

Editorial

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The series of European cost of illness studies presented in this volume aims at updating the information on the average annual cost for patients with multiple sclerosis (MS) at different stages of the disease. The number of participating countries has been increased compared to earlier studies, making it the largest study ever carried out. A summary of the studies has been published earlier this year.¹

A total of 16,808 patients in 16 countries was included and data were collected directly from patients. This allowed the inclusion of all relevant costs (health care and health services, workforce participation, out of pocket expenses and family help), as well as disease-related information and health-related quality of life (HRQoL). Such complete information is currently not available in any dataset or registry. The ambition of this study was to illustrate how costs and HRQoL change as the disability increases rather than total costs of MS in a country. All results are presented by disease severity. This provides important information as treatment in MS aims at slowing this worsening and thus reducing costs in the long term.

It is striking to notice a number of similarities and differences in these European countries. While MS affects people in very much the same way across the continent (Figure 1), its management differs considerably Figure 2.¹ Reasons for this may be found in differences in economic wealth, availability of services, clinical approaches and beliefs, and national characteristics. They cannot be explained by differences in the samples. Even a mean age difference of 20 years and a mean disability difference of 2.6 EDSS points in the samples cannot explain a ten-fold difference in inpatient and day case admissions; a range from 60-90% of patients with consultations in a quarter or a range of 25-81% of patients who see a neurologist; a difference of 5-35% in the proportions of patients who get an MRI or a range of 26-80% who are on treatment with DMTs. Highlighting these facts will hopefully lead to questions being raised and subsequently addressed.

For the first time in such a large survey, patients have been asked to assess the level of fatigue, extent of cognitive difficulties and the effect of MS while working. In view of the large number of participants, the results are very powerful. The overwhelming presence of fatigue, while known, may have been underestimated in the past. Irrespective of the country, 95% of patients felt fatigue was an issue, with a mean level of 5-6 on a scale from 0 to 10, regardless of the severity of the disease. Similarly, cognitive difficulties were recognized by over 70% of patients,

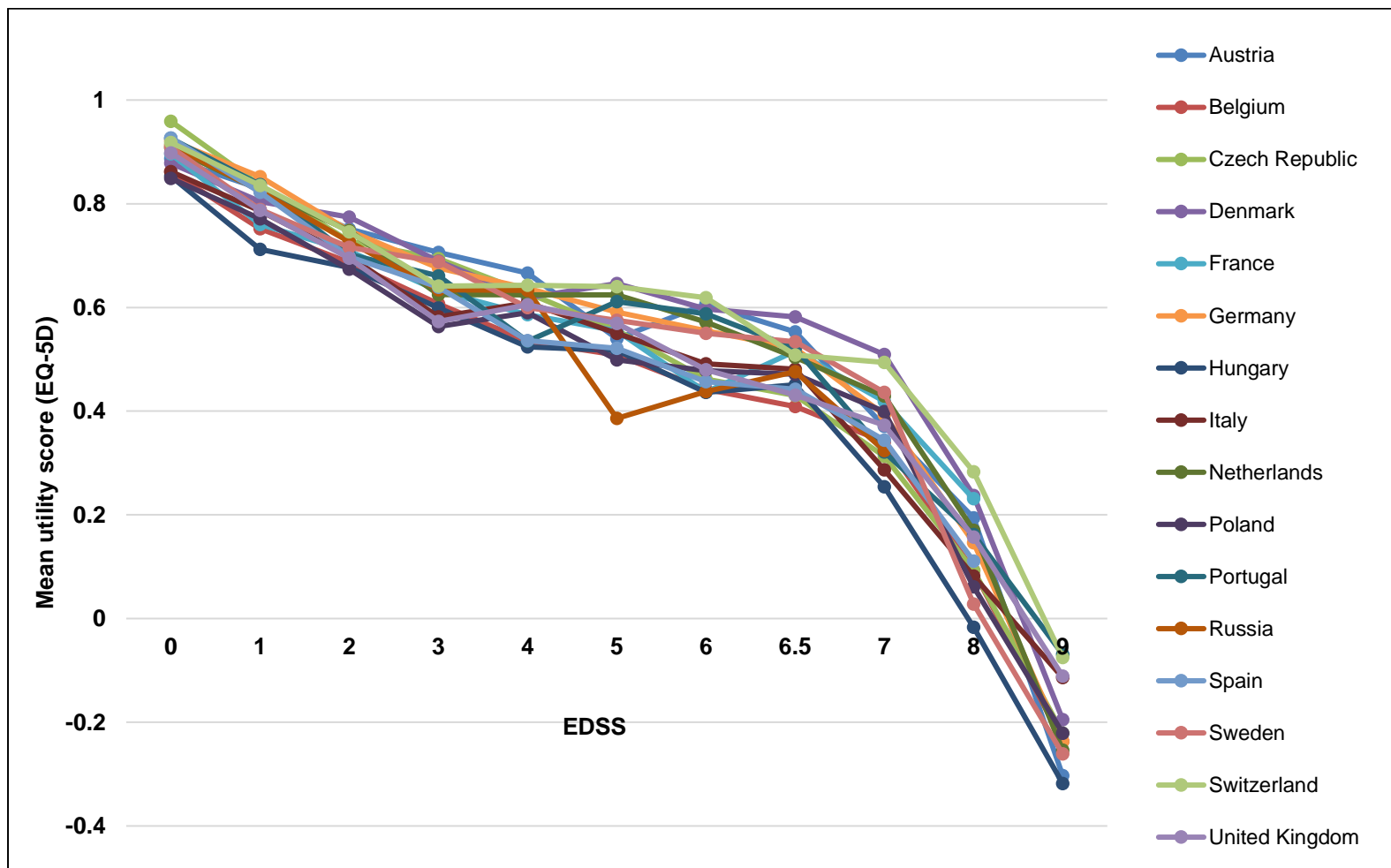
with a severity of 4-5, again irrespective of disability and country. Finally, anxiety appears to be present at the same levels in all countries and at all stages of the disease. These findings argue for more focus on and more effective management of these aspects of the condition.

