The IMPrESS (International Multiple Sclerosis Study); socio-economic burden, health related quality of life and experiences of Multiple Sclerosis patients in France

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Background & Objectives

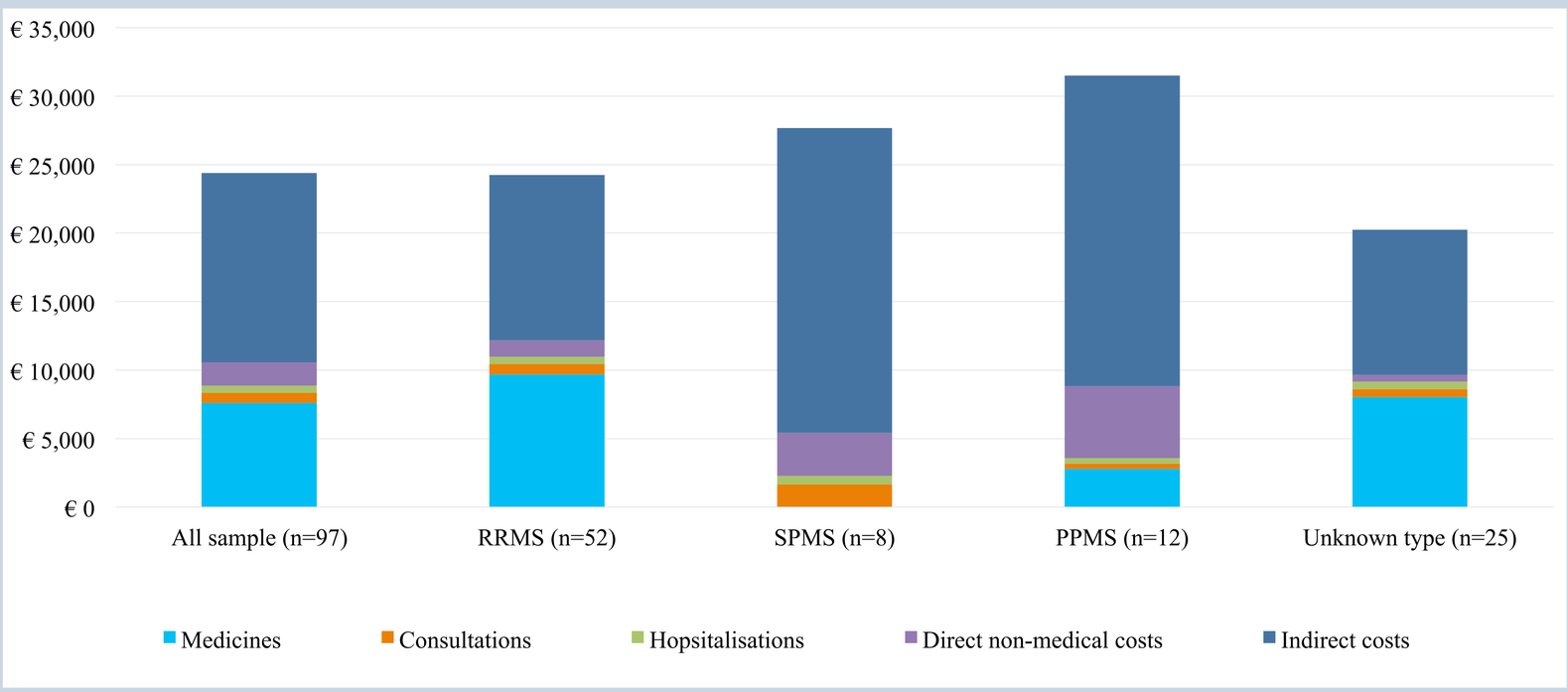
Multiple Sclerosis (MS) is the second most common cause of neurological disability and highest per capita costs among all other neurological disorders [1]. Even though France has the lowest prevalence rates among other north European countries (94.7 per 100.000) [2], in 2009 the total annual cost per patient was estimated at €44,400, translated in an estimated total cost of €1.3 billion per year for MS in France [3].

