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A cost evaluation of multiple sclerosis

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As a chronic and disabling disease, multiple sclerosis (MS) is extremely costly, both for the individual and the family, as well as for the society. Early onset, long duration and effects on employment contribute to the extensive costs related to the illness. Thus far, studies conducted in developed countries have demonstrated that direct costs, including treatment (prior to the approval of beta interferon), medical visits, hospitalization, assistance, etc., are much lower in respect to indirect costs, such as loss of income from reduction of work activity for patients and carers, which account for up to 75% of the total cost. Informal care represents a heavy burden for the families of disabled persons and little is known about the 'intangible' costs of MS, such as those related to the influence of the disease on quality of life. In addition, the cost/benefit ratio for expensive new therapies, such as beta interferon, remains to be determined. *Journal of NeuroVirology* (2000) **6,** S191–S193.

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Introduction

Multiple sclerosis (MS) is a chronic neurological disease affecting young-adults, typically during the most productive years. Often disabling, MS has significant effects on autonomy and employment. More than 50% of persons with MS are unemployed within 10 years from diagnosis, unrelated to the level of disability (Bourdette *et al*, 1993). A long disease duration, mean 40 years (Weinshenker *et al*, 1989), and the introduction of new costly treatments contribute to making MS one of the most expensive neurological diseases, even more so than a stroke or Alzheimer's disease (Whetten-Goldstein *et al*, 1998). An evaluation of the cost of a disease is a matter of growing importance in most developed countries. Public health policy depends more and more on public economic resources, as well as individual therapeutic decisions. This aspect becomes more evident in chronic diseases such as MS, in which a careful evaluation of risk/benefit but also of cost/benefit of therapeutic interventions is necessary.

On the topic of MS, many studies have been conducted in recent years about this matter, but conclusive data are still far from being obtained. Difficulties in the calculation of MS costs depend on many factors such as inconclusive epidemiological data, the variability of the disease course and the recent introduction of costly drugs which seem to be able to modify disease progression. Lastly, a significant challenge in MS is the evaluation of intangible costs, i.e. the personal (psychological, affective, social) burden of the individual with the disease.

Methods of study

When evaluating disease costs, these are usually classified in tangible and intangible (Whetten-Goldstein *et al*, 1996). They can be sustained by the person with MS and/or the family and by the society. Tangible costs are those which can easily be converted into economic terms, and can subsequently be divided into direct (the cost of drugs, medical visits, diagnostic tests, assistive devices, etc.) and indirect (loss of income) costs (Whetten-Goldstein *et al*, 1996; see Table 1). Costs are classified as intangible if they depend on loss of non-paid position and, moreover, if they are related with health related quality of life (Whetten-Goldstein *et al*, 1996).

Cost evaluations of chronic diseases are based on prevalence data (Jönsson, 1995) and utilise 'top-

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Table 1 Classification of disease costs

	Tangible costs	*Intangible costs*
Direct costs	Drugs Medical visits, hospitalisations Laboratory examinations/ procedures Rehabilitation Home nursing care Aids/adaptive devices, modifications to home/ auto	Loss of non-paid position (student, home-maker)
Indirect costs	Loss of income Additional costs to employer Transportation	Decrease in quality of life (value of well-being, absence of suffering, pain and worry, etc.)

down' or 'bottom-up' methods (Whetten-Goldstein *et al*, 1996). Earning loss is typically calculated through the 'human capital approach' (Jönsson, 1995). 'Quality adjusted life years' ('QALYs'), (Kind and Gudex, 1993) are employed in comparing cost/ benefit ratios of different therapeutic interventions. 'Willingness to pay' (how much one would pay to not have that disease) was tested (Whetten-Goldstein *et al*, 1996) to quantify the intangible costs of a pathologic condition.

Early MS cost studies

Since 1995 the first large-scale studies on MS costs were conducted and provided analogous results (Jönsson, 1995; Holmes *et al*, 1995; Asche *et al*, 1997). In the UK the total annual cost for 80 000 individuals with MS was calculated to be £1.2 billion, the annual cost per person was dependent on the disability level (min £336, max £4275; Holmes *et al*, 1995). Direct costs were comprised largely of hospitalisations, which are largely long-term hospitalisations (related to the worsening of disability). Drugs costs (not including beta interferon) were far less (Jönsson, 1995; Holmes *et al*, 1995).

