

Social impact of MS – the family burden

Bucharest, 25 May 2016

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MS in brief

- In Europe, MS is the leading cause of non-traumatic neurological disability in young adults
- Average age of onset of first symptoms of the disease is 29 years
- Commonly occurring symptoms include
 - Depression and anxiety
 - Mobility problems
 - Reduced hand and fine finger control
 - Unclear speech
 - Urinary and faecal incontinence
 - Cognitive impairment
- MS (patients) is estimated to cause 387,000 disability-adjusted life years in Europe



Towards better outcomes in multiple sclerosis by addressing policy change

The **I**nternational **M**ulti**P**LE
Sclerosis **S**tudy (**IMP**RESS)

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Download the full report here:

<http://www.lse.ac.uk/LSEHealthAndSocialCare/research/LSEHealth/MTRG/IMPRESS-Report-March-2016.pdf>

Purpose of study

- Provide the evidence for, and discuss, the merits of potential changes in how MS is managed:
 - Use of better (and more accurate) diagnostic follow up to monitor disease progression
 - Earlier use of disease modifying treatments to achieve better outcomes for individuals
- Assess the socio-economic and personal impact of such a policy change compared to the current status

Methodology

- Observational study of adults with MS (self-reported disease severity) and their caregivers through anonymous online surveys
- Questionnaires available in English, French, German, Greek, Italian, Swedish and Romanian
- Data captured on:
 - Direct medical costs (medication costs, visits, hospitalisation)
 - Direct non-medical costs (help from caregivers)
 - Indirect costs (productivity loss)
 - PWMS and their caregiver HRQoL (EQ-5D-5L)
 - Aspects of the health status that are valued by PWMS
 - Disability (Barthel-Index)
 - Satisfaction with the treatment received
 - Burden among caregivers
 - Societal, HRQoL and economic impact of MS management

EQ-5D-5L (Euroquol)

- EQ-5D is a standardised instrument for use as a measure of health outcome
- 5 domains, 5 levels per domain
 - Mobility
 - Self-care
 - Usual activities
 - Pain/discomfort
 - Anxiety/depression
- EQ-5D is used as the basis of cost/QALY calculations
- Sample is the general population

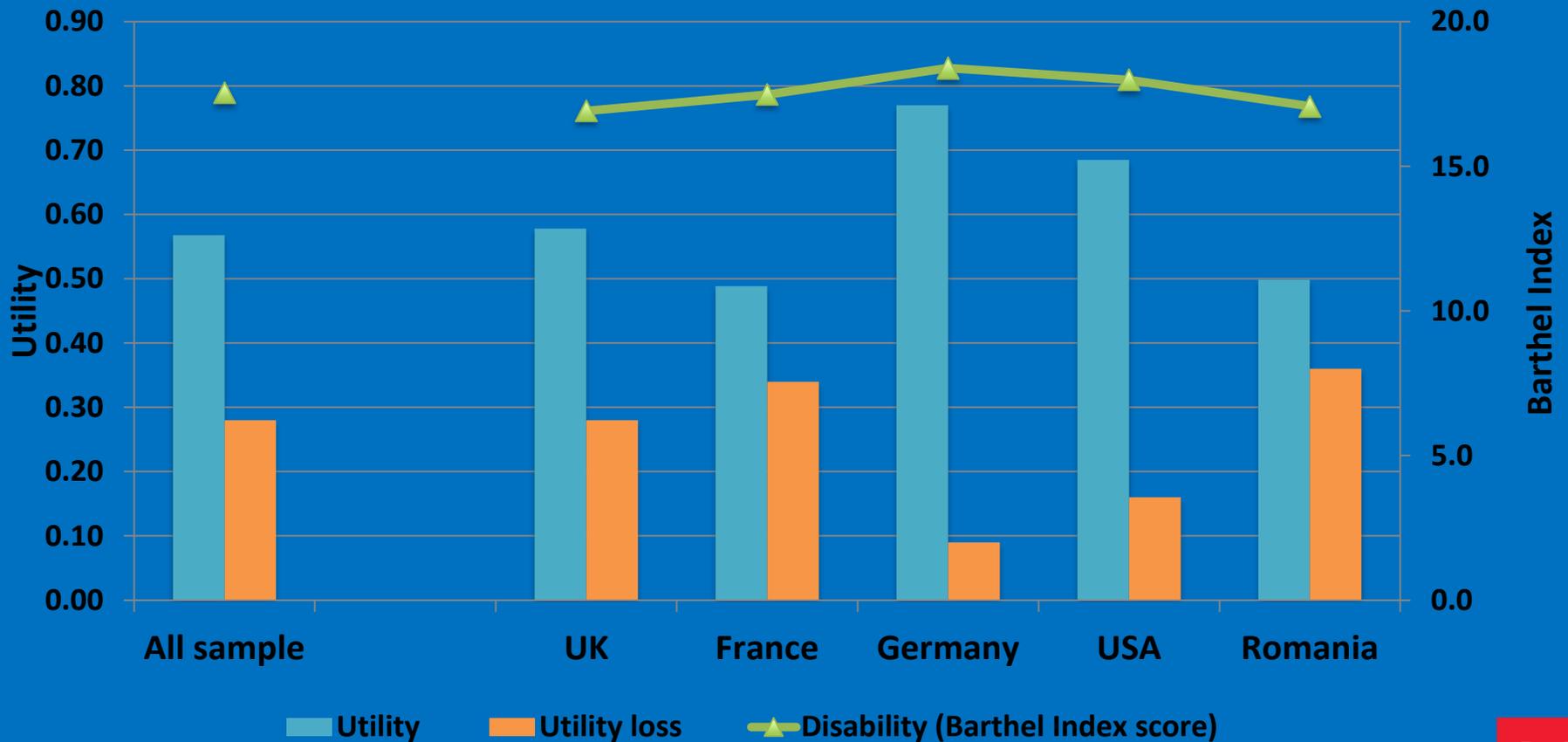
Example 5 levels: Mobility characteristics

