

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

B. van Hille<sup>1\*</sup>, O. Heinzle<sup>2</sup>, P. Dourgnon<sup>3</sup>, G. Molinier<sup>4</sup>, M. Chekroun<sup>5</sup>, J. Longin<sup>1</sup>,

<sup>1</sup> Direction des Affaires Médicales, Merck 37 rue Saint Romain, 69008 Lyon, France.; <sup>2</sup> Hôpital De Poissy, 10 Rue Du Champ Gaillard, 78300 Poissy; <sup>3</sup> IRDES, 10 rue Vauvenargues, 75018 Paris; <sup>4</sup> Ligue Française contre la Sclérose en Plaques, 40 rue Duranton, 75015 Paris; <sup>5</sup> Carenity, 18-20 Place de la Madeleine, 75008 Paris  
\*Corresponding author

## 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 decrease 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 (relapses) 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<sup>1</sup>.

### 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 recurrent-remitting form of MS (RRMS).

### Social impacts of MS

- MS has a strong impact on the patient's quality of life as well as his caregiver's<sup>1,2</sup>.
- In France, between 70,000 and 90,000 people are affected by MS.
- MS is the most common disabling neurological disease and first cause of non-traumatic cause of severe acquired handicap for young adults.
- MS-medical related costs, covered by the ALD status ("Affection 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 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 high cost of MS-related spending per patient<sup>3,4</sup>.

### MS-related costs borne to patients

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

## OBJECTIVES

- MS is a neurodegenerative disease with an ALD status in France, i.e., MS-related medical costs are 100% covered by the National Healthcare system. A study has been performed to measure the direct non-medical costs and impacts borne by MS patients and their caregivers.

## 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 patients insights through online surveys.
- CARENITY performs studies for private and public healthcare-related stakeholders: healthcare professionals, scientists, patient advocacy groups and pharma companies.
- A scientific committee is also organized for any ethical 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 clinician, 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 heightened 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).

### Duration of the Study

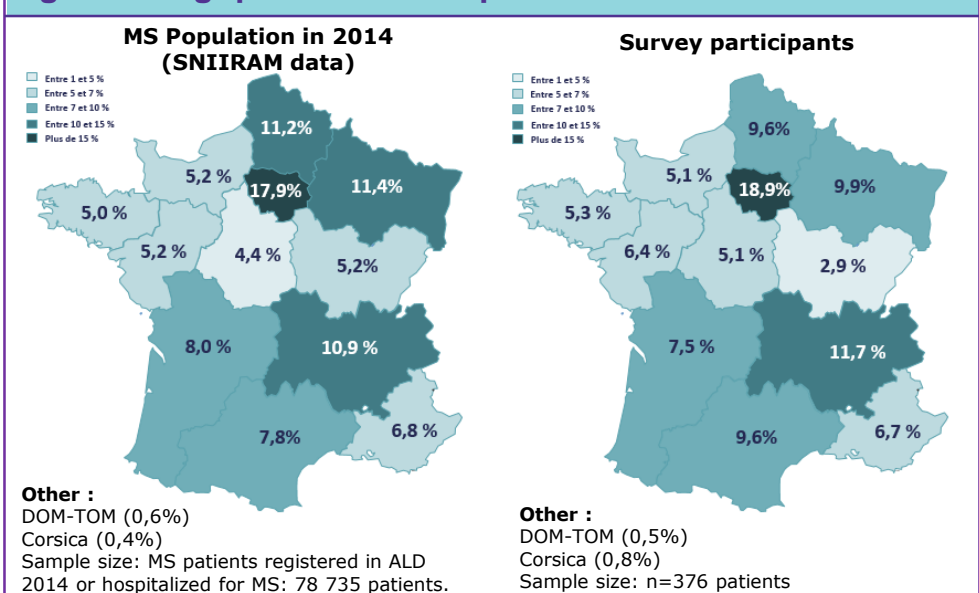
- The study was conducted from September to October 2016.

## RESULTS

### Characteristics of the respondents

- The geographic distribution of participating patients overlapped the distribution of the disease frequency in continental France (SNIIRAM<sup>5</sup> data, Patients SEP 2014), and about 50% of them had RRMS.
- \*SNIIRAM is the database of the French National Health Service.

