

Utilisation and cost of professional care and assistance according to disability of patients with multiple sclerosis in Flanders (Belgium)

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Abstract

Objectives—To assess the utilisation of medical services and social (community) assistance in patients with multiple sclerosis of different disability and to calculate the direct healthcare costs to society.

Methods—(1) One hundred and eighty four patients with multiple sclerosis were classified into four grades of disability according to a simplified Kurzke disability status scale. (2) Patients were interviewed with a structured questionnaire containing questions on their sociodemographic status, the use of inpatient and outpatient medical services and pharmaceutical products during the previous year, the use of social assistance, and the purchase of prosthetics and charges for house adaptations during the previous five years. (3) Data were also prospectively collected by means of four week diary annotations of all medical and social acts and their duration.

Results—After correction for the disability distribution the yearly costs for the 5500 patients with multiple sclerosis in Flanders was estimated to be ECU 13 106 000 for ambulatory care including rehabilitation and district nursing and ECU 3 234 000 for pharmaceutical products. To these direct medical costs ECU 3 491 000 for social assistance and ECU 4 938 000 for prosthetics and adaptations should be added. The yearly costs for admissions to hospital including permanent residence in an institution and pharmacy was ECU 26 581 000. Home nursing and long term or permanent residence in an institution of the most severely disabled, 17% of the multiple sclerosis population, are responsible for 50% of the total direct healthcare costs and care for the 6.5% institutionalised patients accounts for 23%. Direct costs for medical care and social assistance for patients with multiple sclerosis, who account for about 0.1 % of the total population, amounts to 1% of the total healthcare budget in Flanders.

Conclusion—This information on utilisation of medical services and social assistance can be used for good healthcare planning and cost effectiveness studies.

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Keywords: multiple sclerosis; disability; healthcare costs

Multiple sclerosis is a chronic disabling neurological disorder affecting almost 1/1000 in geographical high risk areas such as Canada and the northern parts of the United States and Europe, including Belgium. The disease strikes early in life. The median age at onset is 30-32 years and there is a female preponderance. The initial course of multiple sclerosis is most often relapsing-remitting with accumulating deficit followed within five to 10 years by a secondary progressive course. In a minority of patients the disease is progressive from the onset. The mean time to reach a disability requiring aids for ambulation is 15 years.¹ Survival after onset in high risk areas is in the order of 35 to 40 years.^{2,3} Many patients will end their life bedridden and entirely dependent on professional and informal care and help. Apart from the personal suffering, the financial consequences for these patients and their family and the economic burden for society are enormous.

Information on utilisation of medical and social services is essential for good healthcare planning, and awareness of the medical and social costs is a prerequisite for cost containment. So far few studies considering the cost of multiple sclerosis have been published.^{4,5,6} The problem of cost effectiveness is a topical subject in multiple sclerosis as new therapeutic agents are being developed which possibly can delay the progression of the disease but at an extremely high cost.

Patients and methods

PATIENTS

Ascertainment of patients

Data were collected over a period of 19 months (from 1 March 1995 until 30 September 1996 inclusive). The selection of the patients for this cost of illness study was biased on purpose to yield an overrepresentation of patients expected to be great consumers of medical care and assistance—namely, the more severely disabled and those in hospital. One hundred and ninety eight patients with a well established diagnosis of multiple sclerosis according to the criteria of Poser *et al*⁷ were ascertained from various sources: (1) neurologists in general hospitals (n=104), (2) neurologists in special neurological institutes (SPN) for long term care and rehabilitation of patients with neurological diseases (n=40), (3) nursing homes (n=12), (4) the Wit-Gele kruis which is the most important organisation for district nursing in Belgium (n=11), and (5) the Flemish Multiple Sclerosis Society (n=31).

Patients were contacted by telephone by one of three social nurses and visited at the place

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where they resided at that moment: at home, in sheltered housing, with a 24 hour activities of daily living help, in general hospitals, SPN institutes, or nursing homes.

