

The economic impact of multiple sclerosis in Australia in 2010

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Abstract

Background: Multiple sclerosis (MS) has a major impact on health and is a substantial burden on patients and society. We estimated the annual costs of MS in Australia from individual and societal perspectives using data from the Australian MS Longitudinal Study (AMSLS) and prevalence figures from 2010.

Methods: Direct and indirect costs were estimated from a subsample of 712 AMSLS subjects who completed baseline and follow-up economic impact surveys. All costs are in 2010 Australian dollars (AUD).

Results: Annual costs per person with MS were AUD48,945 (95% CI: 45,138 to 52,752). Total costs were AUD1.042 (0.9707 to 1.1227) billion based on a prevalence of 21,283. The largest component was indirect costs due to loss of productivity (48%). Costs increased with increasing disability: AUD36,369, AUD58,890 and AUD65,305 per patient per year for mild, moderate and severe disability, respectively. Total costs of MS to Australian society have increased 58% between 2005 and 2010.

Conclusions: This study confirms that MS imposes a substantial burden on Australian society, particularly impacting on productivity. The burden increases with worsening disability associated with the disease. Investment in interventions that slow progression, as well as resources, services and environments that assist people with MS to retain employment, is supported.

Keywords

Multiple sclerosis, cost of illness

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Introduction

Multiple sclerosis (MS) is a common disease of the central nervous system, with a typical age of onset in Australia between 20 and 40, when people are establishing careers and families.

Cost of illness (COI) analyses are descriptive studies measuring all costs related to a specific illness. The results of these studies provide useful information to policy makers and researchers by providing a snapshot of the distribution of costs related to a disease in a given environment at a given point in time. They provide information on the main cost drivers, thereby informing priority-setting for resource allocation.¹

Prevalence-based COI analyses studies give the cost of all cases in a given time period, usually one year, and are typically undertaken for chronic conditions.²

Economic costs associated with health care can be categorised as direct, indirect and intangible. Direct costs are broken down to medical and non-medical. Direct medical includes the costs of prescription drugs, physician services,

hospital separations and nursing home stays. Direct non-medical includes the cost of informal care and home- and community-based services. Indirect costs include lost wages from lost productivity. Intangible costs include the pain, grief and social impacts of living with a progressive disease resulting in reduced quality of life.^{2,3}

The objective of this study was to estimate the COI of MS in Australia in 2010 from an individual and societal perspective using cost data collected from the Australian MS Longitudinal Study (AMSLS) combined with updated Australian MS prevalence data.

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Methods

The AMSLS is an ongoing research project that includes ~3100 representative volunteers with MS from all states and territories of Australia.^{4,5} The AMSLS has conducted two large-sample nationwide AMSLS Economic Impact Studies (AMSLS EIS) in Australia.⁶ These studies consisted of a baseline questionnaire and cost diary on economic circumstances. The surveys were distributed to participants in the AMSLS in September 2003, and four years later in 2007. The survey captured information that could be used to determine direct costs such as pharmaceutical, medical, nursing, community and private services, hospitalisations, home and car alterations, special equipment and informal care, and indirect costs such as sickness leave and early retirement. Thus, availability of this large and comprehensive data set provided a unique opportunity to determine the full societal cost of MS in Australia.

Data from the 712 subjects who completed both the baseline questionnaire and the cost diary as part of the 2007 AMSLS EIS were used in the analysis. Of 2555 people with MS invited to participate in 2007, 1329 completed the baseline questionnaire (52%), of whom 712 went on to complete the six-month cost diary (28% of invited sample). The baseline questionnaire provided information on the cost of informal care and the indirect costs related to lost productivity. The informal care costs were assessed directly from the average weekly earnings of the carer, pre- and post-care provision collected in the survey. The difference was inflated using an annual wage inflation factor of 4%. In cases for which the average weekly earnings were missing and the average hours of work pre- and post-care provision was recorded, an average hourly wage rate of Australian dollars (AUD)34.50 obtained from the Australian Bureau of Statistics (ABS) Employee Earnings and Hours for May 2010 was used.⁷

The indirect costs from lost wages were estimated from the baseline questionnaire when people were asked "Whether or not you are currently employed". Subjects indicated their Australian Standard Classification of Occupations (ASCO) employment occupation category currently and prior to displaying MS symptoms. A wage was attributed to each subject pre- and post-MS symptoms using the average wage by occupation and gender from the ABS Employee Earnings and Hours – 6306.0 – May 2010 data. The ABS currently uses Australian and New Zealand Standard Classification of Occupations (ANZSCO) (1220.0) to classify occupation and the 2007 baseline survey used ASCO. The occupation estimates were converted from ANZSCO to ASCO using the ABS concordance file. Subjects ≥ 65 years of age were allocated indirect costs of AUD 0 unless they indicated that they were currently part of the work force.

