

Economic Burden of Multiple Sclerosis on patients: Research Findings from Greece

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Abstract The Multiple Sclerosis (MS) is a chronic autoimmune, inflammatory disease, which is the third cause of serious disability for the ages between 20 and 40 years old. More than 8,000 Greeks suffer from this disease. The scope of our research is to estimate the economic burden on patients with MS, through the analysis of their out - of - pocket payments. The study was conducted in 2010 to a random sample of 400 patients, from whom 288 (103 men and 185 women) completed the research questionnaire. The average annual out - of - pocket payments of MS patients, found to be 8,334€, significantly varying by the gender and the severity of the disease. From our research it was unveiled the significant economic burden on patients with MS in Greece. Consequently, it is appointed the imperative need of research on the social and economic cost of MS and of introducing an integrated support system for the patients.

Keywords: multiple sclerosis, health economics, out - of - pocket payments, cost of illness, Greece

1. Introduction

The MS is a chronic autoimmune, inflammatory disease, which has variety of symptoms [1]. The causes of MS are not yet found although scientists know the disease's pathophysiology. Common symptoms, include upper and lower extremity disabilities, visual disturbances, balance and coordination problems etc [2,3,4,5].

Patients and their families experience major changes in their lives on a social and professional level as well as in their day to day life [6,7]. The MS is the third cause of serious disability for the ages between 20 and 40 years old with current prevalence rates estimated to 30 per 100,000 populations. Generally, MS affects more 1 million young people all over the world and globally 200 individuals are diagnosed weekly with the disease [9-16]. It is estimated that there are about 250,000 Americans, 80,000 British and 8,000 Greeks suffering from the disease.

Interesting research has been done in various countries in order to estimate the financial burden of the disease, as well as to bring forward the consequences of the disease for the patients and their families [17-26].

Table 1, presents the cost analysis of MS in various countries, as it was estimated in 2007 by combined studies [27].

In Greece, unlike other European countries, no sufficient research to estimate the cost of the illness has been carried out, except from the one of the *Greek Society for MS* which conducted to a limited sample of 43 patients with MS [28].

2. Materials and Methods

The scope of this paper is to estimate and present the economic burden on patients with MS, through the analysis of their out - of - pocket payments and the reduction of their annual income.

A total of 400 patients were included in the study, from which 288 completed the research questionnaire. The response rate was 0.72. The patients were 103 men and 185 women aged ≥ 15 years, who had clinically or laboratory supported definite MS according to neurologist, the diagnosis of the MS have been onset at least 12 months before starting the study, regardless of time of symptoms. Patients were excluded if they had other acute or chronic illness.

The study was conducted during the period March to July 2010, from various regions of Greece. We used a reliable and weighted questionnaire which consisting of 91 questions given by the *Greek Society for MS* (but adapted to the needs of our research). Furthermore to identify patterns of the disease (level of functional disability), the questionnaire asked for information on resource consumption, medical and non-medical expenditure, work absenteeism and informal care. The patients were called to participate in the study voluntarily, they were informed for its purpose via letter which was attached to the questionnaire and they first signed the relevant consent statement. Also, the questionnaire was completed through personal interviews with the patients or their family members. Finally, the questionnaire used to MS specific tools; the Expanded Disability Status Scale [29], the Multiple Sclerosis Quality of Life (MSQOL - 54)

[30], the Multiple Sclerosis Impact Scale (MSIS -29) [31], which have been also used in several studies. Finally, the statistical analysis of the study was conducted using the SPSS 17.00 and Excel 2007.

Table 1. Financial cost of MS (in US Dollars)

Country	Total Direct Medical Costs (2007)	Total Direct Non Medical Costs (2007)	Total Indirect Costs (2007)	Total Cost (2007)
Australia	\$18,809	\$16,167	\$6,890	\$41,866
Austria	\$20,738	\$10,010	\$17,569	\$48,317
Belgium	\$13,746	\$10,108	\$13,267	\$37,121
Canada	\$3,162	\$2,421	\$15,932	\$21,514
France	\$6,078	\$4,718	\$5,582	\$16,378
Germany	\$20,246	\$6,986	\$19,946	\$47,178
Italy	\$13,001	\$19,225	\$13,237	\$45,462
Netherlands	\$9,845	\$8,910	\$15,849	\$34,605
Norway	\$10,995	\$12,472	\$31,023	\$54,489
Poland	\$3,495	\$2,713	\$11,423	\$17,631
Spain	\$15,973	\$16,498	\$11,544	\$44,015
Sweden	\$15,431	\$21,607	\$17,427	\$54,465
Switzerland	\$10,211	\$13,365	\$14,473	\$38,048
United Kingdom	\$10,969	\$19,858	\$17,995	\$48,822
United States	\$23,975	\$7,844	\$18,888	\$50,707

Source: Tsitsolini M, Honeycutt A, Wiener J, Lesesne S, «Global economic impact of Multiple Sclerosis», MSIF, London, United Kingdom, 2010

3. Results

3.1. Sample Demographics

Table 2 presents the sample (patients) characteristics. A total of 288 patients were included in the analysis. The mean age was 46.2 years, 35.8% were male and 64.2% female. Moreover, the majority of patients was married (55.6%) and had children, while 81.9% live in the big city. On the other hand, 8.7% live in the village. 34.7% indicated unemployed and their family help them to cover the costs of MS. Furthermore, 54.2% of the patients are insured in Social Insurance Institute. Finally, 52.8% of the survey, the primary care for patients comes from their family, which confirms that in Greece the family has undertaken to support both financially and psychologically people with Multiple Sclerosis, hence affecting and changing the everyday life of their close relay.

