



Social economic costs, quality of life and experience in multiple sclerosis patients and their caregivers: the IMPRESS survey

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The International Multiple Sclerosis Study (IMPRESS)

Background & Objectives

Multiple-sclerosis (MS) is the most common cause of disability among central-nervous-system (CNS) diseases. The available data provide limited information on the impact and burden of MS as experienced by people living with MS (PwMS)/caregivers. If decisions on MS management and treatment availability are to reflect patient needs, international evidence to capture the full picture of the multiple domains of MS burden is needed.

The objectives of this study were to assess and compare the costs, health-related-quality-of-life (HRQoL), and experience reported by people living with MS/caregivers across international settings.

Methods

Information from patients/caregivers were collected through an anonymous online survey. Participation was open to adult MS/caregivers. The study was available in fifteen countries in Europe and overseas. Individuals were enrolled through MS-societies and clinics. The survey captured data on direct and indirect costs, patients' and caregivers' HRQoL (EuroQol-5D), patients' disability (Barthel-Index), burden among caregivers (Zarit-Burden-Interview), participants' experience, as well as demographic variables, and disease information. The societal, HRQoL and economic impact of MS management were evaluated across countries.

Results

PwMS - Responses received from 1005 individuals, 736 completed and used for analysis: France 16.3%; Spain 15.6%; USA 13.6%; Poland 11.8%; Greece 10.1%; Romania 8.2%; England 5.6%; Australia 4.1%; Croatia 3.9%; Italy 3.1%; others less than 3% (Sweden, Portugal, Slovenia, Canada, Serbia, the Netherlands, Switzerland, Germany).

• Access to healthcare resources (for examples see figures 1 and 2) and utilities (see figure 3) for PwMS varied across healthcare systems and types of MS. They did not vary according to early disease modifying therapy (within 12 months of a single neurological attack with MRI enhancing lesions) or late (after 12 months; data not shown).

• The average utility value reported was 0.6 (60% of perfect health), with a loss of 25% compared with the general population.

• **Caregivers - Responses received from 450 individuals, 122 completed and used for analysis:** Spain 23.8%; Romania 18%; USA 13.1%; Greece 10.7%; Poland 7.4%; England 6.6%; Germany 5.7%; France 4.1%; Italy 3.3%; others less than 3% (Croatia, Australia, Sweden, Serbia).

• Caregivers reported better utility compared with PwMS (78% vs. 60% of perfect health; see figure 4). Both PwMS and caregivers reported a mild level of disability (14.4, Barthel score) and discomfort (16.3, Zarit score) respectively. Their experience of MS care varied across country settings.

Conclusions

MS results in a significant socioeconomic impact as experienced both by PwMS and their caregivers. Further data collection will strengthen available evidence across country settings and inform the development of future services.

More on the research

LSE Towards better outcomes in multiple sclerosis by addressing policy change

The International Multiple Sclerosis Study (IMPRESS)

The full report is available here: <http://www.lse.ac.uk/LSEHealthAndSocialCare/research/LSEHealth/MTRG/IMPRESS-Report-March-2016.pdf>



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Figure 1: Healthcare visits and hospitalisations (mean, last year)