Measurement of disability

A simplified and abbreviated Kurtzke disability status scale (DSS),⁸ was administered to assess the neurological dysfunction of the patients. On the basis of this rating scale patients were divided into one of four disability grades: group I (DSS 0 to 2) contained patients with no or a minimal disability, grade II (DSS 3 to 5), patients with moderate disability but able to walk independently, grade III (DSS 6 to 7), patients requiring mobility assistance or the use of wheelchairs most of the time, and grade IV (DSS 8 to 9), patients confined to bed or chair or totally helpless.

DATA COLLECTION

Standardised questionnaire

A structured questionnaire was used to ensure that all patients were asked identical questions. It contained questions concerning (1) their sociodemographic status (occupational and marital status, family composition, and residence); economic status, and income; (2) their current disability; (3) the use during the past year of professional inpatient and outpatient medical services including medicines and nursing equipment as well as the delivery of social and community assistance; (4) the informal (non-professional) support during the past year from persons living with the patients and by volunteers; and (5) house adaptations, purchase of prosthetic and adaptive devices, and transport aids over the past five years. It was explicitly asked that only costs and assistance caused by the disease were reported.

Four week prospective diary

Data were prospectively collected during the four weeks after the interview by means of a diary booklet in which professional carers noted, from day to day, the acts that they had provided and the time needed to perform these. Professional medical carers included general practitioners (GPs), medical specialists, nurses, physiotherapists, occupational therapists, speech therapists, and psychologists. Professional providers of social assistance included social workers, home carers and helpers in activities of daily living. In the same diary booklet daily use of medicines and nursing devices was also recorded.

Hospital invoices

To estimate the costs of admissions to hospital, hospital invoices were collected from patients institutionalised in the year preceding the interview, during the four week diary registration, and the months until the end of the data collection (September 1996).

Spot check of the utilisation of different institutional facilities by a representative multiple sclerosis population

All five hospitals and six nursing homes located in a well delineated area around Leuven as well

as two rehabilitation (SPN) centres in the neighbouring region agreed to participate in a spot survey to detect all institutionalised patients from this representative area where according to a recent age and sex adjusted prevalence study⁹ 220 patients with multiple sclerosis from a population of 250 000 reside. In the present study, these institutions were recontacted by telephone every six months or a total of seven times. They provided information on the duration of stay in hospital, sex, age, and disability class of the patients with multiple sclerosis in their institution who were residents of the representative Leuven area. Information on the presence of patients with multiple sclerosis in sheltered housing in Flanders was obtained from the Flemish Multiple Sclerosis society.

DETERMINATION OF COSTS

Cost of professional medical care and social assistance provided to outpatients

General practitioners, medical specialists, and physiotherapists provide services for outpatients on a fee for service basis. Officially agreed on charges were used to calculate the cost of these services.

The cost of medical services provided by nurses, speech therapists, occupational therapists, and psychologists and the cost of social assistance provided by social workers, home carers, and helpers with activities of daily living were calculated using cost-wage scales of mid-1996 for a professional worker with 10 years of seniority.

Cost of professional care and help provided to patients in institutions

Costs of stay in hospital were based on the invoices from the patients who had stayed in a general hospital, SPN institute, or nursing home during the study period. The invoices of SPN institutes were considered separately depending on the duration of stay of the patient.

The frequency and durations of stay in hospitals for the temporarily institutionalised patients were assessed from retrospective data of patients interviewed at home only. To avoid a selection bias of patients prone to be more often admitted to hospital, patients who were residing in an institution at the moment of the interview were not considered.

The prevalence of permanent residence in an institution was derived from the data of the spot check in the representative Leuven area.

Charges for house calls were used to calculate the costs of the visits by GPs in nursing homes. For the wages of hospital medical specialists, physiotherapists, speech therapists, social workers, psychologists, and nurses, their hourly cost was calculated and multiplied by the time they spent treating each patient.