Table 2. Demographics of the Sample

Gender	Frequencies	Percent
Male	103	35.8
Female	185	64.2
Total	288	100
Age		
Mean age: 46.2		
15 – 24	6	2.1
25 – 39	38	13.2
40 – 54	169	58.7
55 – 64	51	17.7
65 – 79	7	2.4
Missing	17	5.9
Total	288	100

3.2. Financial Burden on the Patients (Out – of – Pocket Payments)

Before mentioning the findings of our research we should clarify that almost all studies are based on the EDSS scale for determining the financial cost of MS. In our study 69.5 percent of patients had mild disease (Expanded Disability Status Scale [EDSS] score of 0–3), 27.6% had moderate disease (EDSS score of 4–6.5) and 3% had severe disease (EDSS score of ≥ 7). The mean EDSS score in the sample was 3. In Table 3, an allocation of the patients to the EDSS Score, is presented.

Table 3. EDSS Score allocation

EDSS Score	Frequencies	Percent
0	9	3.1
1	51	17.7
2	49	17
3	91	31.6
4	23	8
5	54	18.8
6	2	0.7
7	3	1
8	5	1.7
9	1	0.3
Total	288	100

To test for whether there is any relationship between the variable *Severity (EDSS Score)* and the variables *Gender* and *Age*, we performed the chi-squared test. The results in Table 4 and Table 5 show that there's a strong relationship.

Table 4. Age BY severity Chi-Square Test

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	37.316 ^a	9	.000
Likelihood Ratio	43.994	9	.000
N of Valid Cases	288		

a. 9 cells (45.0%) have expected count less than 5. The minimum expected count is .36.

Table 5. Gender BY severity Chi-Square Test

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From our research it is found that the average annual income of the patients decreased by approximately € 2,000, mainly during the first 2 years of the disease onset, a fact that leads to greater financial loss of patients due to the disease. This income decrease is mainly due the early loss of ability to work and the impact of physical and psychological disabilities.

Moreover, the average annual out - of - pocket payments of MS patients, found to be €8,334 varying by the gender (€8,942 for women and €7,241 for men) (see Figure 1) and the severity of the disease (from €3,629 for EDSS= 0 to €22,800 for EDSS= 9) (see Figure 2).

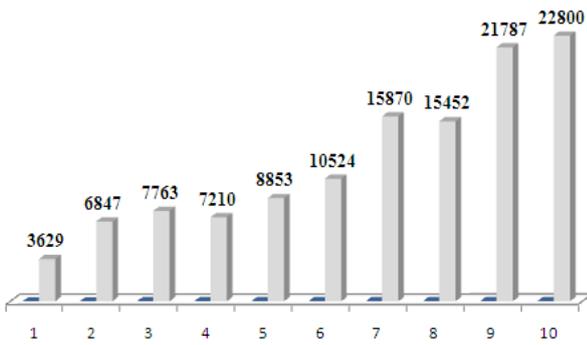


Figure 1. EDSS and average annual out - of - pocket payments

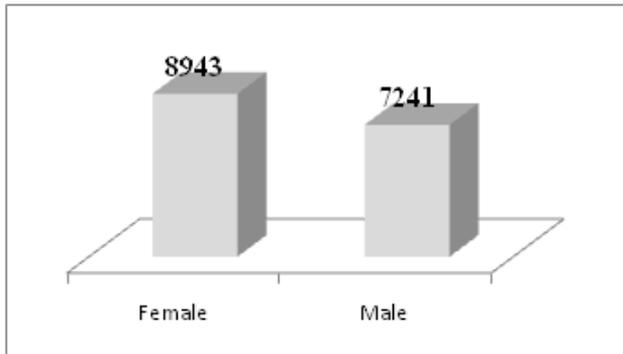


Figure 2. Gender and average annual out - of - pocket payments

We used a one-way ANOVA to explore the effect of the categorical variable (explanatory variable) *Severity (EDSS Score)* on the continuous variable (outcome) *Total*. The results are shown in Table 6 and Figure 3.