❖ Due to the advances observed in Disease Modifying Therapies (DMTs) for MS since 2012 (such as the approval of the oral agents Dimethyl fumarate and Fingolimod) which might imply higher direct costs but also higher efficacy and compliance rates [4, 5], we aimed to provide an updated analysis on the socioeconomic burden, Health Related Quality of Life (HRQoL) and experience of MS patients in France.

Methods

- Data collection was based on a web-survey (Qualtrics ®) of non-institutionalised individuals with MS.
- Three patient associations (either national or supranational) were invited to cascade the surveys to their network of patients.
- Data were collected on i) demographic, ii) disease and clinical related variables, iii) Disease Modifying Drug (DMD) consumption, iv) healthcare resource and informal care utilisation, v) productivity losses, vi) QoL (EuroQoL 5-domain; EQ-5D-5L), EQ-5D-5L VAS and vii) Physical disability (Barthel Index).
- In addition, the survey gauged patients' experience with MS through questions on i) treatment satisfaction, ii) future treatment expectations, iii) caregiving arrangements and iv) preferred sources of information for MS.
- Microsoft® Excel 2010 was used to generate descriptive statistics and SPSS (v.21) to test for treatment group differences (using one way ANOVA and independent samples t-test).

Figure 1. Average annual cost (€ 2014-15) per patient across all sample and type of MS in France



Results

Socio-economic burden

- On average annual cost of MS per patient in France was estimated at **€24,403 (±18,538)** (Figure 1).
- 57% of total costs (€13,838, ±15,796) accounted for indirect costs due to productivity losses and 36% (€8,877, ±8,497) and 7% (€1,686, ±4,309) accounted for mean, annual direct medical and non-medical costs respectively.
- Indirect costs were primarily driven by **permanent work disability (€7,701 ±14,727)** and temporary sick leave (€3,091 ±7,101), corresponding to 42% and 12% of mean annual costs respectively).
- Direct costs were shaped by **DMD utilisation (€7,609 ±8,271)**,formal/informal caregiving (i.e. direct non-medical costs) (€1,686, ±4,309) and ambulatory/inpatient care (€1,267±1,414) (i.e. 31%, 7% and 5% of mean annual cost respectively).
- Average annual cost per patient amounted **up to €31,514 (±23,400)** for individuals with Primary Progressive MS (PPMS), €27,664 (±22, 992) for those with Secondary Progressive MS (SPMS) and €24,261 (±17,775) for those with Relapsing Remitting MS (RRMS) (Figure 1).
  - ❖ Indirect costs due to productivity losses accounted for **72% (€22,684), 80% (€22,233) and 49.7% (€12,075)** of the above total costs respectively.
- Statistically significant differences ***(p<0.05)*** were observed between all cost categories across types of MS apart from inpatient and formal care costs.

HRQoL

- Mean EQ-5D-5L index and VAS scores were **0.49 (±0.3)** and 60.5 (±22) respectively, whereas the Barthel index score reflected that overall the sample was **mildly dependent (i.e. 15-19)** in carrying out their daily activities (Table 1).
- HRQoL (EQ-5D-5L index and EQ-5D-5L VAS) and Barthel Index outcomes fluctuated between the different types of MS, with statistically significant ***(p<0.001)*** differences observed between groups in EQ-5D-5L utility, utility loss and Barthel Index scores (Table 1).

Experience with MS

- Overall, a **moderate satisfaction (7.4 out of 10)** was observed with the health care received by the national health system and this dropped to 6.6 for individuals with PPMS, although no statistically significant differences were observed between types of MS (Table 1).
- An unmet need to receive formal/informal care was reported by 7% of respondents and an unmet need for a new therapy that targets of **Mobility and Fatigue/ Weakness** (43% and 40% of respondents respectively) among others (Figure 3).
- MS websites are the preferred sources of information for individuals with MS (48% of respondents) while 4% of individuals have not looked for information (Figure 2).