Cost of pharmaceutical products for outpatients and patients in institutions

Pharmacy costs included different drugs as well as nursing aids such as syringes, pampers, catheters etc. As β -interferon was not yet fully available and not reimbursed during the study period, the cost of this drug was not included in the

pharmacy costs. The cost for outpatients was derived from the four week diary. For patients in institutions the pharmacy costs recorded on the hospital invoices were used.

Costs of adaptations to the house and car, and costs of mobility aids, prosthetics, and adaptive or adapted devices

Information was collected by interview on the number and types of adaptations fitted to the house and the number of devices or aids bought or rented as a consequence of multiple sclerosis in the previous five years. The average cost per disability class was calculated by multiplying the mean number of adaptations made or devices bought during the past five years by the mean price of the adaptation or device, based on the reported prices during the past five years.

WEIGHING BY THE DISTRIBUTION OF THE DISABILITY GRADES IN FLANDERS

Because the selection was biased deliberately towards the more disabled patients, representative costs were obtained by weighing the crude costs in this study by the population frequency of each of the four disability grades. The proportional distribution of the four disability classes was obtained from two prevalence studies in neighbouring regions, southern Hesse¹⁰ in Germany and Groningen¹¹ in The Netherlands. The weighting was done by their joint distribution: grade I: 35%, grade II: 24%, grade III: 23%, and grade IV: 18%.

STATISTICAL ANALYSIS

Descriptive and univariate analysis was performed using the SAS 6.08 computer package.

Results

PATIENTS

One hundred and ninety eight patients were asked to participate in the study. Seven refused and seven dropped out before the end of the study: one patient died, one moved abroad, two dropped out for social reasons, and three found the study too troublesome. Table 1 shows detailed population characteristics of the 184 remaining patients. One hundred and thirty four patients had stopped working as a consequence of the disease. Of these 23% did

Table 1 Population characteristics

| | Mean | SD |
|--------------------------------|-------|------|
| Age | 49.2 | 12.7 |
| Age first symptoms | 31.03 | 9.63 |
| Age diagnosis | 35.6 | 10.2 |
| Disease duration | 13.8 | 10.4 |
| N | | % |
| Marital status: | | |
| Married | 124 | 67.4 |
| Not married | 29 | 15.7 |
| Widow(er) | 11 | 6 |
| Divorced (legally or actually) | 20 | 10.9 |
| Occupational status: | | |
| Employed/working | 31 | 16.8 |
| Housewife/-man | 17 | 9.2 |
| Student | 2 | 1.1 |
| Unemployed (worked before) | 3 | 1.6 |
| Temporary sick leave | 4 | 2.2 |
| Long term sick leave | 89 | 48.4 |
| Retired | 38 | 20.7 |
| Gender: | | |
| Male | 71 | 38.6 |
| Female | 113 | 61.4 |

so within the first year of the appearance of the first clinical manifestation, 50% stopped working within the first five years of the disease.

Seventeen patients belonged to disability grade I (DSS 0–2), 44 to grade II (DSS 3–5), 61 to grade III (DSS 6–7), and 62 to grade IV (DSS 8–9). One hundred and thirty two (71.8%) patients were interviewed and completed the four week diary at home, six of whom were in sheltered housing, and 52 (28.3%) completed the diary in institutions, 12 of whom were in a nursing home.

UTILISATION OF PROFESSIONAL CARE AND ASSISTANCE

Frequency of use and duration of medical and social services for outpatients

Table 2 shows the mean number of medical interventions, recorded in the four week diary by the different professional care providers, as well as the mean number of interventions by social workers, home carers, and helpers in activities of daily living.