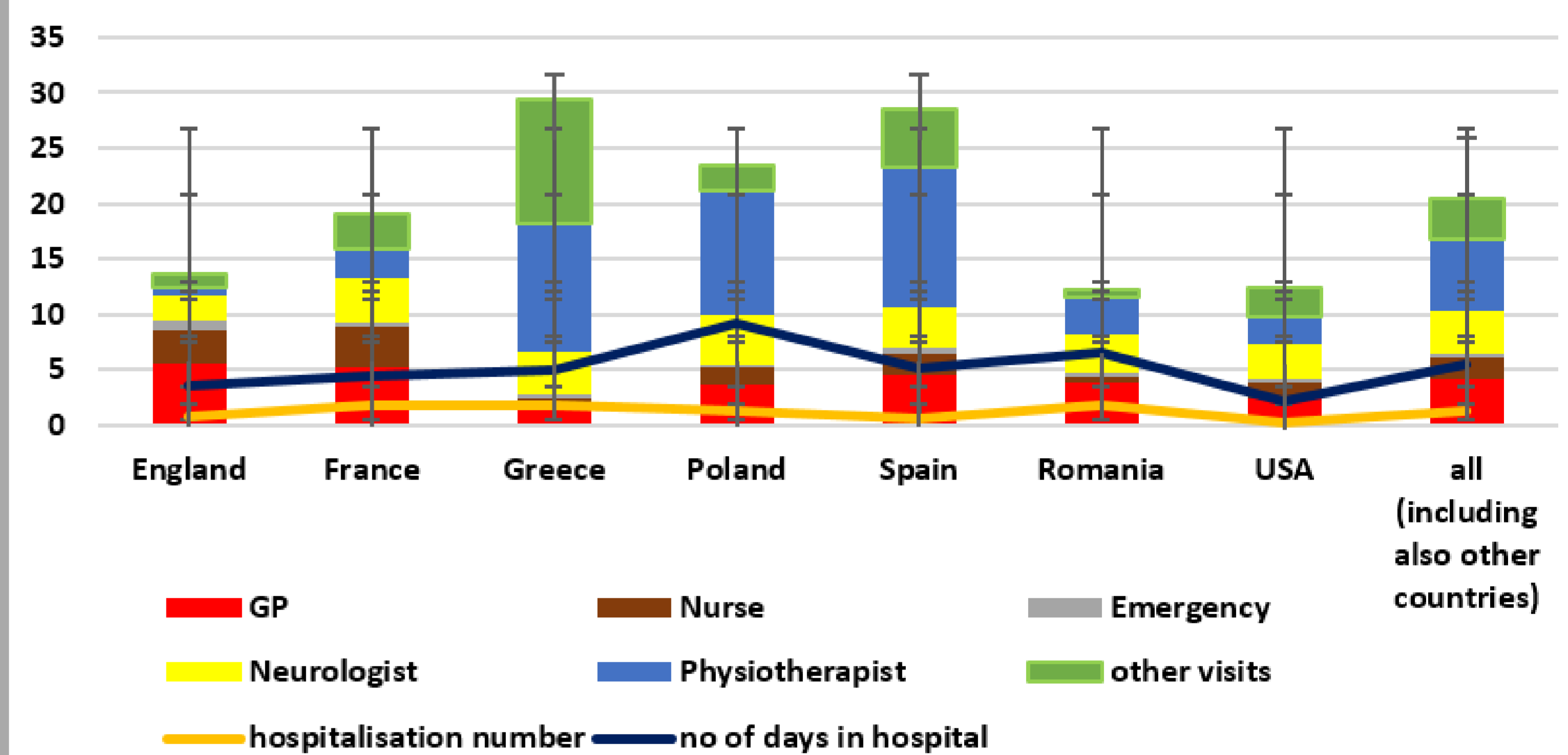


Figure 2: Access to informal care

