Services for patients with multiple sclerosis

The development of β-interferon treatment for patients with multiple sclerosis has dramatically focused attention on and encouraged debate about the delivery of services to these patients. Furthermore, patients with multiple sclerosis are now more interested in seeing their neurologists; the reverse is also true and all parties are interested in service provision. The purpose of this editorial is to inform the debate about services for this group of patients; it is biased towards considering disability services.

My aim is to enable purchasers, providers, and patients to discuss issues from a common, agreed perspective. I highlight some current problems, and then outline some principles underlying choices, present a framework of illness, discuss the processes of disease management, draw attention to the different phases of the illness caused by multiple sclerosis, and finish by outlining the aims and objectives of a service and discussing the organisation of services. I do not review, systematically or otherwise, all relevant evidence but cite evidence where possible. I argue that the problems faced by patients are complex and multifactorial, and that there will rarely be evidence to guide decisions on the specific problems faced by individual patients. Thus the conclusion is that the most effective and efficient service delivery will come from specialist services which focus on neurological disease and disability.

Current problems

There are two areas of agreement between all interested parties: the challenges posed by multiple sclerosis are important; and the challenges are not currently well met. Multiple sclerosis undoubtedly poses an economic challenge to the Health and Social Services of all western countries. Although the incidence is relatively low, the prevalence in most western countries is high. More importantly at least half of all patients are significantly dependent upon others for mobility and other activities, and patients with multiple sclerosis are major users of long term care and support services in people aged under 65.

None the less, because epidemiological research has focused on investigating the aetiology of the disease, little is known about the epidemiology of the need for services—for example, how many people present for diagnosis each year (both with and without multiple sclerosis); how many people will be eligible for β-interferon; how many people have a relapse each year requiring methyl-prednisolone; how many people first need a wheelchair each year; how many people require expert urological assessment and advice each year; how many and what urological interventions are needed etc? Estimated answers to some of these questions have been published.

The clinical challenges are considerable. The diagnosis cannot be made with absolute certainty; the natural history is variable and giving an individual prognosis is impossible; the range of possible impairments is huge, and the combination of possibilities endless; consequently similar disabilities may arise in many ways; patients come from a wide range of social circumstances and have different expectations; and most patients live a nearly normal life span. Every patient with multiple sclerosis will use health and other services to a greater or lesser extent for much of their life, usually for over 30 years.

Health services are still largely based on the premise that people will only need to make intermittent use of them, and then for acute, reversible illnesses. They do not respond very well to the needs of patients with chronic illness. Patients with multiple sclerosis complain about health service provision in many ways—for example, the diagnosis was told badly; there is no cure; the future is uncertain; the disease is progressive, and the progression is not being stopped or reversed; fatigue, urinary urgency, sensory change etc are still causing problems; help is often slow in arriving and not adequate; and long term support is poor.

Thus the challenge for health services over the next decade is to develop appropriate and responsive services that help people with long term illness, many of whom will have neurological illness. This challenge arises because each patient’s situation is likely to change with time, and no two patients are in the same situation. Multiple sclerosis is an important index disease for monitoring the success of (health) service delivery.

Equity, effectiveness, and efficiency

In debates on service provision the socially determined principles which might impinge on decisions about resource allocation are often not formally acknowledged. Although health care is delivered in many different ways, varying from society to society and culture to culture, most people want the system to be just. The elements of just health care systems can be summarised in three words: equity, effectiveness, and efficiency.

An equitable system ensures that resources are distributed in a reasonable and unprejudiced way in relation to need. Equity is not absolute. It depends on agreement about the goals of the health service(s) concerned (the boundaries of legitimate concern) and on a system for prioritising needs. For example, patients with significant dis-
ability arising from multiple sclerosis face important and unresolved disputes concerning both the extent to which providing support, care, and rehabilitation is even the responsibility of agencies funding health services—private health insurance rarely funds ongoing rehabilitation—and also the relative priority of disability services as against “medical” treatment.