In the outpatient population the crude number of contacts with GPs was 4.5-fold more frequent than with medical specialists. The vast majority (92.7%) of the contacts with rehabilitation therapists were with physiotherapists, 4.8 % were with occupational therapists,

Table 2 Mean number (N) and duration in minutes (M) of contacts per patient with professional care and assistance providers of outpatients during 4-week diary

| | Disability grade | | | | | | | | | | | |
|------------------------|------------------|-----|-------------|-----|-------------|-----|------------------|-----|-------------|-----|------------------|-----|
| | I | | II | | III | | IV | | | | | |
| | n=17 (N) | (M) | n=42 (N) | (M) | n=46 (N) | (M) | n=3* (SH) (N) | (M) | n=21 (N) | (M) | n=3* (SH) (N) | (M) |
| Medical doctors | | | | | | | | | | | | |
| GP | 0.41 | 24 | 0.69 | 24 | 1.30 | 23 | 1.33 | 18 | 0.90 | 17 | 1.67 | 32 |
| Specialist | 0.29 | 57 | 0.24 | 51 | 0.20 | 24 | 0.00 | 0 | 0.05 | 20 | 1.67 | 15 |
| Nurses | 0.06 | 15 | 0.29 | 10 | 4.48 | 22 | 2.33 | 24 | 34.00 | 33 | 43.66 | 37 |
| Rehabilitation | | | | | | | | | | | | |
| Physiotherapist | 0.71 | 45 | 5.50 | 49 | 9.78 | 47 | 14.67 | 36 | 13.33 | 34 | 16.00 | 30 |
| Occupational therapist | 0.00 | 0 | 0.17 | 60 | 0.46 | 30 | 2.33 | 58 | 1.10 | 60 | 0.00 | 0 |
| Speech therapist | 0.00 | 0 | 0.00 | 0 | 0.07 | 30 | 0.00 | 0 | 0.57 | 50 | 0.00 | 0 |
| Psychologist | 0.06 | 75 | 0.17 | 60 | 0.00 | 0 | 1.33 | 60 | 0.19 | 30 | 0.00 | 0 |
| Social assistance | | | | | | | | | | | | |
| Social worker | 0.00 | 0 | 0.14 | 71 | 0.02 | 60 | 0.00 | 0 | 0.14 | 32 | 1.00 | 60 |
| Home carer | 0.00 | 0 | 0.19 | 240 | 1.50 | 270 | 5.00 | 236 | 1.43 | 240 | 7.33 | 284 |
| ADL helper | 0.00 | 0 | 0.00 | 0 | 0.00 | 0 | 37.33 | 24 | 0.00 | 0 | 28.33 | 101 |

* Patients in sheltered housing (SH).

Table 3 Frequency and duration of hospital admissions in the previous year of patients interviewed at home

| | Disability grade | | | |
|---|------------------|------------|-------------|--------------|
| | I | II | III | IV |
| Number of patients | 17 | 42 | 49 | 24 |
| Number of patients hospitalised per year | 4(24%) | 20 (48%) | 19 (39%) | 15 (62%) |
| Number of hospitalisations per year | 5 | 28 | 33 | 20 |
| General hospital | 5 | 24 | 24 | 4 |
| SPN-institute | 0 | 4 | 9 | 16 |
| Mean length of hospitalisations in days (range) | 6.4 (4-7) | 7.3 (1-19) | 22.6 (1-98) | 53.3 (7-238) |
| General hospital | 6.4 | 7.7 | 19.6 | 10.5 |
| SPN institute | | 5.2 | 30.8 | 64.2 |

Table 4 Average costs in ECU* of 4 weeks of medical services, social assistance and pharmaceutical products for an outpatient