- I have no problems in walking about
- I have slight problems in walking about
- I have moderate problems in walking about
- I have severe problems in walking about
- I am unable to walk about

Assessment

- EQ-5D-5L
- Two supplementary questions asked
 - Are there any aspects of your illness which have had a big impact on your health that were not covered in the questionnaire?
 - If yes, please tell us what they were
 - Have the aspects of your illness which have had a big impact on your health changed over the course of your illness?
 - If yes, please tell us what those changes were

Quality of life of people with MS



Data from the study

Factors affecting access to MS specific treatments	UK	France	Germany	Romania
Received early diagnosis	56%	53%	24%	61%
Availability of MS specific neurologists	64%	70%	90%	64%
% of treatment reimbursed by NHS	92%	95%	92%	81%
Use of DMTs among treatment eligible PWMS (affordability)	56%	53%	70%	41%

DMT – disease modifying treatments

Country rankings for access to MS treatment

UK	France	Germany	Romania	Source
3	2	1	4	Primary data from this study
4	2	1	3	Wilsdon T. <i>et al</i>
3	1	2	4	Kobelt G. and Kasteng F.

Health status: Aspects identified as having a big impact by PWMS

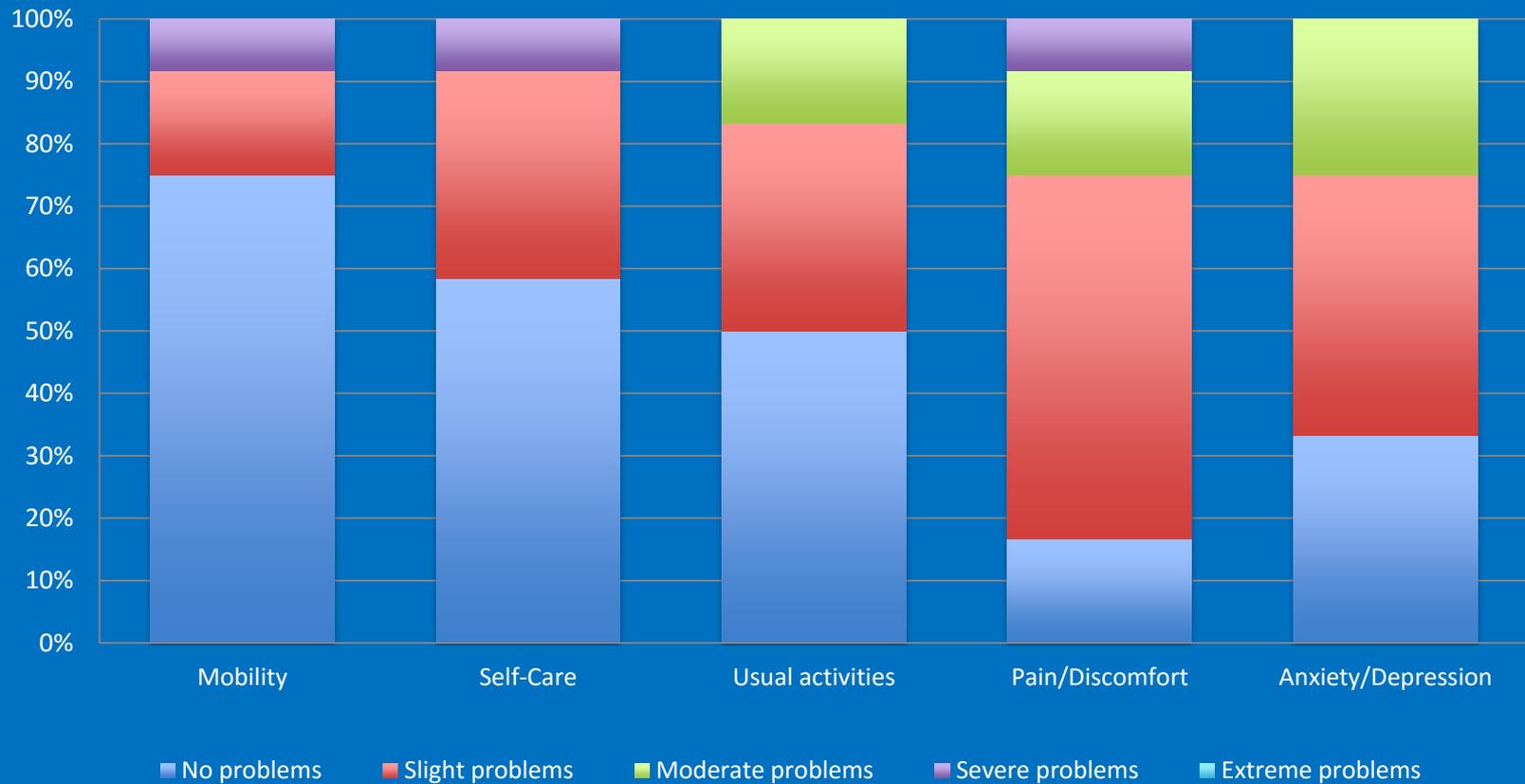
Fatigue and weakness	54%
Mobility	54%
Balance problems and dizziness	49%
Usual activities	48%
Pain/discomfort	42%
Bladder problems	38%

