Neuroendocrine Tumor (NET) European (EU) Patient Experience: Results From the First Global NET Patient Survey—A Collaboration Between the International Neuroendocrine Cancer Alliance (INCA) and Novartis

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BACKGROUND

- Patients with NETs experience a unique spectrum of symptoms and a reduced quality of life (QoL).
- A recent comparative analysis of 125 patients with NETs in the USA demonstrated significantly lower health-related QoL (HRQoL) in patients with NETs versus the general population.
- Despite the considerable impact NETs have on patients: daily lives, the journey for patients with NETs has only recently been published; only a few small qualitative studies have been published in this area.

OBJECTIVE

- To raise awareness of the NETs’ impact and share patient perspectives on NETs, medical treatments, and educational needs.

METHODS

- From February through May 2016, patients with NETs participated in a 25-minute anonymous questionnaire that explored patients’ experience of disease in terms of physical, psychological, social, and emotional aspects of life. The questionnaire was translated into 14 languages and distributed through 1139 organizations in 114 countries.
- The survey was conducted online, allowing respondents to complete it according to their own pace and convenience. The survey was also promoted through social media and word of mouth.

RESULTS

- A total of 1025 patients with NETs were included from >12 countries in the Americas, Asia, and Europe. The majority of respondents were from USA (50.2%) and Italy (17.9%).

Figure 1. Countries participating in the global NET patient survey.

Figure 2. Time since diagnosis.

Figure 3. State of tumor at time of diagnosis.

Figure 4. Impact of NETs on Patients’ Daily Lives.

Figure 5. Patient knowledge regarding NETs.

Figure 6. ICP understanding of how NETs affect patients’ lives.

Figure 7. Lifestyle and Work-Related Changes Following a NET Diagnosis.

Figure 8. Patients who had to stop working as a direct result of NETs.

Figure 9. Improvements in the Quality of Life of Patients With NETs.

Table 1. Functional States and Grade of NETs.

<table>
<thead>
<tr>
<th>Functional States of NETs</th>
<th>Grade of NETs</th>
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<tbody>
<tr>
<td>QoL (G1)</td>
<td>64%</td>
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<tr>
<td>QoL (G2)</td>
<td>26%</td>
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<tr>
<td>QoL (G3)</td>
<td>9%</td>
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| QoL (G4) | 1%

Lifestyle and Work-Related Changes Following a NET Diagnosis

- Lifestyle-related changes included dietary modifications (62%) and increased travel (59%) or related spending (61%).
- Patients with NETs (84%) were more likely than those with LC (80%) or MCNET (80%) to consider their dietary changes in the following months.
- Work-related changes included not being able to stop working for a period of time (18%), not being able to work full-time in the same job (16%), and changes in working hours (10%).
- Many patients (16%) had to stop working as a direct result of their NET (Table 1).

Figure 8. Patients who had to stop working as a direct result of NETs.

LIMITATIONS

- This global NET patient survey had several important limitations that might have affected results: Patient recall bias: Patients’ memories were not verified. Standardized, validated QoL assessments were not used. Biased data: The survey was completed primarily through healthcare professionals (50%) and online sources (30%). The sample might have been non-representative of the global NET population.

CONCLUSIONS

- Results from this large global survey demonstrated that NETs have a major impact on patients’ lives, affecting various aspects of their daily lives and work. Patients experience significant changes in QoL and need additional support, education, and assistance.

REFERENCES