Access to the service must also be equitable in two ways. The first is straightforward: Can the person physically reach (access) the service? The second is more important: Can the person avail themselves of the service? The obstacles may be bureaucratic (for example, if the person has to be referred by someone professional, then the service may become inaccessible); economic (for example, if funds are not available to the patient for the service, or equipment, or treatment then it is not accessible); or cultural (for example, if the patient is a woman whose religion does not allow her to be seen by men but where the same religion or other factors mean that most or all doctors are male).

The potential for patients with multiple sclerosis to be subject to inequitable service provision is huge. The great majority of patients with multiple sclerosis have no real “need” for acute medical investigations or treatments for most of their illness; their need is for alleviation of their impairments and disabilities through symptomatic treatments and other means. Health resources tend to be given preferentially to high technology investigations or treatments and tend to be related to acute events that are “curable.” Thus, the resources given to multiple sclerosis are against other neurological diseases may be reduced, and within multiple sclerosis services few resources will be committed to disability.

Effectiveness refers to the extent to which any intervention or action achieves its intended goal. Health systems should avoid interventions known to be ineffective (or, worse still, harmful) and should use any intervention known to be effective. However, when discussing priorities there may be disagreement about the goals of health service interventions. The doctor’s goal may be to reduce changes on MRI, whereas the patient’s family may be more concerned with reducing dependence. Unfortunately for patients with multiple sclerosis there is little or no evidence on the relative effectiveness of almost all actions currently undertaken and, even more unfortunately, the absence of evidence may be wrongly used to reduce expenditure on some aspects of health provision.

Efficient services achieve the expected outcomes at least cost in terms of resource use. At present there is no useful evidence on efficiency.

Four levels of illness and illness management

Illness is a state experienced by a patient, and can be considered at various levels. The World Health Organisation (WHO) has codified this in the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) and although there is continuing debate about some of the terms and constructs there is no doubt that the underlying model which recognises four levels of illness is both widely accepted and very useful. The WHO ICIDH model emphasises several important matters concerning disability.

The connections between the different levels of illness are not always strong, thus challenging the unspoken assumption and current position that most resources should be focused on curing pathology. Secondly, as time progresses the focus of attention should move both from pathology (diagnosis and treatment of the disease process) towards disability and handicap and, at the same time, attention needs to move from the patient to the patient’s physical, social, and cultural environment. Hospital systems rarely recognise this shift in the focus of attention. Thirdly, the disabling effects of specific impairments cannot usually be predicted in isolation, but depend on the combination of other impairments present, and on environmental and other factors. This is particularly important in neurological diseases such as multiple sclerosis because specific disabilities and handicaps may arise from many different combinations of impairments.

The management of illness by health services can essentially be considered as the process of solving problems posed by patients. Patients with multiple sclerosis often present with problems spanning all four levels. When managing a problem the service necessarily starts by collecting enough data either to resolve the problem or at least to decide if further information or action is needed. This is “diagnosis” or “assessment” (depending on whether it is a medical or disability service). The clinician then devises sets of goals for any intervention, and undertakes the intervention which either may modify something (treatment) or may simply to maintain life and the status quo (give care). Finally the situation is reassessed to determine if any further actions are needed.

Three features distinguish “medical” from “disability” services. The time frame is usually short in medical contexts. The ultimate goals are usually more explicitly social in disability services. Lastly, the range of variables to be assessed and modified is usually much greater in a disability service in which health service provision cannot be seen in isolation from social policies and other services provided by social services, employment services, housing agencies, etc. However, the important points are that in both medical and disability services: (1) the management processes are similar; and (2) the provision of care to maintain the patient is necessary.

Phases of the multiple sclerosis illness

In any disease, but especially with multiple sclerosis, it is important to recognise that there may be different phases or stages within the illness (and, in multiple sclerosis, possibly different types of illness within the single diagnosis). Patients with multiple sclerosis have unpredictable futures, but four different phases of illness can be identified:

- The first presentation, when the diagnosis is made
- Acute relapses, usually from a stable state
- More insidious progression, at a faster or slower rate
- A relatively static state often of high dependence

At present patients will usually see a neurologist for initial diagnosis and in relation to relapses in the early stages but will be much less likely to be seen by a doctor with neurological expertise at a later stage. Conversely, they are unlikely to be seen by an expert in disability until late in their illness, if at all.