The 2007 cost diary collected detailed information on the costs and resource use related to MS. Subjects completed the diary daily over six months. Subjects were

asked to record all costs and resource use relating to their MS, regardless of whether they paid for them. The diary included questions on all expenditures related to: prescription medication; non-prescription medication and other products; disposable equipment and continence items; health professional services (other than nurses); nursing services; community and private services; medical tests; hospital stay/rehabilitation stay/nursing home visit/respite care, stay/hospital in the home; special equipment purchased over the last five years; and alterations to car or house undertaken over the last five years. Costs collected for special equipment and alterations to car or house were based on costs incurred over a five-year period while all other costs were based on a six-month period. For each item, the study participants recorded how much they paid and who paid the balance. Special equipment and alterations to car or house costs were annualised by dividing the costs reported by five. All other costs based on a six-month period were annualised by multiplying by two. The annualised 2007 direct costs were inflated to 2010 levels using an annual inflation factor of 3.2% based on the health price index.⁸

The prescription medications costs were calculated using the Pharmaceutical Benefits Schedule (PBS) cost schedule (1 December 2010). For MS-specific immunotherapies the average co-payment of AUD9.60 was applied based on an analysis of data from the Pharmaceutical Benefits Pricing Authority (PBPA) 2009/2010 annual report.

It was not possible to estimate nursing home and equivalent high-support care costs from the AMSLS data as only four of 712 subjects indicated that they resided in a nursing home. This is likely to be an underestimate as subjects who are in nursing homes are unlikely to be able to complete the cost diary. The 2009 ABS Survey of Disability, Ageing and Carers (SDAC) estimated that the proportion of people with MS in nursing homes is 5.7% (95% confidence interval (CI) 2.9% to 8.4%). The Australian Institute of Health and Welfare (AIHW) estimate of accommodation support of AUD75,057 per person (for 2008–2009), where accommodation support includes institutional accommodation, group homes and other accommodation type,⁹ was applied. We included the 95% CI for the proportion of people entering a nursing home to calculate a nursing home estimated cost of AUD4384 95% CI (AUD2269 to AUD6498) per person with MS. These costs were inflated to 2010 values and multiplied by the prevalence to give an average cost of nursing home care per person. Due to the lack of information on the nursing home distribution of persons with MS by disease severity, a uniform distribution across disease severity was assumed. This assumption was made so that nursing home costs can be factored into the total costs within each category and the category totals add to the overall total. Unlike the cost categories collected in the cost diary, nursing home costs were unable to be distributed by subgroups such as severity, and an average has been applied

Table 1. Costs of MS by cost categories.

Cost category	Mean costs per person with MS (AUD)	95% CI	Total AUD	95% CI
Direct costs – personal	3697	3016 to 4378	78.7 million	64.2 to 93.1 million
Direct costs – community/government	10,721	9977 to 11,465	228.2 million	212.3 to 244.0 million
Nursing home and equivalent costs	4384	2269 to 6498	93.3 million	48.3 to 138.3 million
Informal care	6857	5182 to 8531	145.9 million	110.3 to 181.6 million
Indirect costs	23,286	21,095 to 25,477	495.6 million	449.0 to 542.2 million
Mean total costs (AUD)	48,945	(45,138 to 52,752)	1.0417 billion	0.9707 billion to 1.1227 billion
Mean total costs (USD)	51,142	(47,150 to 55,102)	1.0883 billion	(1.00348 billion to 1.17274 billion)
Mean total costs (EUR)	41,022	(37,826 to 44,206)	0.8730 billion	(0.8050 billion to 0.9408 billion)

MS: multiple sclerosis; AUD: 2010 Australian dollars; USD: United States dollars; EUR: euros; CI: confidence interval; one AUD = 1.044560 USD; one AUD = 0.837995 EUR.

to all individuals with MS. One-way sensitivity analysis was performed on the costs of nursing home by varying this cost through its CIs and assessing the impact on the total costs per person with MS. In addition to AUD, cost results were also expressed as United States dollars (USD) and euros (EUR) using the following exchange rates (one AUD = 1.044560 USD; one AUD = 0.837995 EUR).¹⁰

Assessment of disability

No direct measures of disability were included in the surveys; however, physicians' estimates of mobility using Disease Steps were available for a majority of respondents within 12 months of the 2003 survey. The Disease Steps scale is mobility based and correlates highly with the Expanded Disability Status Scale (EDSS), but has the advantage of low inter-rater variability so that specialist training in use of the scale is not required.⁶

Statistical analysis

Mean costs and 95% CIs were calculated for the total costs. For the sake of brevity, only mean costs were reported when broken down by category, disease severity, or collapsed EDSS. The total population estimate was evaluated by multiplying the costs per person by the prevalence estimate of 21,283.¹¹ The population cost estimates by category are evaluated by allocating the 21,283 patient estimates according to the distribution of the 712 samples within the specific category. Analyses were undertaken in SAS version 9.1.3.

