geriatric assessment. They found that medication reviews and self-medication programs may be beneficial. They suggested that more research was needed to look at cost-effectiveness, a consensus on outcome measures, and agreement on which components of geriatric rehabilitation are most effective.

Another general review examined the effect of physical training on physical performance in institutionalized elderly patients with multiple diagnoses.¹⁸ Six trials scored as high quality. There was a large heterogeneity in the studies concerning sample size, types of interventions and types of assessments. Despite this, there was strong evidence for a positive effect of physical training on muscle strength and mobility; moderate evidence for an effect on range of motion. There was contradictory evidence regarding gait, activities of daily living, balance and endurance. The authors concluded that more studies are required, with a greater focus on quality of life and mortality.

Coronary heart disease

A systematic review of exercise-based cardiac rehabilitation in patients with coronary heart disease at all ages included 48 trials with a total of 8940 patients.¹⁹ Compared with usual care, cardiac rehabilitation was associated with reduced all-cause mortality and cardiac mortality with improvements in many risk factors. Health-related quality of life improved to similar levels with cardiac rehabilitation and usual care. The effect of cardiac rehabilitation on total mortality was independent of coronary heart disease diagnosis or type of cardiac rehabilitation or dose of exercise intervention.

Stroke

A meta-analysis of data from trials of rehabilitation from the Cochrane Collaboration continue to show that rehabilitation in stroke units is effective at reducing both mortality and morbidity.²⁰ Furthermore, these benefits can last for over 10 years.²¹ However, further research into the aspects of a stroke unit that were effective was hampered, because the quantity and methodological quality of the research studies were insufficient, and the number of prognostic factors investigated was limited by the absence of a conceptual framework in the studies, including a good definition of the prognostic social factors likely to have an important effect.²²

Rehabilitation of patients after a stroke has also been found to be effective by augmenting the stroke-unit phase with therapy-based rehabilitation services for stroke patients living at home.²³ This increased the ability of patients to do personal activities of daily living. The authors concluded that therapy-based rehabilitation services, targeted at selected patients resident in the community after stroke, improved their ability to undertake personal activities of daily living and reduced the risk of deterioration in ability. In contrast, the use of care pathways in the management of people with stroke was not supported by the evidence, largely because of a lack of good trials on the subject.²⁴

Fractured femur

Geriatric service interventions after hip fracture are complex; their form and outcomes are strongly influenced by local conditions. A systematic review of geriatric rehabilitation after hip fracture

showed that comparative studies looked at different treatments and were of poor to moderate quality.¹⁶

They found, looking at seven studies of reasonable quality, that as an overall strategy for rehabilitation after hip and other lower-limb fractures, geriatric orthopaedic rehabilitation units (GORUs) are unlikely to be cost-effective, but some frailer patients may benefit by reduced readmission rates and need for nursing-home placement. Geriatric hip-fracture programmes (GHFPs) and early support discharge programmes (ESD) are probably cost-effective, since they appear to shorten the average length of hospital stay, and are associated with statistically significant increases in rates of return to their previous residence.

These programmes are not, of course, mutually exclusive; an optimal GHFP is likely to involve several elements. As ESD is suitable only for less disabled patients, an alternative programme for more disabled patients is needed; this may require transfer following surgery, either to an inpatient setting, which might be provided in a GORU or a mixed assessment and rehabilitation unit (MARU). No direct comparison of GORUs and MARUs has been published. Both comparisons of packages of care (such as the GORU or MARU) and comparison of individual elements in these packages require further research.

Mental illness

At any one time, one adult in six suffers from one or other form of mental illness. In other words, mental illness is as common as asthma. They range from more common conditions such as deep depression to schizophrenia, which affects fewer than one person in a hundred. Mental illness is not well understood: it frightens people and all too often it carries a stigma. Despite its prevalence and importance, mental illness has not received the attention it deserves. This is why the government is determined to give it a much higher priority: it is why mental illness has the same priority as coronary heart disease in the National Service Framework, which will lay down models of treatment and care which people will be entitled to expect in every part of the country.