Multiple sclerosis service aims and objectives

The ultimate aims of any health service are (or should be) to maximise the social role functioning of the patient; to minimise the pain and distress experienced by the patient; and to minimise the stress on and distress of carers (family etc). The table shows objectives likely to achieve these aims; the objectives relate to six different areas although there are obvious overlaps between the areas. This section discusses some of the service objectives which may require debate.

At the level of pathology there are several areas of potential debate. Firstly, how is the diagnosis achieved most efficiently? What level of detail is needed? Multiple sclerosis is a single disease label, but clinically there seem to be different types which may someday need to be distinguished both for prognostic and for treatment reasons. How is the diagnosis best told? There is no...
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Table 1 Objectives of a multiple sclerosis service by level of illness

<table>
<thead>
<tr>
<th>Level</th>
<th>Objectives of service(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pathology</td>
<td>Make initial diagnosis as rapidly as possible</td>
</tr>
<tr>
<td></td>
<td>Always check or confirm diagnosis, especially if new impairment</td>
</tr>
<tr>
<td></td>
<td>Diagnose (and manage) any secondary diagnoses arising as complication</td>
</tr>
<tr>
<td></td>
<td>Diagnose (and manage) any incidental diseases</td>
</tr>
<tr>
<td></td>
<td>Institute and monitor any disease modifying treatments</td>
</tr>
<tr>
<td>Impairment</td>
<td>Identify impairments present</td>
</tr>
<tr>
<td></td>
<td>Check that (new) impairments are due to multiple sclerosis (see pathology)</td>
</tr>
<tr>
<td></td>
<td>Consider significance/importance of impairment, and potential for amelioration</td>
</tr>
<tr>
<td></td>
<td>Institute and monitor impairment specific treatments</td>
</tr>
<tr>
<td>Disability</td>
<td>Identify disabilities present</td>
</tr>
<tr>
<td></td>
<td>Assess (diagnosis) to discover impairments underlying disability (and check cause of impairments; see above)</td>
</tr>
<tr>
<td></td>
<td>Assess (diagnosis) to discover environmental factors influencing disability</td>
</tr>
<tr>
<td></td>
<td>Institute and monitor impairment specific treatments (see impairment)</td>
</tr>
<tr>
<td></td>
<td>Institute and monitor treatments to reduce disabilities</td>
</tr>
<tr>
<td></td>
<td>Institute and monitor changes in environment (physical or personal)</td>
</tr>
<tr>
<td>Handicap</td>
<td>Identify previous, present, and wished-for social roles</td>
</tr>
<tr>
<td></td>
<td>Identify local resources which might facilitate increase in social activities</td>
</tr>
<tr>
<td></td>
<td>Assess for and obtain all financial and other benefits allowed</td>
</tr>
<tr>
<td></td>
<td>Institute and monitor actions to facilitate social role functioning</td>
</tr>
<tr>
<td>Patient distress</td>
<td>Provide information and emotional support, especially (but not only) at time of initial diagnosis</td>
</tr>
<tr>
<td></td>
<td>Control pain and other distressing impairments (for example, spasticity)</td>
</tr>
<tr>
<td>Carer stress</td>
<td>Provide information and emotional support, especially (but not only) at time of initial diagnosis</td>
</tr>
<tr>
<td></td>
<td>Provide practical support to extent wanted by patient and family</td>
</tr>
</tbody>
</table>

Evidence to guide on whether,14 15 when, or how to do this. What disease modifying treatments reduce disability,16–19 how are they best monitored, and what proportion of the limited resources should be allocated to them?20

At the level of impairment there is some evidence concerning a few specific interventions: desmopressin can reduce nocturia;21–24 amantadine may reduce fatigue;25 exercise may increase fitness;26–28 expiratory muscle training may increase expiratory muscle strength;29 and cognitive therapy may control depression.30 However, much of this evidence is of little value in clinical practice, and there is much scope for debating the importance and actual benefits of any effects. At the level of an individual patient there will always need to be discussion about the risks and benefits of intervention.

The objectives concerning the reduction of patient pain and distress are closely linked to those at the level of impairment. There is no evidence available concerning counselling and it is arguable that services should concentrate on providing accurate information and simple emotional support, and that specific counselling is not a justified use of resources.