Caregivers

Respondents

- 67% female
- Average age 51 years
- About 75% of individuals were the spouse of a person with MS, and cared for a person with MS for an average of 8 years
- About 67% of respondents were employed
- For about 50% of caregivers in employment, caring for the person with MS meant some work-related problem in the previous 12 months

Caregiver quality of life using EQ-5D-5L



'Intangible' costs for caregivers

- The average time spent by a non-professional caregiver in caring for a person with MS was 22.4 hours per week
 - A recent UK study found that caregivers of cancer patients spent 17.5 hours per week caring
- Respondents reported an average utility of 0.70 (utility loss of 0.15 compared with the general population)
- The majority of the caregivers felt no (83%) or mild burden (17%) because of their status as a caregiver
- Caregiver costs related to productivity losses are about €31,000, almost double those reported by PWMS (€16,000)
 - Limited healthcare services available to PWMS, usually lead to a greater use of informal care
 - Caregiver cost element is generally not reimbursed by health care systems, impacting both family income and caregiver quality of life
- Caregivers reported better quality of life compared with PWMS (70% vs. 60% of perfect health)

Caregivers' comments

- My own physical and mental health issues and caring for my son
- I am also sick (ankylosing spondylitis)
- Being aware of my own health: I know I need to be in the best of health to care for her for the rest of her life
- Aching knees –they don't think about the fact his wife has MS, rather put it down to ageing
- Worsened arthritis in ankle that was broken 12 years ago
- Importance of self care and encouraging independence in wife with MS

Report recommendations

There is an urgent need to achieve better outcomes for PWMS

The evidence suggests that this is possible if policy makers address the following issues.

- **Diagnosis, treatment and management goals should be set to provide the best health outcome for every person with MS**
- **(Further) robust evidence should be generated and used in order to make appropriate decisions about care management in MS strategies**
- **Improve the responsiveness of health care systems to new evidence on MS**

Conclusion

- MS is an illness with a major impact on the wider family, not just the person with MS
 - Impact on caregiver is financial as well as health-related
- Impact of limited access to effective treatment is poorer outcome for person with MS
 - Increased burden on caregiver
- Health related quality of life of the caregiver should be taken into account when considering the cost-effectiveness of treatment
- There is an urgent need to implement policy change to improve outcomes in MS for the person with the illness and the wider family

Thanks to:

- All who completed the questionnaires
- European Multiple Sclerosis Platform, MS Society UK, MS Trust UK, National Multiple Sclerosis Society, the Romanian Association of Multiple Sclerosis, the Rocky Mountain Multiple Sclerosis Center and Foundation ARSEP (French MS Research Society) who facilitated data collection.
- **Rozalina Lapadatu**, Alessandra Ferrario, Elena Nicod and Olivier Wouters for translating the questionnaires.
- Birgit Bauer and **Rozalina Lapadatu** for additional insights and support in the development of the questionnaires and facilitating their distribution to respondents.
- F. Hoffmann-La Roche provided the sponsorship that allowed the LSE to carry out this research.

If you would like to participate in the survey, please contact:

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Or use link direct to survey

Patients

https://lse.qualtrics.com/SE/?SID=SV_9ohAaqS8pmUk4IZ

Caregivers

https://lse.qualtrics.com/SE/?SID=SV_1R1uRyVjktBp9s1

Physicians

https://lse.qualtrics.com/SE/?SID=SV_6EWjsORqDZa92o5

- The Barthel Index (BI) consists of 10 items that measure a person's daily functioning, particularly the activities of daily living and mobility. Response options range from 0 (severely dependent) to 20 (independent).
- The Zarit Burden Interview, a popular caregiver self-report measure used by many aging agencies, originated as a 29-item questionnaire (Zarit, Reever & Bach-Peterson, 1980). The revised version contains 22 items. Each item on the interview is a statement which the caregiver is asked to endorse using a 5-point scale. Response options range from 0 (Never) to 4 (Nearly Always).