Figure 2. Geographic distribution of patients



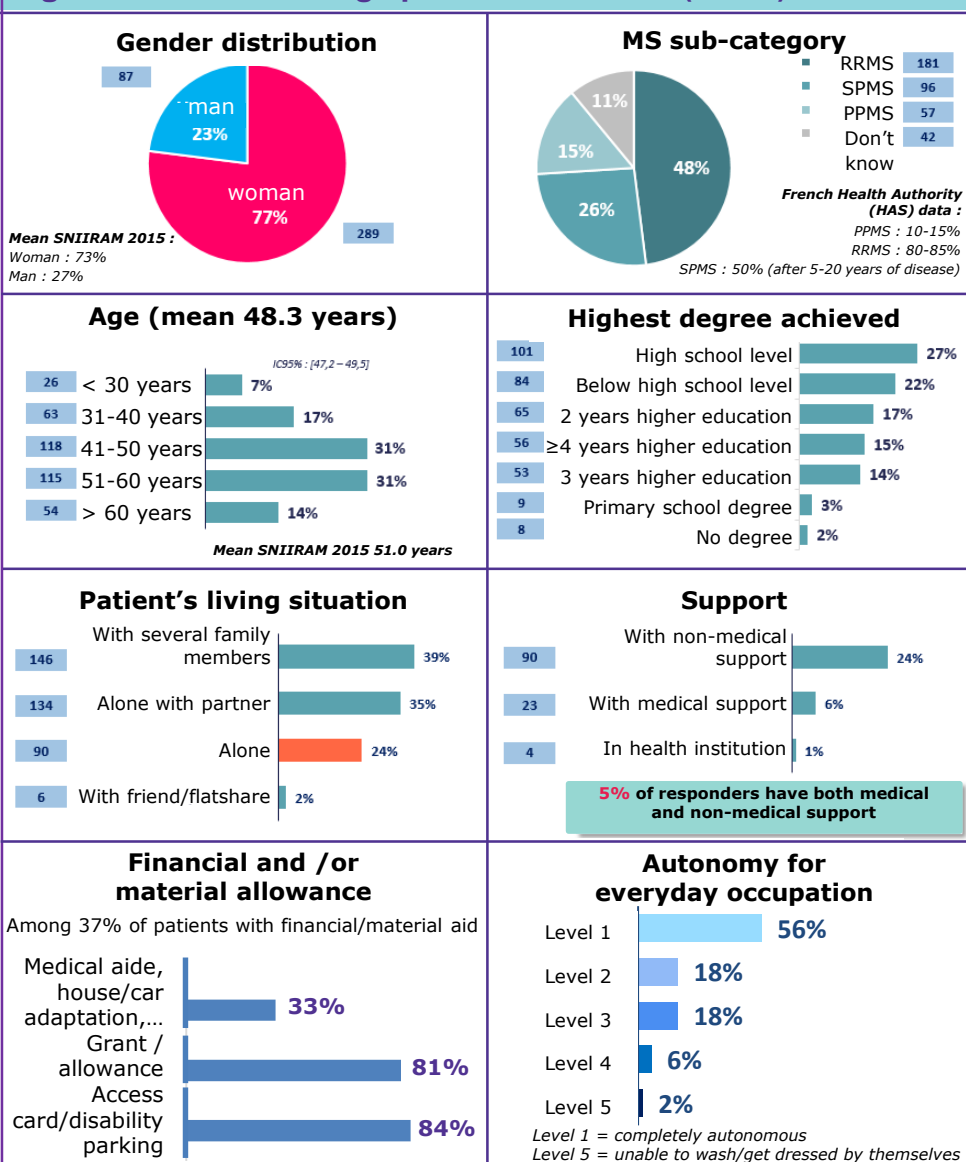
## RESULTS – PATIENTS

### Patients' profile (Fig. 2)

- 436 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 48.3 years. 24% of patients lived alone.
- 25% benefited from medical and /or non-medical help, and 37% from financial or material support.
- Nearly half of respondents had difficulties being autonomous for everyday occupation.