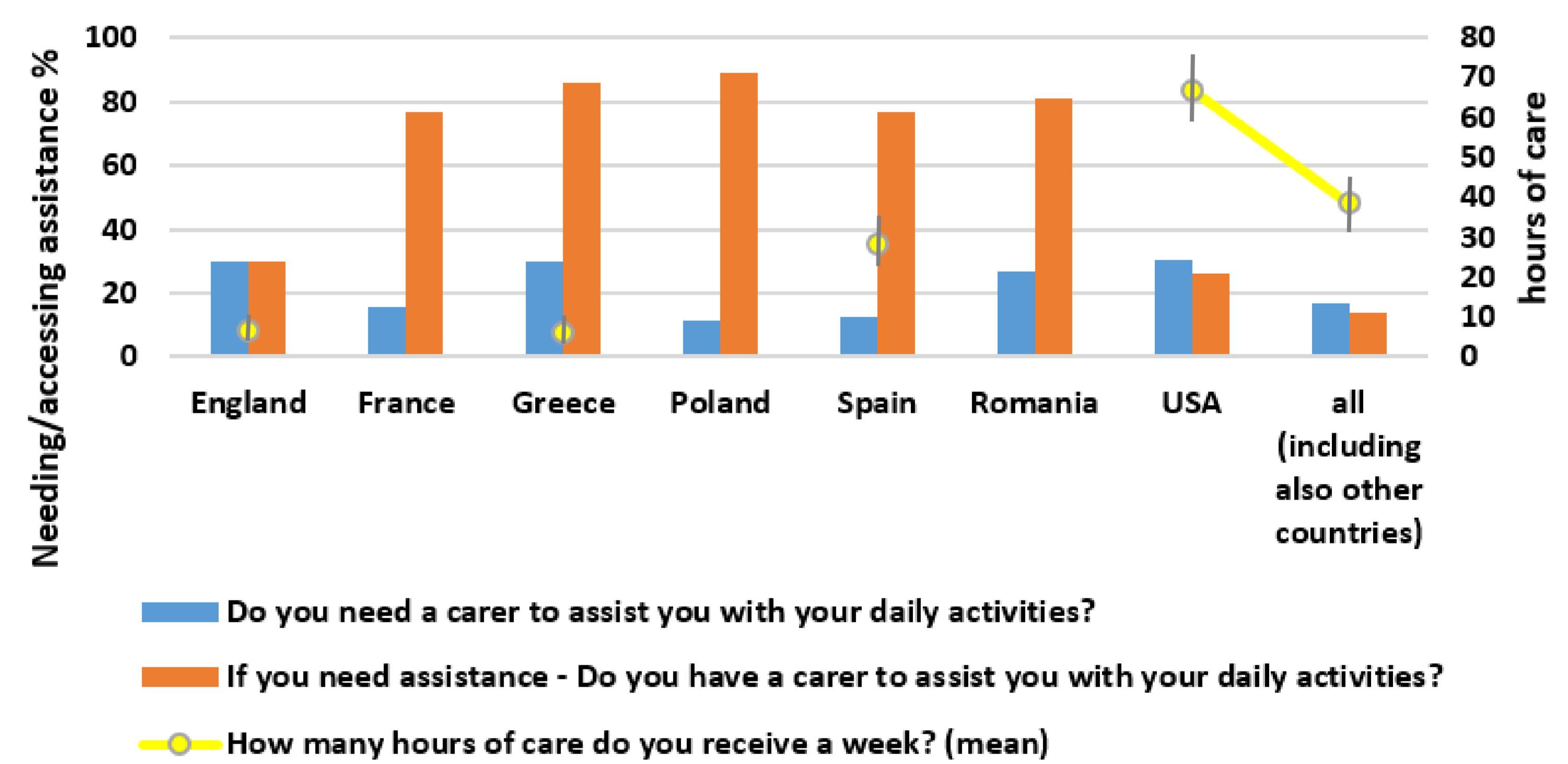


Figure 3: EQ5D5L, satisfaction and disability (Barthel score)