| Residence | Disability grade | | | | | |
|-------------------------|------------------|-------|-------|--------|--------|--------|
| | I | | II | | IV | |
| | Home | Home | Home | SH | Home | SH |
| Medical doctors | | | | | | |
| GP | 9.6 | 9.4 | 17.6 | 18.0 | 12.2 | 22.6 |
| Specialist | 6.4 | 5.1 | 4.4 | | 1.3 | 35.5 |
| Nurses | 0.4 | 1.4 | 46.8 | 25.9 | 523.8 | 397.4 |
| Rehabilitation | | | | | | |
| Physiotherapist | 14.0 | 117.9 | 203.0 | 231.0 | 198.3 | 210.0 |
| Occupational therapist | | 4.5 | 6.0 | 59.1 | 28.9 | |
| Speech therapist | | | 0.9 | | 12.5 | |
| Total medical services | 33.3 | 144.5 | 278.7 | 384.1 | 782.9 | 665.6 |
| Social assistance | | | | | | |
| Social worker | | 6.2 | 0.8 | | 2.8 | 37.7 |
| Home care | | 14.1 | 125.0 | 364.6 | 105.3 | 642.4 |
| ADL help | | | | 381.6 | | 1229.8 |
| Total social assistance | | 20.3 | 125.8 | 746.2 | 108.1 | 1909.9 |
| Drugs and nursing aids | 14.6 | 44.1 | 70.5 | 133.5 | 132.1 | 371.3 |
| Total ambulatory costs | 47.8 | 209.0 | 475.0 | 1263.8 | 1023.1 | 2946.8 |

1€ = 1.5 ECU.

Table 5 Average yearly hospital cost per patient of different disability grades

| Residence | Disability grade | | | | SPN | NuHo |
|------------------|------------------|--------|--------|---------|-------|-------|
| | I | II | III | IV | | |
| General hospital | t=1.88 | t=4.40 | t=9.61 | t=17.5 | | |
| Care | 579 | 1433 | 3317 | 583 | | |
| Pharmacy | 85 | 203 | 371 | 93 | | |
| Subtotal | 664 | 1635 | 3688 | 676 | | |
| SPN institute | | t=0.49 | t=5.66 | t=42.71 | t=365 | |
| Care | | 146 | 1234 | 7035 | 46255 | |
| Pharmacy | | 1.4 | 28 | 253 | 1706 | |
| Subtotal | | 147 | 1262 | 7288 | 47961 | |
| Nursing home | | | | | | t=365 |
| Care | | | | | | 24966 |
| Pharmacy | | | | | | 794 |
| Subtotal | | | | | | 25760 |
| Total for year | 664 | 1782 | 4950 | 7964 | 47961 | 25760 |

SPN = special neurological; NuHo = nursing home; t = time in days spent in institution (according to interview).

and only 1.4% and 1.1% were with speech therapists and psychologists respectively.

Frequency and duration of stay in hospital

Table 3 shows the number of stays in hospital and their average duration for patients still living at home with different disabilities. A typical patient living at home with a disability corresponding to grade I spends an average of 1.88 days per year in a hospital, a patient of grade II spends 4.89 days a year in a hospital of which 4.40 days (90%) are in a general hospital and 0.49 days (10%) are in an SPN institute. A patient of grade III spends on average 15.27 days a year in a hospital of which 9.61 days (63%) are in a general hospital and 5.66 days (37%) in an SPN institute. A patient

of grade IV who lives at home spends an average of 44.46 days a year in a hospital, of which only 1.75 days (4%) are in a general hospital and 42.71 days (96%) are in an SPN institute.

Percentage of patients in sheltered housing, temporarily in hospital, and permanently in an institution

According to the Flemish Multiple Sclerosis society 30 patients or 0.5% of the 5500 Flemish patients with multiple sclerosis resided in sheltered housing during the study period. These patients were evenly distributed between grade III and IV. Furthermore the spot checks representative in the Leuven area indicated that at any moment on average 19.9(9%) of the 220 patients known to live in the Leuven area were in an institution; an average of 5.6 (2.5%) were temporarily in hospital and 14.3 (6.5%) were institutionalised for more than 12 months, most probably permanently. All the last patients belonged to disability grade IV. Of these patients with a long stay in an institution more than two thirds (4% of the total multiple sclerosis population) permanently resided in a nursing home and almost one third (2.5% of the total multiple sclerosis population) were in an SPN institute.

COST ESTIMATES

Average four week cost of professional ambulatory care according to disability

Table 4 shows the costs for medical services, professional social assistance, and pharmaceutical products.