Results

The costs/person with MS in 2010 were AUD48,945 (95% CI: 45,138 to 52,752) (USD51,142 (95% CI: 47,150 to

55,102); EUR41,022 (95% CI: 37,826 to 44,206) with the costs for all people with MS in Australia totalling AUD1.0417 billion (95% CI: 0.9607 billion to 1.1227 billion) (USD1.0883 billion (95% CI: 1.0035 billion to 1.1727 billion); EUR0.8730 billion (95% CI: 0.8054 billion to 0.9408 billion) (Table 1). The largest component was the indirect costs (48%), representing lost productivity. Direct costs (30%) were also a substantial component, as were the costs of informal care (14%). Nursing home costs were 9% of the total.

Costs were analysed by severity of MS (Table 2); personal costs increased with disease severity, while informal care and indirect costs increased markedly as severity increased from mild to moderate, as people with MS need greater care and their ability to participate in the workforce diminished as the symptoms of the condition worsened. A breakdown of the direct costs (personal and community/government) by MS severity demonstrated that the cost of pharmaceuticals was similar for mild and moderate categories but decreased when the condition became severe (Table 3). This is likely to be due to the MS-specific immunotherapies being reimbursed in Australia for relapsing–remitting MS only, and having limited efficacy in progressive forms of MS. Those with more severe disease were unlikely to be prescribed these treatments. Other key contributors to direct costs were alterations to car and home, and community and private services which increased with disease severity. Despite high costs of MS-specific immunotherapies, direct costs for mild and moderate disease were less than for those with severe disease. The trends observed in the analysis of costs by severity were confirmed when broken down by EDSS (Table 4). There was a substantial increase in personal costs when an EDSS level of 7–9 was reached. This occurred at a time when income as evidenced by indirect costs is decreasing. Direct costs were reasonably constant

Table 2. Costs of MS by severity.

	Mild	Moderate	Severe	Not stated
Costs per person with MS (AUD)				
Direct costs – personal	2062	4097	7380	3788
Direct costs – community/government	10,181	11,098	12,042	9304
Nursing home and equivalent costs ^a	4384	4384	4384	4384
Informal care	3395	9569	11,111	6227
Indirect costs	16,347	29,743	30,388	20,354
Total costs per person with MS (AUD)	36,369	58,890	65,305	44,057
Total costs per person with MS (USD)	37,990	61,514	68,215	46,018
Total costs per person with MS (EUR)	30,475	49,346	54,727	36,921

MS: multiple sclerosis; AUD: 2010 Australian dollars; USD: United States dollars; EUR: euros; mild severity includes Expanded Disability Status Scale (EDSS) levels 1–3; moderate includes 4–6; severe includes levels 6.5–9; ^a: Nursing home costs are not broken down by MS severity. Nursing home costs are available for the total population only. Total cost in each category is calculated from the category population and the overall mean cost. Therefore no inference should be made for the difference in cost between categories.

Table 3. Direct costs – by cost category and disease severity – per person with MS.

	Mild	Moderate	Severe
Prescription medication	9387	8725	5508
Non-prescription medication	226	303	400
Disposable equipment	53	121	468
Health professional	617	1061	1071
Nursing services	81	615	1501
Community and private services	273	911	3056
Medical tests	188	294	203
Hospital stay	125	326	921
Alterations to car/home	1157	2320	4839
Special equipment	137	519	1455
Total (AUD)	12,244	15,194	19,422
Total (USD)	12,782	15,862	20,278
Total (EUR)	10,259	12,731	16,274

MS: multiple sclerosis; AUD: 2010 Australian dollars; USD: United States dollars; EUR: euros; mild severity includes Expanded Disability Status Scale (EDSS) levels 1–3; moderate includes 4–6; severe includes levels 6.5–9; Nursing home costs were not included.

while informal care and indirect costs increased markedly with severity.

