French patients with MS and their caregivers have to financially support direct non-medical costs linked to their disease.

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BACKGROUND

Multiple Sclerosis (MS)
- Multiple Sclerosis (MS) is a chronic autoimmune degenerative disease of the central nervous system (CNS), which includes the brain and spinal cord.
- MS is characterized by inflammation leading to demyelination and axonal loss, hence decreases of functional neurons in the brain and spinal cord, and clinical signs and symptoms of MS. Early in the disease course, most patients suffer episodes of clinical exacerbation (remanents) characterized by neurological issues, followed by partial or complete recovery, as in the case of the relapsing-remitting MS (RRMS), the most common clinical form of MS.

Clinical impacts of MS
- Symptoms of MS may vary through a wide scope and they progressively lead to irreversible disabilities.
- Currently, available treatments do not cure the disease, though they prevent the occurrence of relapses in the relapsing-remitting form of MS (RRMS).

Social impacts of MS
- MS has a strong impact on the patient’s quality of life as well as on its caregivers.1,2
- In France, between 70,000 and 80,000 people are affected by MS.
- MS is the most common disabling neurological disease and first cause of non-traumatic cause of anos acquired handicap for young adults.
- MS-related medical costs, covered by the ADL status (‘Attestation de Longue Durée’) from the French national healthcare system, are free of charge for patients, but non-medical costs occur.
- The MS therapeutic landscape has dramatically evolved over the last 10 years.
- French Health Authorities have prioritized neurodegenerative disease patient care (national orientation “Plan national” for 2014-2019) with a special emphasis on the quality of life of patients and their caregivers.
- Over the last 10 years, several studies in different countries have demonstrated an overall cost of MS-related spending per patient.3-5

MS-related costs borne to patients
- Non-medical costs borne by patients are many, such as domestic help, babysitting since 2-3 newly diagnosed patients are women of childbearing age, homework, meal delivery, car and home fitting, etc.

RESULTS – PATIENTS

Objectives

1. To determine the demographic characteristics of MS patients.
2. To define the main financial aspects and the main financial impact of MS on patients’ lives.
3. To identify the number of patients with financial/material aid (and/or) support and the most frequent types of aid/suppor.

Patients profile (Fig. 2)
- 43% members of the Carenity community have filled the survey: 376 MS patients and 60 caregivers of MS patients.
- 77% of patients were women, and mean age was 48.5 years. 34% of patients lived alone.
- 23%, benefited from medical and/or non-medical help, and 33% from financial or material support.
- Nearly half of respondents had difficulties being autonomous for everyday occupation.

RESULTS – CAREGIVERS

Objectives

1. To determine the demographic characteristics of MS caregivers.
2. To define the main financial aspects and the main financial impact of MS on caregivers’ lives.
3. To identify the number of caregivers with financial/material aid (and/or) support and the most frequent types of aid/suppor.

Caregivers profile (Fig. 4)
- 11% of caregivers were mothers, mean age was 52.5 years, and 45% of them were men.
- In addition, 17% of caregivers benefited from financial aid for the patient they take care of.

METHODOLOGY

Web platform Carenity.com
- Carenity is an international online patient community devoted to people with chronic diseases. It exists since 2011, and allows patients and caregivers to share their experience as well as information, follow the course of their disease and contribute to medical research in various therapeutic areas, including MS, by generating real-world patient data through online surveys.
- Carenity performs studies for public and private healthcare stakeholders: healthcare professionals, scientists, patient advocacy groups and pharma companies.
- A scientific committee is also organized for each medical or scientific issue.

Survey
- The online survey submitted to Carenity’s members has previously been set up by Carenity and approved by the scientific committee consisting of a doctor, a patient advocacy group’s representative (LFSEP, ‘Ligue française contre la sclérose en plaques ’) and a health economist (IRDES).
- Members of Carenity’s MS community have been invited to answer the survey through invitations and reminders sent by email.
- Members of the LFSEP were also informed through the Facebook page of the patient advocacy group as well as invitations and reminders sent by email.

Inclusion criteria
- MS Patient or their adult caregiver registered on Carenity and living in France, including DOM-TOM (French islands and territories outside Europe).
- Age (mean 48.3 years)
- Among 37% of patients with financial/material aid

RESULTS

Figure 2. Patients’ demographic characteristics (n=376)

Figure 3. Financial impact of MS on patients (Fig. 3)
- Direct non-medical costs cover many domains, including domestic help, babysitting, homework help, meal delivery, car and home fitting, etc.
- Over the last 12 months, 20% of patients stayed in healthcare facilities, 16% of them had to pay for related fees, for part or all cost.
- Nearly one third of respondents benefited from domestic help. Among them, 71% had to cover at least part of the costs.
- 41% of patients bought a walking-aid device and 23% a manual wheelchair.
- 56% of patients financially supported at least one service (mean = 4, other and/or equipment).

Figure 4. Caregivers’ demographic characteristics (n=60)

Figure 5. Impact of non-medical costs on caregivers

Financial impact of MS on caregivers (Fig. 5)
- Over the last 12 months:
  - More than half of the caregivers whom relatives have been staying in a healthcare facility had to financially contribute to the charges, the main expense being transportation in 28% of cases.
  - About 40% of caregivers financially contributed to home services fees, especially car and house adaptation.
  - Overall, about 40% of caregivers financially supported at least one service (mean 1.3) to help a MS patient.

CONCLUSIONS

- MS has a strong financial impact on patients and their caregivers.
- MS require patients to adopt their home and/or car, as well as domestic help. Hence, direct non-medical costs have to be absorbed by patients and caregivers.
- These results indicate that, depending upon services, about 65% of patients and 45% of caregivers dedicate part of their financial resources to cover non-medical costs directly linked to MS.

REFERENCES
1. Site des associations de patients Unesap à Agen
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DISCLOSURES
- 6. Joli and Doli are Merck’s employees.

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