Average daily cost of hospital care per disability class

One hundred and eighteen invoices were reviewed: 73 from general hospitals, 40 from SPN institutes, and five from nursing homes.

Table 5 shows the average daily cost in the different institutions for patients of different disability classes. The decreasing costs for stay in hospital in SPN institutes with increasing duration of hospital stay was taken into account for these calculations.

Yearly costs for house adaptations and medical equipment/devices and prosthetics

These costs are reported and added to the total professional cost (table 6).

ESTIMATION OF THE TOTAL COST OF PROFESSIONAL CARE FOR PERSONS WITH MULTIPLE SCLEROSIS IN FLANDERS

Estimation of the total direct cost of multiple sclerosis in Flanders

Based on the distribution of the disabilities of the patients with multiple sclerosis in Flanders, the location (home or institution) where the services were provided and the average daily costs of the various services, the yearly cost for 100 patients with multiple sclerosis can be calculated (table 7). The yearly expenditures to the community for the 5500 patients with multiple sclerosis in Flanders was estimated to be ECU 13 106 000 for ambulatory care to which ECU 3 234 000 for pharmacy costs should be added. With an estimated cost of ECU 25 040 000 for hospital care and

Table 6 Yearly cost per patient for house and automobile adaptations, mobility aids, prosthetics, and adaptive devices

| Residence | Disability grade | | | | | |
|--|------------------|------|-------|------|------|------|
| | I | | II | | IV | |
| | Home | Home | Home | SH | Home | SH |
| Adaptions of house, kitchen, bedroom and bathroom: | | | | | | |
| Mean number per patient in 5 years | 0.18 | 1.31 | 1.57 | 0 | 1.14 | 0 |
| Mean price of adaption | 2775 | 1469 | 2.159 | 0 | 1419 | 0 |
| Costs per patient per year | 100 | 385 | 678 | 0 | 324 | 0 |
| Adaptions of automobile: | | | | | | |
| Mean number per patient in 5 years | 0 | 0.17 | 0.54 | 0 | 0.33 | |
| Mean price of adaption | 0 | 1650 | 10130 | 0 | 5281 | 0 |
| Costs per patient per year | 0 | 56 | 1094 | 0 | 299 | 0 |
| Mobility aids: crutches, wheelchairs: | | | | | | |
| Mean number per patient in 5 years | 0 | 1.12 | 1.91 | 2.67 | 2.24 | 1.33 |
| Mean price of adaption | 0 | 459 | 931 | 0 | 1658 | 0 |
| Costs per patient per year | 0 | 103 | 356 | 497 | 743 | 441 |
| Prosthetics and devices: | | | | | | |
| Mean number per patient in 5 years | 0 | 1.19 | 1.04 | 2.33 | 3.75 | 6 |
| Mean price of adaption | 0 | 396 | 591 | 0 | 496 | 0 |
| Costs per patient per year | 0 | 94 | 123 | 275 | 354 | 596 |
| Total | 100 | 638 | 2250 | 772 | 1719 | 1037 |

ECU 1 540 000 for hospital pharmacy this amounts to a total of ECU 42 920 000 for medical care/year. To this amount ECU 4 391 000 yearly cost for social and community services and ECU 4 938 000 for adaptations and prosthetics should be added.

Discussion

ON THE METHODOLOGY OF STUDIES OF COST OF ILLNESS OF PATIENTS WITH MULTIPLE SCLEROSIS Few studies estimating the cost of multiple sclerosis have been published.⁴⁻⁶ The most recent and comprehensive one was conducted in 1991 by Jonsson in Sweden⁶ and published in 1995. This was a top down study. Costs of admission to hospital were derived from statistics of the National Board of Health and Welfare. Although there are advantages to this prevalence approach and to the top down method, they have their limitations as no information is available on disability measures of the patients and costs cannot be related to specific patient groups.