When costs were assessed by sex, total costs per female with MS were slightly lower than for males, mainly because of differences in indirect costs (Table 5). More men were in paid employment and on higher salaries prior to the onset of MS; thus there was a greater decline in paid work foregone as assessed by monetary value when a male stopped work prematurely.

Varying of costs due to nursing home admission through its 95% CI (i.e. between AUD2269 and AUD6498) had little impact on the total costs, with the total costs ranging from AUD46,830 to AUD51,059.

Discussion

This study used updated prevalence and cost data to assess the COI of MS in Australia in 2010. Two previous COI studies in MS have been published for Australia. In 2005, Access Economics performed an analysis of the economic costs of MS in Australia.¹² The study primarily took a ‘top-down’ approach supplemented by a ‘bottom-up’ approach where data were available. The analysis also included an estimate of the intangible costs resulting from the burden of disease due to suffering and premature death from MS. The Access Economics study estimated that the total (direct and indirect) financial costs of MS in 2005 were AUD37,333 per person with MS, corresponding to more than AUD600 million (0.07% of gross domestic product (GDP)). The intangible costs were estimated at an additional AUD1.34 billion, twice the financial costs. The current analysis does not include the intangible cost associated with MS, which resulted in a more conservative estimate of the total costs when compared to the approach used in 2005. The intangible cost could be estimated by quantifying the reduction in either quality of life^{2,13} or disability¹² and valuing this loss using society’s willingness to pay for a year of life. While valuation of the intangible cost enables a monetary value to be placed on the pain and grief associated with MS, this is generally omitted in COI studies. This study aimed to identify the financial cost of MS from a society perspective. To this end, the valuation of pain and suffering has not been estimated in monetary terms.

This analysis included the indirect costs resulting from the use of informal care and productivity loss. The cost of informal care contributed 14% of the cost per person with MS while productivity losses contributed 48% and was the highest single element of cost. These costs are less visible as they do not represent a direct expenditure outlay; however, they do have a very real and significant impact on the community. The requirement for informal care and the foregone income due to the inability to participate in

Table 4. Costs of MS by Expanded Disability Status Scale (EDSS).

EDSS	0–1	2–3	4–5	6	6.5	7–9
Costs per person with MS (AUD)						
Direct costs – personal	1237	2754	3511	4608	4859	10,338
Direct costs – community/government	10,517	9660	11,912	10,387	9567	14,944
Nursing home and equivalent costs ^a	4384	4384	4384	4384	4384	4384
Informal care	849	5721	6070	12,623	11,442	10,722
Indirect costs	9801	19,481	23,969	34,784	29,547	31,375
Total costs (AUD)	26,788	42,001	49,846	66,786	59,799	71,764
Total costs (USD)	27,976	43,862	52,053	69,745	62,448	74,948
Total costs (EUR)	22,443	35,184	41,757	55,948	50,092	60,119

MS: multiple sclerosis; AUD: 2010 Australian dollars; USD: United States dollars; EUR: euros; NC: not classified; ^a: Nursing home costs are available for the total population only and therefore are not broken down by severity of disability.

Table 5. Costs of MS by sex.

Costs per person with MS (AUD)	Male	Female
Direct costs – personal	3504	3751
Direct costs – community/government	10,114	10,896
Nursing home and equivalent costs ^a	4384	4384
Informal care	7543	6692
Indirect costs	29,529	21,714
Total costs (AUD)	55,073	47,437
Total costs (USD)	57,512	49,539
Total costs (EUR)	46,134	39,738

MS: multiple sclerosis; AUD: 2010 Australian dollars; USD: United States dollars; EUR: euros; ^a: Nursing home costs are available for the total population only and therefore were not broken down by sex.

the workforce represent a substantial burden to persons with MS and their families.

Taylor et al.¹⁴ estimated costs of MS in Australia in 2004 using a ‘bottom up’ approach based on the results of a questionnaire completed for 100 people with MS in Tasmania. The questionnaire was completed by the study investigator for persons with MS attending the MS clinic of the Royal Hobart Hospital. Overall, the average annual direct and indirect costs per person with MS were AUD20,396 and AUD15,085, respectively, totalling AUD35,481.