The National Service Framework for Mental Health spells out national standards for mental health, what they aim to achieve, how they should be developed and delivered and how to

measure performance in every part of the country. These standards are founded on a solid base of evidence, which has been examined and validated by the External Reference Group chaired by Professor Graham Thornicroft. Their thorough and professional work should help raise standards, tackle inequalities and meet the special needs of women, men, and different ethnic groups.

This National Service Framework fleshes out the policies announced in the White Paper 'Modernizing Mental Health Services'. It will be a guide to investment in mental health services, including the extra £700 million which the Government is providing over this year and the next two. It will be backed up, in due course, by changes to bring the law on mental illness up to date to reflect modern treatments and care, following the root-and-branch review conducted by the independent expert group under Professor Genevra Richardson.

Most people who suffer from mental illnesses are vulnerable and present no threat to anyone but themselves. Many of these patients have not been getting the treatment and care they need, partly because the system has found it so difficult to cope with the small minority of mentally ill people who are a nuisance or a danger to both themselves and others.

The government seems committed to delivering a modern and dependable health service, fit for the new century. Mental health services and the professionals who provide them will get the attention and resources they deserve. This National Service Framework will set the standards and these standards will be met.

Other diseases

Evidence in support of specialist co-ordinated rehabilitation services is less strong in other fields. For instance, a systematic review did not indicate that specific exercises are effective for the treatment of acute low back pain.²⁵ Exercises may be helpful for patients with chronic low back pain to increase return to normal daily activities and work.

Specific interventions

The evidence for specific interventions is extensive but, because it covers a huge range of treatments, often not specifically tied to single diseases, it is difficult to construct an analytic framework,²⁶

let alone access and review it. However, recent research, again mostly related to stroke, does support various hypotheses.

Firstly, even quite small levels of intervention can have quite powerful and specific effects, and a dose-response relation may exist between intervention and outcome. After a stroke, for example, an additional two to three hours of therapy focused on the impaired leg each week can significantly improve mobility, whereas giving the same amount of attention to the arm does not alter mobility.²⁷ No current evidence exists, however, to identify a minimum or maximum effective intervention.

Secondly, evidence is strong that assessment for and provision of simple equipment is extremely cost-effective. In this study by Mann *et al.*, the health services paid for all aids that should have been provided, but weren't, by other agencies, illustrating how budgetary borders may hinder effective rehabilitation²⁸; moreover, the costs to the health services were reduced.

Thirdly, some evidence suggests that even the provision of information may be effective.²⁹

Finally, high quality research in rehabilitation is possible using randomized controlled-trial methodology. This finding and the recognition of it are two great advances.

Pharmacological treatment

Evidence now supports some specific pharmacological treatments for impairment. Injection of Botulinum toxin has been studied in a systematic review.³⁰ Of a large number of studies, only two randomized-controlled trials (RCTs) met criteria of minimal validity. There is evidence of the effectiveness of BTX-A treatment on reducing muscle tone and improving passive range of motion at all arm-hand levels in chronic stroke patients for approximately three to four months. There is also preliminary evidence of a synergistic effect of concomitant electro-stimulation. However, effectiveness of BTX-A treatment on improving functional abilities could not be convincingly demonstrated, although two subgroups could be identified that might benefit: (1) patients with mild spasticity and a potential for voluntary extensor activity and (2) patients with severe spasticity suffering from problems with positioning and taking care of the affected arm and hand.

Methodology

For this review I searched the PubMed database by the National Library of Medicine website for the past 15 years, and from review of the authors, titles, abstract, and source location, articles in full were selected for further examination. The main search was undertaken on 25 June 2004. I also searched the Internet using the Google search engine. References were selected according to the authors' identification of relevant topics for the review and did not include non-English language papers. Articles and their abstracts were initially collected using Reference Manager v.10.

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