The main debates at the level of disability concern the allocation of resources for interventions. Disability services are expensive. However, it is often forgotten that a major proportion of the expenditure of disability services (and indeed of all hospital services) relates to the provision of care (maintaining life and limb) and not to the specialist assessment and treatment services being provided. This may lead to discussions about partial funding of disability services by health budgets, and to debate about the sources of other funding.

There is only limited evidence on the effectiveness of disability services, and this evidence covers only a small proportion of all interventions and resource use. There is some evidence (from randomised controlled trials) to support a few patient centred interventions. For example, service dogs may reduce dependence30 and inpatient therapy may29 or may not26 reduce disability. The evidence for environmental interventions is less strong, but it is probably unnecessary, for example, to “prove” that providing a wheelchair will allow someone independent mobility in a suitable environment.

There is obvious scope for debate about the clinical significance and applicability of some of these interventions. None the less it is vital to understand that the lack of evidence for efficacy does not equate to evidence for lack of efficacy.

There is one area of further debate. Some people argue that services at the level of disability are not the responsibility of health providers at all. This attitude is held by many British health insurers for example. More sensibly, the proportion of health resources that should be allocated to disability services can be debated (bearing in mind the predominant cost of care).

The remaining two groups of objectives relate to ameliorating handicap and to supporting carers. It is obvious that most interventions are or should be long term, and that most fall outside health services. However, it is arguable that the health service would be seriously compromised if it did not allocate some resources to investigating and organising interventions designed to minimise handicap and carer stress even though there is currently no evidence in relation to this.

Service structure and organisation

Patients with multiple sclerosis present with a wide range of complex problems not dissimilar to the range and complexity seen after stroke. Research in the field of stroke management would suggest that well organised specialist disability services are cost effective at managing patients in the first six months after presentation (when change has occurred).30–32 In other areas of medicine in which patients present with complex, multifactorial problems specialised services have also been considered the most effective and efficient.33 Is this also true for services with multiple sclerosis?

Service effectiveness depends on the timely and accurate identification and analysis of any new problems. The service must ensure that impairments which can be ameliorated are identified when they arise (for example, poor bladder control is notoriously under recognised). Effectiveness also depends on knowing what interventions are available and being able to deliver or organise these interventions.

Consequently an effective service for patients with multiple sclerosis can only be delivered by an integrated team of clinicians whose collective expertise covers almost all aspects of the illness: medical diagnosis and specific pharmacological treatments; other specific therapies; altering the environment; teaching carers; advising on alternative ways of achieving tasks; giving advice on new roles; arranging care; giving information, emotional, and practical support; and sometimes advising on long term residential care etc. In other words, an effective service must include clinicians from a wide range of professions all of whom must be familiar with (expert in) multiple sclerosis and the likely and common impairments and disabilities, especially those that can be treated, and the specific treatments that are needed.

Efficiency can only be achieved if the patient can receive this range of expert services in a coordinated way. As far as I am aware there has been no research into the organisation and policies of services for patients with multiple sclerosis. For example, should services follow patients routinely or not; should patients remain at all times under a specialist
multiple sclerosis service, or to what degree can other generic services be used; should services be based in hospitals or not? However, it is probable that a single, comprehensive service capable of managing all common problems at all levels will be more efficient that two or more separate services.

Conclusions
I have outlined very briefly some of the concepts and ideas that must be considered when discussing services for patients with multiple sclerosis. I emphasise the multifactorial and complex problems faced by clinicians, these problems arising at several levels that cannot be separated easily. Currently health services manage the acute presentation and easily identified impairments well, and social care services can offer support to patients with stable long-term disability. But most patients with multiple sclerosis spend most of their lives in the middle two phases with fluctuating and unpredictable impairments and disabilities and they need help through the periods of change.

Thus it is concluded that an effective and efficient service should be one that arises within a single organisation that encompasses a large range of professions with a wide span of expertise but all grounded in neurology and neurological disability. The specific need for the active involvement of a neurologically trained doctor at all times is particularly emphasised. There should be a specialised neurological and neuropsychological service spanning all medical and disability needs of all patients.

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*J Neurol Neurosurg Psychiatry* 1997 63: 275-278
doi: 10.1136/jnnp.63.3.275

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