## RESULTS – PATIENTS

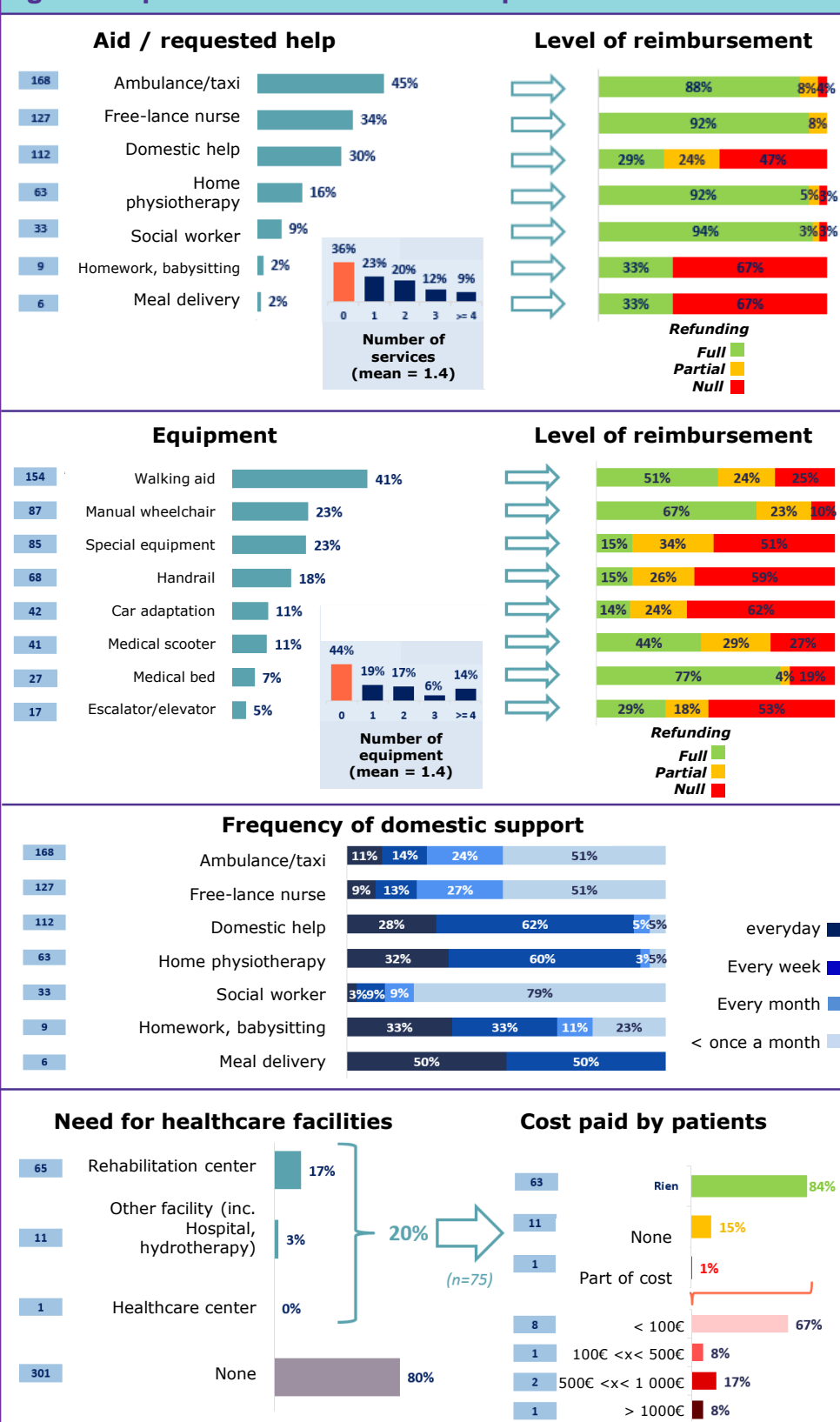
Figure 2. Patients' demographic characteristics (n=376)



### 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 of 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. Adaptation of vehicle and house with handrail are scarcely reimbursed.
  - Overall about 60% of patients financially supported at least one service (mean = 1,4), either aid and/or equipment.