Table 1. Sample HRQoL characteristics [mean *(SD)*] and statistical significance (*p*) of differences between type of MS groups.

	All sample (n=92)	RRMS (n=50)	SPMS (n=7)	PPMS (n=11)	Unknown type (n=24)
EQ-5D-5L Utility	0.48 (0.28)*	0.55 (0.24)	0.23 (0.32)	0.32 (0.37)	0.49 (0.23)
Utility loss	0.34 (0.28)*	0.27 (0.24)	0.6 (0.32)	0.51 (0.37)	0.33 (0.23)
EQ-5D-5L VAS	60.5 (22)	65.2 (21)	46 (25.2)	50.9 (21.3)	59 (22)
Barthel index	17.5 (3.3)*	18.6 (1.9)	14.3 (4.5)	14.4 (4.6)	17.4 (3.3)
Treatment satisfaction	7.4 (2.3)	7.6 (2.2)	7.7 (3.0)	6.1 (2.8)	7.4 (1.7)

**p<0.001*

Figure 2. Preferred sources of information for individuals with MS in France

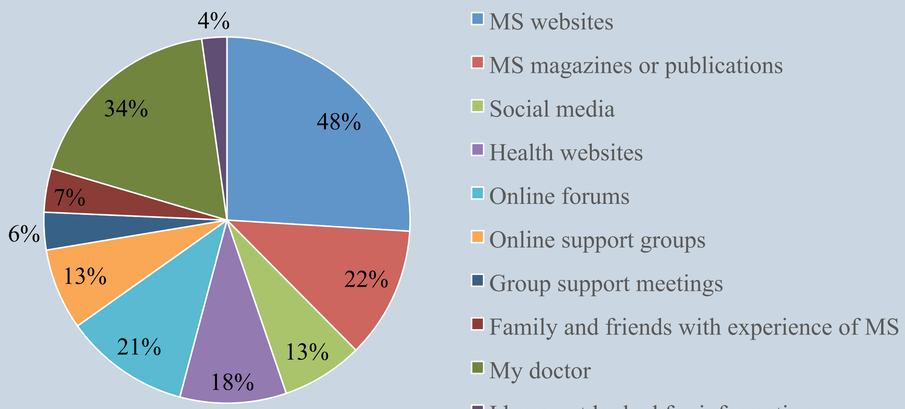


Figure 3. Aspects that a potentially new treatment should keep under control according to individuals with MS (% of respondents, n=97)

Conclusions & Future directions

MS poses a significant cost burden for the French society, with medication and indirect costs representing 88% of total average costs and substantial unmet needs being reported in the clinical management and social care currently received by MS patients in France.

❖ In the absence of long-term, real world data about the cost-effectiveness of receiving DMT earlier in the course of the disease, when to initiate treatment and which DMT to use are still to be determined.

References

1.Gustavsson A et al. Cost of disorders of the brain in Europe 2010. *Eur Neuropsycho- pharmacol* 2011; 21: 655–679.

2.Kingwell E. et al. Incidence and prevalence of multiple sclerosis in Europe: a systematic review. BMC Neurol. 2013;13(128):1471-2377.

3. Kobelt G. et al. The long-term cost of multiple sclerosis in France and potential changes with disease-modifying interventions. Mult Scler. 2009 Jun;15(6):741-51

4. Stavnitser A. et al. Impact of new oral therapies on multiple sclerosis cost and utilization trends. AJMP.com. Available: http://www.ajmc.com/publications/ajpb/20 13/ajpb_janfeb2013/impact-of-new-oral-th erapies-on-multiple-sclerosis-cost-and-u tilization-trends/2#sthash.ugsLgk21.dpuf. Accessed 10 July 2015.

5. Amato MP. Pharmacoeconomic considerations of multiple sclerosis therapy with the new disease-modifying agents.Expert Opin Pharmacother. 2004 Oct;5(10):2115-26.

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