Indirect costs, chiefly reduction or loss of work activity (earning loss, also for the caregiver, lost taxation, state benefits) counted for approximately 75–80% of total costs (Jönsson, 1995; Holmes *et al*, 1995).

A study in the US in 1995 (Whetten-Goldstein *et al*, 1998), estimated the cost of MS to be $9.7 billion total. The per person cost was related to disease course: from $30 500 for each relapsing-remitting MS patient to $50 000 for each progressive. Intangible costs were estimated to be as high as $500 000 per person.

Concerning the burden of the disease for the caregiver, informal assistance is estimated to be the second highest tangible expense following earning loss in MS, but is often not included in cost estimates. A 1997 Belgian study (Cartoon *et al*, 1998) conducted on MS patients with high levels of disability demonstrated that the cost for an individual living at home is approximately 50% of the cost for a permanent resident in an institution. In these cases, the difference in costs is obviously assumed by the family.

When considering the total cost of MS with other diseases, it is typically higher than for a number of more common pathologies, (e.g. asthma or infectious diseases), which is largely due to the early onset and long duration of MS (The Canadian Burden of Illness study group, 1998).

A recent development in MS cost studies is related to the introduction of new immunomodulatory drugs, i.e. recombinant beta interferons, which are quite costly. Interferons have been shown to have a short-term effect on the course of the disease, reducing the frequency and the severity of relapses, reducing the MRI lesion load and rallenting the worsening of disability (The IFNB Multiple Sclerosis Study Group, 1995; Jacobs *et al*, 1996; PRISMS, 1998; European Study Group on IFN1b in treatment of secondary progressive MS, 1998), although efficacy in slowing the progression of disability on a long-term basis is much more uncertain (Rice and Ebers, 1998).

A cost-utility analysis of beta interferon 1-b considered the cost of one relapse compared to the cost 'per relapse avoided' by the treatment (Parkin *et al*, 1998). The cost 'saved' for avoiding a relapse was far greater than the cost of a relapse, in the case of a 30% relapse risk. Although, there was no difference when the risk of relapse increased to 50%. The study did not assess the cost of a relapse on patients' quality of life.

Discussion

Recent controversy in public health policy has increased the interest in the economic evaluation of a number of diseases in developed countries. Particularly in the case of chronic disease, cost-benefit evaluation of treatment influences therapeutic decision-making, both on a global and on an individual basis.

A number of difficult issues remain to be resolved in the evaluation of costs related to MS, including unclear epidemiological estimations, disease course variability, expensive and only partially efficacious new drugs and the difficulty in assigning a value to patients' quality of life.

What is clear is that MS is one of most costly of neurological diseases, due to an early onset, long duration and significant effects on employment.

The single greatest component of MS-related costs are indirect costs (earning loss and consequences), which constitute up to 80% of the total. Employment difficulties are a major issue for MS

persons. Motor symptoms, fatigue and neuropsychological aspects are the most significant causes of reduction/loss of work activity. On the other hand, employment problems are only partially related to disability, in fact, MS patients are reported to leave the workforce relatively early during the course of the disease.

Drugs expenses were the lowest component of direct costs (prior to the beta interferons approval), the largest being costs related to hospitalisation, particularly long-term hospitalisations. This is due to costs related to disability level and the growing need for informal care and assistive devices.

Cost-utility analyses of beta interferons are currently ongoing. Net costs seem to be amortized if relapse risk increases, and initial data on the efficacy of beta interferons on disability progression will likely confirm this trend. On a common-sense basis, it seems evident that avoiding even a mild relapse can be of a significant advantage for the person with MS. Slowing disability progression, in terms of lengthening the time of autonomous living, could signify a more relevant savings for the person with MS. Based on this, any therapeutic device able to prevent even temporary, but also permanent symptoms, is advantageous for an individual with MS. Moreover, social instruments which permit a person to maintain employment can be beneficial both on an individual and on a social level.

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