Comparing all countries.

Data not collected. Data on edaravone use in the UK, Germany, France, Italy, and Spain were not collected because edaravone is not approved in these countries for this indication.

METHODS

• Data were drawn from the Adelphi ALS Disease Specific Programme® (DSP), a multinational, cross-sectional survey of neurologists and people under their care in the USA, UK, Germany, France, and Italy.

• Data were collected between October 2021 and March 2022. The DSP methodology details were previously published.6

• Briefly, neurologists completed questionnaires regarding demographic, disease milestones, and clinical outcomes, including ALS Functional Rating Scale-Revised (ALSFRS-R) scores and symptom duration, for people with ALS under their care.

• Disease milestones were defined as key events occurring during the disease course, encompassing aspects of disease progression and functional loss in ALS.

• For each country, we evaluated the mean time from symptom onset to a milestone in months to the following milestones: first consultation for ALS-related symptoms, ALS diagnosis, employment change, and need for a walking aid, caregiver support, wheelchair, communication aid, respiratory aid, gastrostomy, eye-gaze technology, and care facility.

• Each analysis included only patients reaching the respective milestone.

• Disease progression rate was calculated (Δ 49 – ALSFRS-R score / symptom duration in months) for each person with ALS and the mean presented for each country. Based on this dataset, disease progression rate (in points/month) was divided into tertiles of slow (50.36), intermediate (50.77), and fast (50.77).

• Patient characteristics and time to key milestones were compared across the 6 countries using ANOVA, chi-square, or Fisher’s exact test (P<0.05 considered significant).

RESULTS

• This analysis included 867 people with ALS (mean age 61.3 years; 63% were male).

• On average, people with ALS in the USA were younger and had a shorter time since symptom onset compared with those in Europe (Table 1). Approximately one-third of people with ALS in the USA were on riluzole alone compared with over two-thirds in the UK, Germany, France, Italy, and Spain.

• The time from symptom onset to most adult milestones was on average, shortest in the USA and longest for those in Italy (Figure 1).

• For the USA, UK, Germany, France, and Italy, respectively:

  – Mean (95% CI) time from symptom onset to ALS diagnosis was 7.4 (5.7–9.0), 8.8 (7.2–10.3), 8.3 (6.9–9.6), 10.4 (8.5–12.4), and 11.0 (7.6–14.5) months (P=0.0001).

• The proportions of slow, intermediate, and fast progressors were significantly different between countries: the USA had the highest proportion of fast progressors, and Spain had the lowest proportion of slow progressors (Table 3).

• Time from symptom onset to key disease milestones by country

Table 2. Time from symptom onset to key disease milestones by country

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>USA</th>
<th>UK</th>
<th>Germany</th>
<th>France</th>
<th>Spain</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean (SD), years</td>
<td>59.9 (10.4)</td>
<td>63.0 (10.8)</td>
<td>60.1 (9.7)</td>
<td>65.1 (10.0)</td>
<td>62.1 (11.7)</td>
</tr>
<tr>
<td>Male, n (%)</td>
<td>223 (85.5)</td>
<td>52 (89.4)</td>
<td>40 (81.0)</td>
<td>70 (81.4)</td>
<td>65 (94.6)</td>
</tr>
</tbody>
</table>
| Clinical milestones reflected disease progression and functional loss in people with ALS and occur at specific points in the disease course, with each milestone, medical costs increase substantially. 1,4

LIMITATIONS

• Data from the survey are cross-sectional, with limited information about individual patient journeys or disease history.

• Participation was affected by the willingness to complete the survey and may not reflect a random sample of neurologists or people with ALS.

CONCLUSIONS

• This analysis of real-world data showed that, irrespective of country of residence, people with ALS quickly reached various disease milestones, demonstrating rapid disease progression.

• Variation in time to reach specific milestones was observed across countries, with the time from symptom onset to key disease milestones tending to be shortest for people with ALS in the USA and longest for those in Italy.

• The variation may in part reflect differences in the healthcare systems of the participating countries, in addition to variation in rate of disease progression observed in this study among people with ALS from different countries.

REFERENCES


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