Diagnosis Patterns in Patients With Systemic Mastocytosis in Europe and United Kingdom

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Introduction

Systemic mastocytosis (SM) is a rare, clonal mast cell disease primarily driven by the KIT D816V mutation and characterized by unpredictable and debilitating skin, gastrointestinal, and systemic symptoms1. Previous, a United States (US)-based survey study (Touchstone) reported insights from health care professionals (HCPs) treating SM patients in the US, responses from 119 HCPs revealed that SM diagnosis in the US is challenging and often delayed, involving a variety of specialists, notably allergists/immunologists and hematologists/medical oncologists1.

There is limited insight regarding HCP profiles and their perceptions on the diagnosis and management of SM patients in Europe and the United Kingdom (UK).

The Perceptions Realities and Insights on Systemic Mastocytosis (PRISM) survey study seeks to examine the experiences of SM advanced and non-advanced [eg, indolent] patients, as well as get perspectives from HCPs treating SM in 7 countries in Europe (advanced and non-advanced [eg, indolent]) patients, as well as get perspectives from HCPs treating SM in 7 countries in Europe. Here, we report interim data from PRISM from HCPs in Germany, UK, and Austria and their perspectives on the impact of SM on patients.

Methods

- This interim data set from PRISM HCP responders in Germany, the UK, and Austria showed that a variety of healthcare specialties diagnose and manage SM patients due to the heterogeneous nature of the disease.
- HCPs perceive SM to have a considerable negative impact on patients' QoL and employment opportunities.
- Improving QoL and survival were the primary treatment goals of HCPs for SM patients.
- Do patients lose employment opportunities because of SM?

Results

- A total of 236 HCP responses were collected as part of the PRISM survey from Germany, the UK, and Austria.
- HCP respondents were primarily hematologists/oncologists (n=123) and general practitioners (n=111) (Table 1) with the largest number of HCP respondents from Germany (n=123) (Table 1).
- The number of SM patients seen by provider type varied across countries (Figure 1): a variety of healthcare specialties diagnose and manage SM patients, likely due to the heterogeneous nature of the disease.
- SM patients' life quality (QoL) and employment opportunities, with 68.2% (n=203) reporting SM affected patients' lives “quite a bit” or “a great deal”; 59% (n=175) reported patients lost employment opportunities due to SM (Figure 3). Across all countries, HCPs reported their top primary goals for treatment were focused on better QoL, and improved survival (Figure 4).

PRISM HCP Responses

Table 1. HCP Demographics and Office Setting

<table>
<thead>
<tr>
<th>Specialty</th>
<th>All (n=296)</th>
<th>Germany (n=123)</th>
<th>UK (n=110)</th>
<th>Austria (n=63)</th>
</tr>
</thead>
<tbody>
<tr>
<td>General Practitioner</td>
<td>87 (29.4)</td>
<td>33 (26.8)</td>
<td>41 (37.2)</td>
<td>13 (20.6)</td>
</tr>
<tr>
<td>Hematologist/Oncologist</td>
<td>87 (29.4)</td>
<td>31 (25.2)</td>
<td>42 (38.2)</td>
<td>14 (22.2)</td>
</tr>
<tr>
<td>Dermatologist</td>
<td>35 (11.6)</td>
<td>17 (13.8)</td>
<td>9 (8.2)</td>
<td>9 (14.3)</td>
</tr>
<tr>
<td>Allergist/Immunologist</td>
<td>28 (9.5)</td>
<td>8 (6.5)</td>
<td>11 (10.0)</td>
<td>3 (4.8)</td>
</tr>
<tr>
<td>Gastroenterologist</td>
<td>23 (7.9)</td>
<td>5 (4.1)</td>
<td>17 (15.4)</td>
<td>1 (1.6)</td>
</tr>
<tr>
<td>Internist</td>
<td>18 (6.1)</td>
<td>5 (4.1)</td>
<td>6 (5.5)</td>
<td>7 (11.1)</td>
</tr>
<tr>
<td>Other</td>
<td>10 (3.4)</td>
<td>3 (2.4)</td>
<td>6 (5.5)</td>
<td>1 (1.6)</td>
</tr>
</tbody>
</table>

Figure 1. Mean Number of Patients With SM Seen by HCP Type Across Countries

Figure 2. HCP-Perceived Time From Patient Non-Advanced SM Symptom Onset to Diagnosis by HCP Type Across Countries

Figure 3. Most HCPs Perceive SM to Have a Large Impact on Patient’s Lives and Employment Opportunities

Figure 4. HCPs Report Their Primary Goals for Treatment Are to Improve Quality of Life (QoL) and Survival

Conclusions

This interim data set from PRISM HCP responders in Germany, the UK, and Austria showed that:

- A variety of healthcare specialties diagnose and manage SM patients due to the heterogeneous nature of the disease.
- HCP perception of time to diagnosis varied by specialty but overall was considerably shorter than that reported by SM patients in a previous US-based survey (Touchstone).
- HCPs perceive SM to have a considerable negative impact on patients' QoL and ability to work.
- Improving QoL and survival were the primary treatment goals of HCPs for their patients.

References

1. Patients with SM: 2021. Available at: https://www.patientadvocacysg.org/patients-with-sm/
2. PRISM survey 2021. Available at: https://www.patientadvocacysg.org/prism-survey-2021/

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Disclosures

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