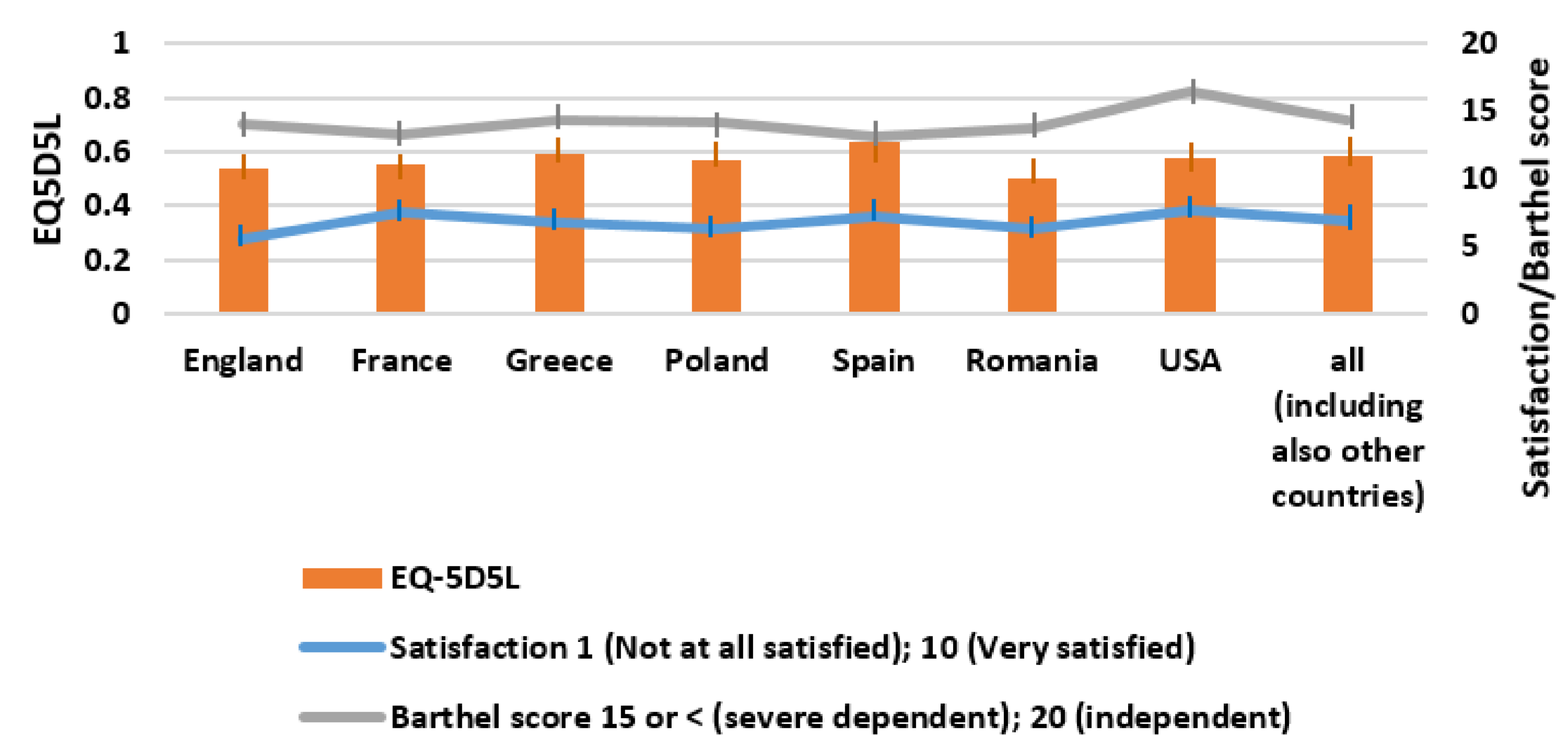
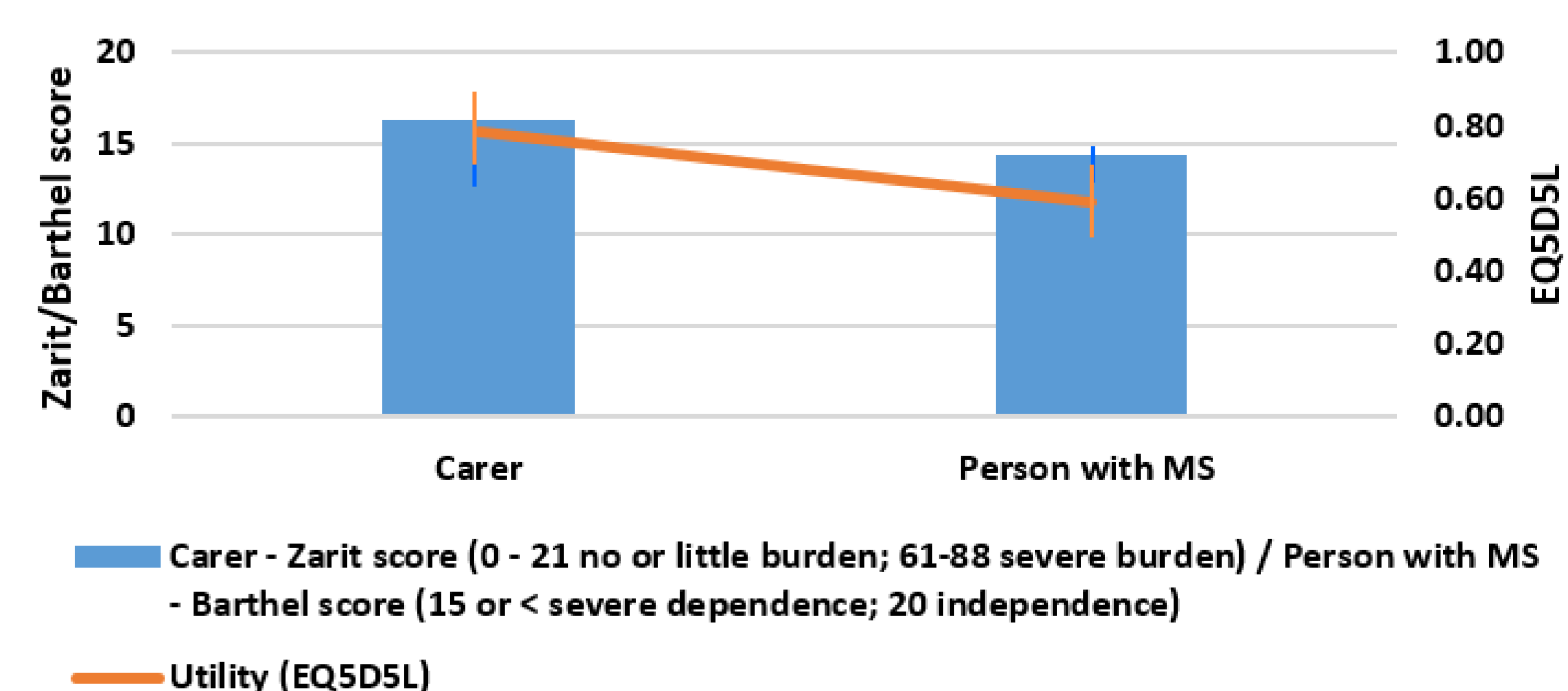


Figure 4: How you feel/disease severity and EQ5D5L



Do you want to take part?

The Research team is inviting all people with MS, caregivers and clinicians to contribute. The surveys for PwMS/caregivers are available in the languages below: Croatian, Dutch, English, Estonian, French, German, Greek, Italian, Polish, Portuguese, Russian, Slovenian, Spanish, Swedish. All surveys (PwMS, caregivers and clinicians) can be accessed from here: <http://www.emsp.org/news-messages/impres-study/>