Introduction

The prevalence of nontuberculous mycobacterial pulmonary disease (NTM-PD) has been increasing in Europe, but, comprehensive analyses and reliable estimates on treatment practices are lacking. We developed methods to assess annual prevalence, and used nationally representative chart audits to evaluate treatment practices in 5 European countries (EUS): United Kingdom (UK), France, Germany, Italy, and Spain.

Methods

I. Prevalence estimation:\(^3\) NTMPD patients diagnosed annually was estimated by a 2-round Delphi method independently by 6 experts, that included anonymous feed-back of the 1st round groups estimates. The panel was asked:

1. To estimate the annual NTM-PD prevalence rate for each of the five countries and the most likely annual prevalence range.
2. To provide comments/rationale for each estimate.

II. Patient data extraction: A representative sample of physicians extracted treatment information from reports of NTMPD patients with a confirmed diagnosis of Mycobacterium avium complex (MAC) or M. abscessus pulmonary disease.

- Phase 1: Survey to determine distribution of physicians that diagnose and treat NTMPD patients by specialty (11 questions)
- Phase 2: Questionnaire related to treatment of NTMPD patients (33 questions with several subquestions)

Results

Table 1: Consensus estimates of annual NTMPD prevalence rate using a 2-round Delphi methodology (\(\ast\)see Methods).

<table>
<thead>
<tr>
<th>Country Region</th>
<th>France</th>
<th>Germany</th>
<th>Italy</th>
<th>Spain</th>
<th>United Kingdom</th>
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<th>France</th>
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<th>Spain</th>
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</thead>
<tbody>
<tr>
<td>Annual NTMPD Prevalence (Pop/100,000)</td>
<td>6.0</td>
<td>6.5</td>
<td>6.1</td>
<td>5.0</td>
<td>6.5</td>
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<tr>
<td>Estimated Number of NTMPD patients</td>
<td>187</td>
<td>239</td>
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<td>Total</td>
<td>4,380</td>
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</table>

Conclusion

Annual prevalence of NTM-PD is estimated to be uniform on a per capita basis in EUS, but heterogeneous within different regions.

- Reliable epidemiological data are missing.
- A surveillance system is urgently needed not only to confirm these data, but to monitor treatment outcome and to plan prospective treatment trials.
- 2/3 of NTMPD patients already have moderate or severe NTM-PD at diagnosis. The percentage of patients treated varies widely by country and severity.
- NTMPD patients need to be diagnosed early in the course of the disease. Physicians need to be better educated about risk factors and screening indications.

Critical gaps in appropriate treatment practices need to be addressed in the future; it may be advisable to refer NTM-PD patients to specialized physicians, who preferably are able to include these in prospective clinical trials.

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