In 1993 Bourdette *et al*⁷ studied the relation between disability and healthcare cost. They used the bottom up approach. The cost of care provided to 165 largely male patients with multiple sclerosis at two Veterans' Affairs (VA) Medical Centres in the United States was correlated with measures of neurological impairment. A limitation of this study is that its population, mainly male veterans, is not

representative for the whole multiple sclerosis population and that some cost classes such as VA benefits are very specific for this population and hardly applicable to other persons with multiple sclerosis in the United States or patients in other countries.

The present study used the bottom up approach and also attempted to be prevalence based. Its strength resides in the facts (1) that data were collected prospectively to prevent recall bias; (2) that it considered several specific cost classes including medical care, social assistance, adaptations, and prosthetics; (3) that it related the costs to disability status; (4) that the costs of multiple sclerosis could be extrapolated to the whole population and therefore be related to the annual healthcare expenditure in the country; and (5) that the results can easily be compared with those of other countries as not only charges, invoices, and bills, which are very much determined by country, but also the frequency and duration of services are recorded. The weaknesses of the present study also need to be considered—namely, (1) that it is not strictly prevalence based and that (2) the whole range of disabilities was reduced to four grades only. The option was taken to study a limited number of patients only, but in detail. To obtain sample sizes allowing calculations the whole disability range was covered by four classes only. These four classes corresponded to the four stages most people with multiple sclerosis can be seen to move through, and they can easily be identified. The selection was purposely biased towards the more severely disabled, who were expected to be the greatest consumers of health care.

The frequency of hospital admissions and permanent residence in institutions were determined in a well delineated area of Flanders around Leuven, where we were able to study all 220 patients with multiple sclerosis.⁹ As the sociodemographic situation and the availability of health care is very similar in the Leuven area and in other parts of Flanders an extrapolation from this area to the whole Flemish population seems justified. In a second part data on healthcare consumption and disability were obtained from patients from inside as well as from outside the Leuven area and costs were determined for different disability stages, which were then extrapolated to the whole population.

Table 7 Yearly costs for 100 patients with multiple sclerosis in Flanders according to disability

| Residence | Disability grade | | | | | | | | Total |
|------------------------------|------------------|--------|--------|-------|--------|-------|-------|--------|--------|
| | I | | II | | IV | | SPN | NuHo | |
| | Home | Home | Home | SH | Home | SH | | | |
| Days per year in institution | 1.9 | 4.9 | 15.3 | 15.3 | 44.5 | 44.5 | 365 | 365 | |
| Prevalence (%) | 35% | 24% | 22.75% | 0.25% | 11.25% | 0.25% | 2% | 4.5% | 100 |
| Medical costs: | | | | | | | | | |
| Ambulatory care | 15087 | 44596 | 79255 | 1200 | 96237 | 1908 | 0 | 0 | 238238 |
| Outpatient pharmacy | 6602 | 13608 | 20055 | 417 | 17034 | 1064 | 0 | 0 | 58780 |
| Hospital care | 20248 | 37888 | 103531 | 1138 | 85704 | 1905 | 92509 | 112347 | 455270 |
| Hospital pharmacy | 2982 | 4895 | 9079 | 100 | 3891 | 86 | 3413 | 3572 | 28020 |
| Subtotal | 44919 | 100988 | 211921 | 2855 | 202866 | 4963 | 95922 | 115919 | 780353 |
| Social assistance | 0 | 6272 | 35658 | 2139 | 13942 | 5472 | 0 | 0 | 63483 |
| Adaptions/prosthetics | 3497 | 15310 | 51190 | 193 | 19341 | 259 | 0 | 0 | 89790 |
| Total direct costs | 48416 | 122570 | 298769 | 5187 | 236149 | 10694 | 95922 | 115919 | 933625 |

ON THE USE OF SERVICES AND COST ESTIMATES

As expected and as already shown in the VA study,⁵ the use of medical services and their ensuing costs rise dramatically with increasing disability.