Figure 3. Impact of non-medical costs on patients

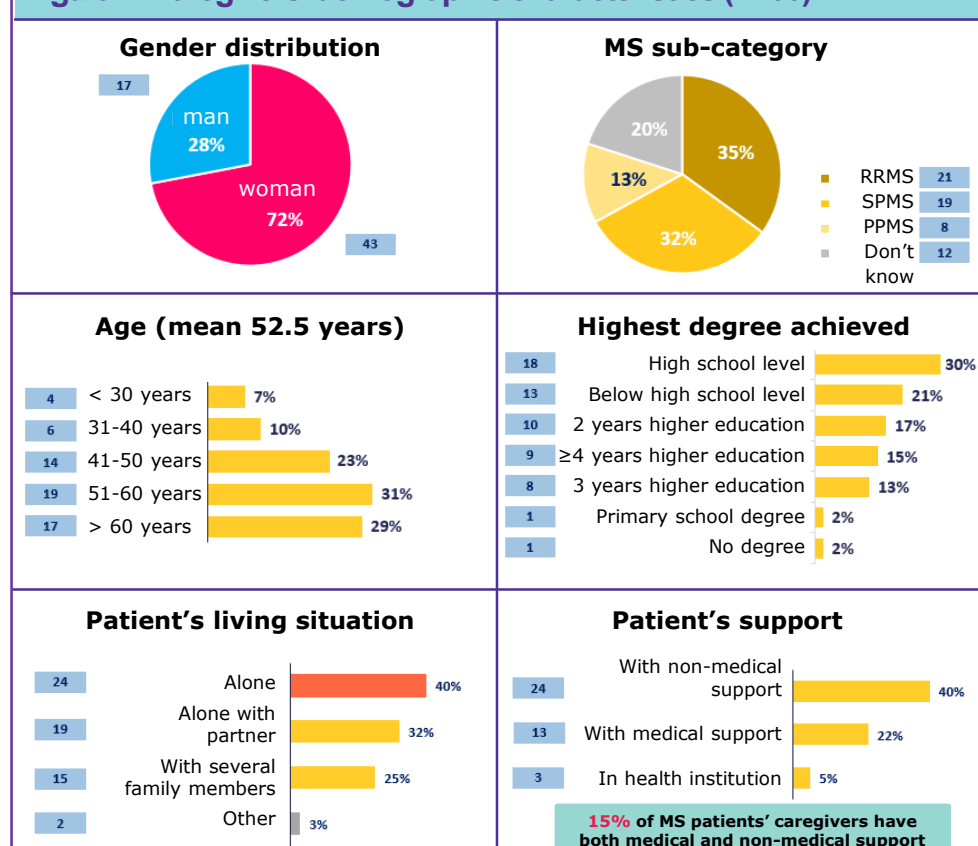


## RESULTS – CAREGIVERS

### Description of caregivers (Fig. 4)

- 72% of caregivers were women, mean age was 52,5 years, and 40% of them were MS patient's partner.
- In addition, 17% of caregivers benefited from financial aid for the patient they take care of.

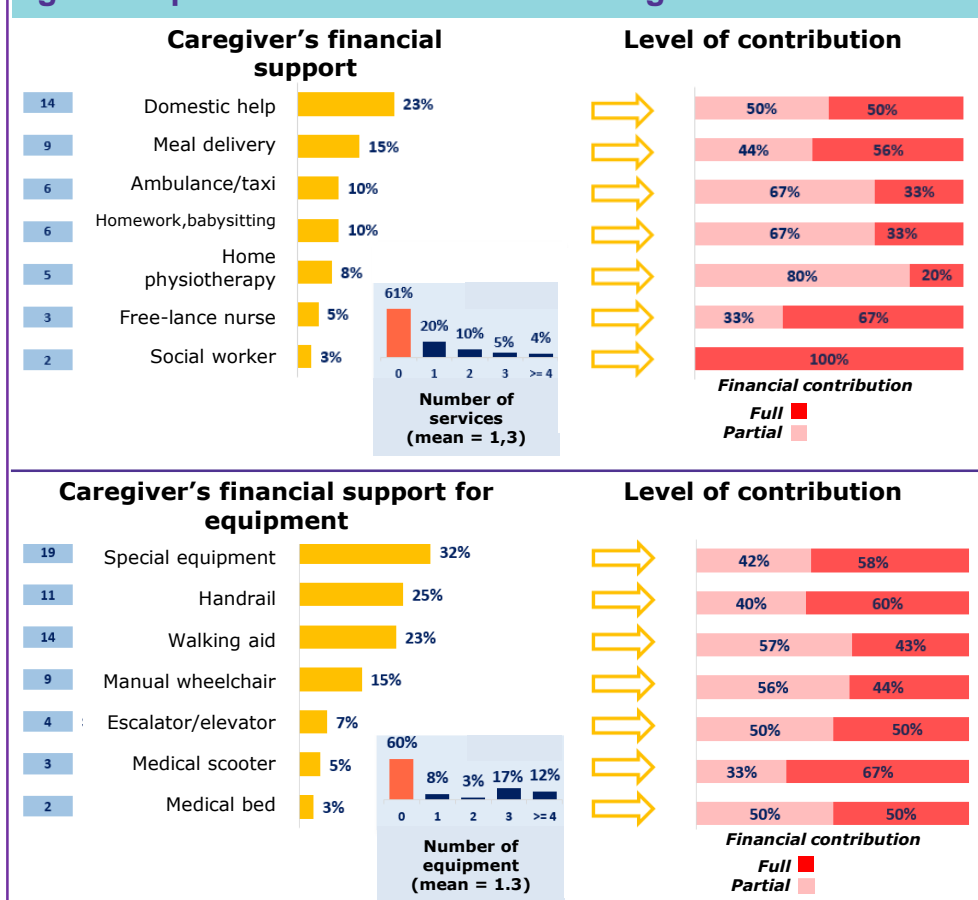
Figure 4. Caregivers' demographic characteristics (n=60)



### 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 38% of cases.
  - About 40% of caregivers financially contributed to home services fees, especially car and house adaptation.
  - Overall, about 40% of caretakers financially supported at least one service (mean 1,3) to help a MS patient.

Figure 5. Impact of non-medical costs on caregivers



## CONCLUSIONS

- MS has a strong financial impact on patients and their caregivers.
- MS requires patients to adapt 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 60% of patients and 40% of caregivers dedicate part of their financial resources to cover non-medical costs directly linked to MS.

## REFERENCES

- Site des associations de patients Unisep et Arsep
- www.social-sante.gouv.fr
- Murphy et al 1998
- Kobelt et al 2006

## DISCLOSURES

- JL and BvH are Merck's employees.



Copies of this poster obtained through QR (Quick Response) code are for personal use only. The use of this code for any other purpose is strictly prohibited.

GET POSTER PDF