The cost per person with MS of AUD48,945 determined in this analysis is consistent with reported estimates from other countries. The Multiple Sclerosis International Federation (MSIF) conducted a review of international data on the costs and quality of life of MS.³ The review found that while the total costs of MS varied by country, the costs were substantial in all countries. In addition to underlying differences in the costs of MS treatment and management, differences in MS costs across countries were due to differences in the categories of costs included in each study, typical care provided to people with MS during the time period of analysis, and cost analysis approaches. There is a considerable range in the estimates due to the methodology adopted for collection of data,

inclusion and valuation of resource use and valuation of the intangible losses. Many of the studies utilise a survey in which respondents with MS recall the costs incurred over a previous period, typically one to three months. Most studies include lost productivity due to a reduction in workforce participation or early retirement. Further, some studies place a value on the intangible cost by applying society’s willingness to pay for a quality-adjusted life year (QALY) and avoid the reduction in quality of life as measured by the individual’s loss of amenity of life. These differing approaches lead to a range of estimates, and care must be taken when comparing results from different studies. The total average cost per person with MS varied from USD16,378 in France to USD54,489 in Norway, with an overall prevalence-weighted average of USD41,335.³

The costs per person of MS in Australia in 2010 were largely unchanged in each category except indirect costs, when compared to the corresponding costs in 2005.¹² When adjusted for inflation, all direct-costs categories were similar on a per-person basis in this study compared to the Access Economics study of 2005, with less than 10% difference in values reported in each category. There were substantial differences in indirect costs per person reported in each study. The increased indirect-cost component (from AUD17,580 per person in 2005 to AUD23,286 per person in 2010) is likely a consequence of the increase in salaries of 23% over this time.⁷

The total cost to society increased 58% from AUD659 million to AUD1,038 million, driven by the increase in the prevalence and to a lesser extent an increase in indirect costs. The prevalence in 2010 is estimated to be 21,283 while the Access Economics 2005 report assumed a prevalence of 16,081.

There was a consistent trend towards increased cost with progressive severity of MS. This finding was observed when severity was classified as mild to severe by EDSS score or assumed based on age. This was despite the cost of prescription medication being much higher in the mild subgroup (AUD9387 per person per year) compared with

AUD5508 in the severe subgroup. The increased costs in the severe subgroup are primarily due to community and private services, alterations to car and home, and special equipment. Indirect costs and informal care are also higher in the moderate and severe subgroups as a consequence of foregone income due to increased disability. This increased financial burden is exacerbated by increased direct personal costs in these subgroups.

While there was a higher proportion of females with MS, the costs were similar with the exception of the indirect costs, which again reflects the lower foregone income in this group.

A limited number of COI studies for other diseases have been conducted in Australia that can be used to provide a context for MS. One study estimated the cost per person with schizophrenia was AUD46,180 (in 2000 dollars),¹⁵ not dissimilar to the cost of MS estimated in this report. The AusDiab study reported that the cost of type 2 diabetes mellitus to be AUD10,900 per year (AUD5360 per person for direct and indirect costs plus AUD5540 in Commonwealth benefits).¹⁶ These costs need to be interpreted with caution as being derived with different methodologies; nevertheless they suggest that the cost of MS is similar to other severe illnesses and higher than diabetes mellitus, which is considered to be a substantial burden to the individual and community as a whole.

A strength of this study is that detailed information on all costs incurred because of MS was captured by a large sample of people with MS. The use of a cost diary that was completed every day obviated the need for recall, which is a frequently cited concern in surveys for which participants with MS are required to remember what occurred in the past.

A possible limitation is that the 712 participants with MS may not be representative of all Australians with MS. However, a comparison of those filling out the 2007 baseline questionnaire and cost diary ($n = 712$) with those who completed the baseline questionnaire only ($n = 617$) indicated that gender ratios were similar (79.5% and 76.5% female, respectively), and decadic age groups were similar, with 5.2% vs. 7.7% aged less than 35 years, 16.4% vs. 19.0% aged 35–44, 30.2% vs. 29.0% aged 45–54, 31.4% vs. 30.9% aged 55–64, and 16.8% vs. 13.4% aged ≥ 65 years for those who filled out the cost diary and those who completed the baseline questionnaire only, respectively.

As with all surveys for which participation requires time commitment, the incentive of patients with MS to participate and express their experience may be more pronounced for patients with severe MS. This may be balanced by patients with greater levels of disability finding it harder to respond to such a survey. Less severe patients may also be motivated by the opportunity to share their experiences; however, this subgroup may also be less accepting of their condition and therefore less inclined to spend the time required completing the survey.

Conclusions

This study provides an important insight into the cost burden of MS. There are substantial costs associated with MS that increase with severity. The burden increases with increasing severity, suggesting that delay or ideally prevention of progression could bring substantial rewards. Considering the impact of lost productivity, investment in resources, services and employment environments that assist people with MS to remain in employment is of paramount importance.

Conflict of interest

The authors declare that there are no conflicts of interest.

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