As for ambulatory patients the rising costs related to increasing disability are almost entirely determined by the great use of rehabilitation and district nursing. Rehabilitation is responsible for 85% of the costs of medical services for patients with mild disability (grade II) and for 75% of the cost for those moderately disabled (grade III) (table 4). Occupational therapy, which is only applied to the moderately and most severely disabled patients and speech therapy to the most severely disabled patients (grade IV), represented only a minimal fraction of the ambulatory medical services and costs. Costs for district nursing also increased along with the disability of the outpatients (table 4). It became precipitous for the totally dependent patients (grade IV), and amounted to two thirds of their costs for ambulatory medical services.

With increasing disability an up to 10-fold rise in the costs for pharmaceutical products was noted and depending on the disability grade they constituted 10%-20% of the total ambulatory cost. The main reason for these high costs was that pharmaceutical products not only included drugs but also pharmaceutical aids such as catheters and other nursing material. Costs for adaptations and prosthetics were also high and almost comparable with the pharmacy costs. The frequency of doctors' visits, about once every month, remained fairly constant during all stages of the disease. This rather surprising finding was also noted in the VA study.⁵ As a consequence the relative contribution of doctors fees become progressively less important in the overall costs of medical care for outpatients: from 30% for grade I to 1.5% for grade IV. Social assistance included subsidised services such as social work, home care, and help with activities of daily living. The costs became important only for the moderately and severely disabled. It is noteworthy that patients with a similar disability but residing in sheltered housing consumed six times (for grade III) to 20 times (for grade IV) more social assistance than patients in their own home (table 4) where this help is provided by the family. However, the very high yearly cost of a severely disabled patient living in sheltered housing of ECU 42 777 (by contrast with ECU 20 991 at home) is to be compared to the costs for society of permanent residence in institutions, which amounts to ECU 25 760 in a nursing home and ECU 47 961 in an SPN institute.

By contrast with ambulatory costs, the daily charges for a stay in hospital do not seem to increase with increasing disability but rather have a tendency to decrease. The increasing yearly hospital costs for patients of increasing disability was almost entirely related to the increasing proportion of patients being admitted to hospital (from 24% of patients of grade I to 62% of patients of grade IV) and to the increasing mean durations of the hospital stays

(from two days for grade I to 44 days in grade IV). Taking into consideration the long hospital stays of the most severely disabled who still live at home, the high costs of these persons when they reside in sheltered housing and in particular the costs of the 6.5% of patients who are permanently institutionalised, it is evident that the costs of long term care outstripped those of acute medical management.

The average yearly medical cost for a patient with multiple sclerosis in Flanders is ECU 7800. It is ECU 8700 if adaptations and prosthetics and ECU 9300 if social assistance and community aid are included. In the Swedish survey⁶ where house adaptations, prosthetics, and community assistance were not included it amounted to ECU 5625 or less than 75% of the cost in Flanders. However, rehabilitation of outpatients and district nursing at home, which constitute the two major expenditures of ambulatory care in Flanders, as well as pharmaceutical products other than drugs were not included in the Swedish calculation. The average cost of health care including prosthetics for a VA patient in the United States is \$35 000 or ECU 30 000, which is roughly the yearly cost for a most severely disabled patient in Flanders. This much higher cost compared with Flanders and Sweden probably reflects the higher costs of health care in the United States but certainly also the higher proportion of more severely disabled persons in the VA study than patients with multiple sclerosis in the general population.

Johnson extends his economic evaluation of multiple sclerosis in Sweden⁶ to an assessment of the indirect cost of multiple sclerosis due to absence from work and early retirement. The total indirect cost of loss of production in Sweden was 2.5 times higher than the direct cost of healthcare services.⁶ This was also the case in an earlier study by O'Brien in England and Wales.⁴ One quarter of the patients in our study had lost their work within one year after the appearance of the first symptoms and half of them had lost their occupation within five years. Both of these direct and indirect costs as well as the value of informal (non-professional help) by relatives and friends are to be considered when cost effectiveness of treatments is studied. A paper on the contribution of informal assistance to the total cost of illness of multiple sclerosis in Flanders is being prepared by Pacolet *et al.*

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