The data in this study series provide a wealth of information on the current situation in MS provided by a large number of patients. They are important for clinicians, health technology assessment agencies, policy makers and, not least, for patient organisations who, in this case, are also the owners of the data. The large amount of patient-level data should trigger more research activity in a number of areas, including into the determinants of costs. Overall it is hoped that they will contribute to adopting a more effective approach to management which will result in better outcomes for patients.

Reference

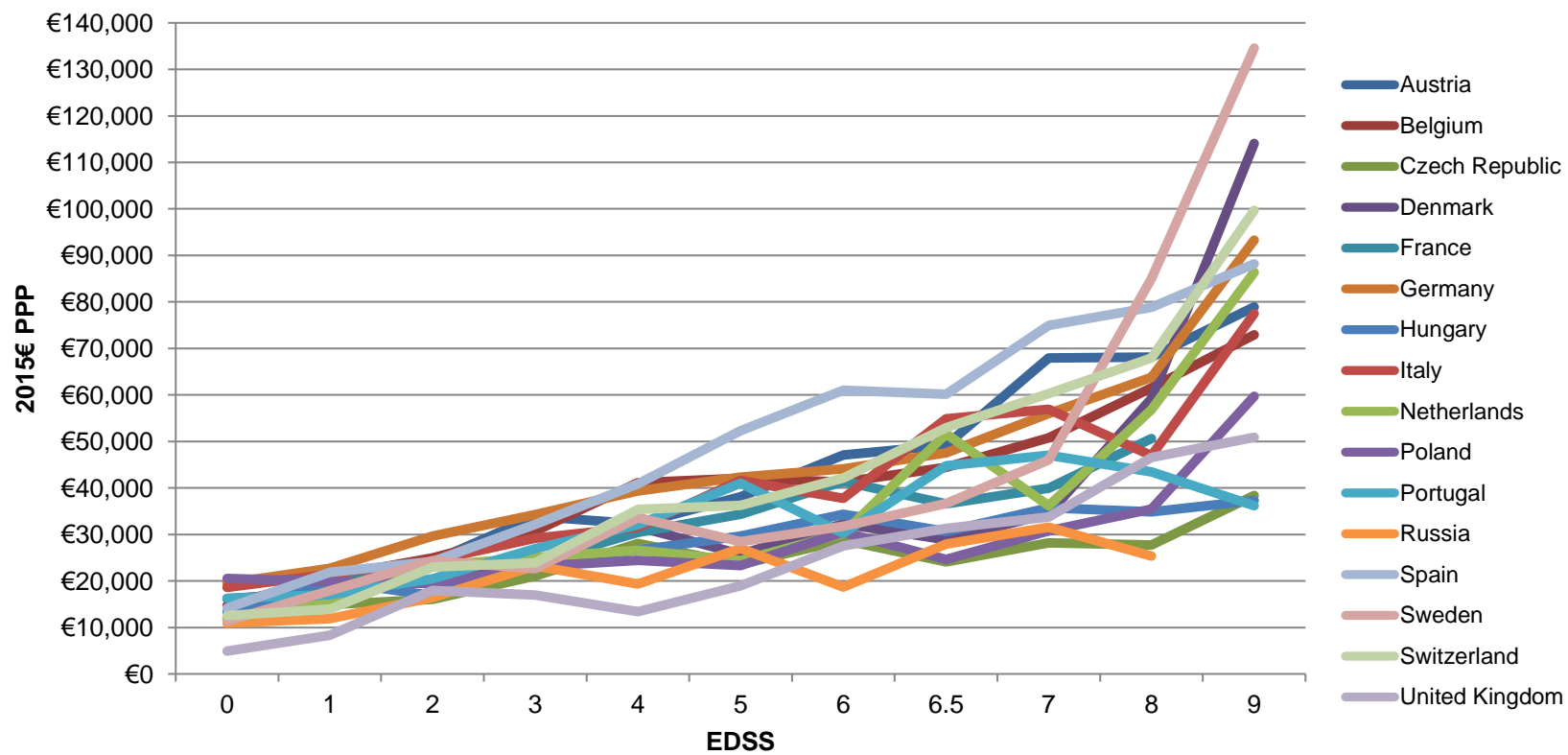
Kobelt G, Thompson A, Berg J, et al. New insights into the burden and costs of multiple sclerosis in Europe. *Mult Scler*. 2017: 1352458517694432.

Figure 1 – Utility scores related to EDSS levels in 16 countries



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Figure 2 – Mean annual cost per patient related to EDSS levels in 16 countries



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