The SURVIMUS study
A large multicenter study on long-term mortality of multiple sclerosis patients in France

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Background

• Survival in MS (registries and large databases, USA & EU)
  • Median time: 24 to 45 years after MS clinical onset
  • Standardised Mortality Ratio (SMR) ~ 2.5 to 3
  • Life expectancy reduced ~ 6 to 12 years

• Our experience in West France, 2004 (Leray et al., Mult Scler, 2007)
  • 1879 patients, followed up for 13 years after MS onset
  • Death rate: 2.8 per 1000 patients-years; SMR = 1.3 [1.0-1.7]
  • Limitations: short follow-up duration, selection bias?

→ Initiation of a large multicenter study: the SURVIMUS study
Objectives

The SURVIMUS study aimed to:

- Measure death rate and life expectancy in MS patients,
- Describe causes of death,
- Assess prognostic factors for MS mortality,
- Compare mortality in MS patients to that of the general French population, matched for age, sex, and calendar period,
- Assess for some geographic variations in MS mortality.
Study population

French EDMUS users

~ 33,000 MS patients

Inclusion criteria:

1. Definite diagnosis of MS (Poser, McDonald 2005)
2. MS clinical onset < 2009
3. Vital status known

End-of-study date: 1st January 2010
Study population

- EDMUS users
- SURVIMUS centers

Potential = 30,000
Methods

• Registration of deaths
  • Not exhaustive in EDMUS databases
  • Linkage to two national registers (vital status and causes of death), after ethics committee approval

• Statistical analysis
  • Death rates
  • Kaplan-Meier analysis
  • Comparison to the general French population using probabilities of dying from the life tables (sex, age, calendar year), SMR calculation (ratio observed/expected)
Flowchart of the study population

30,413 files in the 15 centres

29,517 MS patients

EXCLUSION:
- 778 MS onset > 2009
- 446 possible MS
- 5,922 unknown vital status

22,371 MS patients

21,159 alive patients

1,212 deaths

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• Characteristics of the 22,371 MS patients

  • Sex ratio F:M = 2.3
  • Mean age at MS onset: 31.9 ± 14.8 years
  • Mean follow-up duration from MS onset: 15.8 ± 10.3 years
    • Median 13.7 years; Range: from 6 months to 70 years
  • Phenotype at onset:
    • 85.6 % relapsing onset
    • 14.4 % progressive onset
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Up to 1\textsuperscript{st} January 2010: 354,111 patients-years (PY) of follow-up

1,212 deaths
5.4\% of MS patients
3.4 per 1,000 PY

Out of the 773 available death certificates:
401 MS-related deaths (51.9\%)

SMR ~1.5
Discussion

**Preliminary results**

- Large study (> ¼ MS cases)
- Characteristics comparable to most of MS populations
- Exhaustivity of deaths
- Mortality results close to those from West France...
- Selection bias?

**Perspectives**

- Decrease the exclusion rate (20% patients with unknown vital status... missing data/mistakes...)
- How to precisely estimate the number of expected deaths?
- Which risk factors for death? Demographic, clinical, DMDs...
- What is an MS-related death?
Thanks for your attention