Table 6. ANOVA for Total

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	16890437.608	9	1876715.290	10.636	.000
Within Groups	48700677.361	276	176451.730		
Total	65591114.969	285			

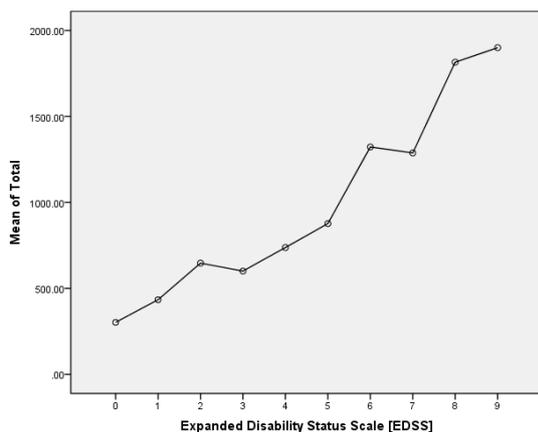


Figure 3. ANOVA for Total

For better fit the data, we excluded two (2) extreme values from the variable *Total*. In this model, the *F* value, which is the between-group mean square divided by the within-group mean square, is large at 10.636 and is significant at $P = 0.000$. This indicates that there is a significant difference in the mean values of the 10 parity groups.

Finally, the average annual out - of - pocket payments for outpatient and others diagnostic medicals tests found to be € 1,853, for doctors' visits € 1,894, for inpatient € 7,672, for pharmaceuticals € 869, for physiotherapy and rehab and gym € 1,780, for alter treat and diet € 1,552, for transportation € 1,304 and for home adjustment € 2,130 (See Table 7).

Table 7. Out - of - pocket payments for patients with Multiple Sclerosis

Out - of -pocket payments	Frequencies	Minimum	Maximum	Mean
Diagnostic medicals tests e.t.c	236	120	25,800	1,853
Doctor visits / year	163	240	18,000	1,894
Inpatient / year	34	600	22,800	7,672
Pharmaceuticals / year	220	180	8,400	869
Physiotherapy and gymnastics/ year	161	.00	12,996	1,780
Alter Treatanddiet	97	.00	6,000	1,552
Transportations and car / year	165	.00	14,400	1,304
Home Adjustment	8	600	3,600	2,130
Total	288	600	52,200	8,334

4. Discussion

In comparison to other countries, Greece lacks sufficient research concerning MS financial impact [32]. This void leads to the absence of adequate support to the patients and their families. The benefits granted by the government are limited and therefore they cannot cover the significant out-of-pocket amounts for this specific disease, as it is a chronic disease. Patients depend mostly on their family for their daily needs and also for their financial support. This fact was confirmed by our research.

Although the health system in Greece should be open and accessible to everyone, its services are mainly concentrated in large cities. Therefore, patients with MS who live in rural regions must always move or travel to urban areas where they can have access to the proper health services. Unfortunately, this case causes increased out-of-pocket expenses, as these are not always and fully covered by the social security organization, though it is noteworthy that it covers a large amount of the total expenses for the patients with MS. Our research findings confirmed the previous *Greek Society for MS* study results [28]. Its study showed that 75% - 100% of the expenses are covered by social security schemes but the amounts provided are not enough to pay for special treatments.

For the calculation of all our research findings concerning the financial burden of MS, the EDSS scale must be used for adjustment. Specifically, the research which was carried out in the United Kingdom had an average EDSS rate of 5.1 [21], in Germany 4.4 [22], whereas in Greece, the rate is 3, which concludes that in our research the patients are fully peripatetic and have mediocre function disability. Nevertheless, patients with MS and their families have to adapt a new way of life, as their daily routine changes. Their direct and indirect expenses due to the disease are quite increased, therefore they are not always able to cover. This global problem, although its impact varies between various countries, is unveiled by our research in Greece too.

According to our findings, we can notice a significant reduction in the income of our sample with MS, especially

during the first two years of the illness onset. Specifically, their average income before the disease was €14,714 one year later it is reduced to €13,555, five years later it was €12,824, a fact which points out a reduction of approximately €2,000.

In addition, our findings conclude that the average out-of-pocket payments of the patients and their families in Greece amount to €8,334. Furthermore, we must mention that this amount is much more as the EDSS scale rises reaching the €22,800 when a patient is confined to bed (EDSS =9-10), but it is rather lower (€3,629) when EDSS = 0-1.

If to the out-of-pocket expenses calculated above, we add the reduction of patients' income, because of its illness, the average financial burden per year escalates to €10,334. This amount might be considered much higher in the case that the patients with MS are unable to work any longer (something quite common) or if a family member stops working to stay home and take care of them [33].

5. Conclusions

In Greece, no specific legislation has been founded concerning patients suffering from MS and their families, which makes it difficult for them to face their daily needs due to their disease. Patients and their family members must be provided with a secure job or an extra benefit, which would ensure that they could cover their day to day needs as well as their out-of-pocket medical expenses.

Most patients with MS leave their jobs because they become severely ill. This could have been avoided if they had the option of a part time job. Flexible working hours is not the only intervention, as there are other suggestions, well applied abroad; i) employers and employees should be informed of how the disease affects patients' ability in order to make them more sensible. ii) a specific rest area for them to relieve so that they can keep on working.

Furthermore, organized scientific groups should be working altogether in order to point out and resolve problems concerning patients with MS and their carers. These services must be provided free of charge by the National Health System or by the social security organization.

Concluding, in Greece, research concerning the financial and social cost of MS must be encouraged because this will help unveiling the economic burden to patients, as well as to their family members, which will lead in taking the right measures in order to support them.

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