Neuroendocrine tumors (NETs) are a diverse group of malignancies that arise from neuroendocrine cells throughout the body. Symptoms of NETs may be nonspecific or absent and may evolve over time.

- Malignant NETs: Tumors that produce symptoms caused by the secretion of hormones, eg, somatostatin, glucagon.
- Neuroblastoma: Malignant neuroendocrine tumor below the age of 18.

**BACKGROUND**

**Presented at the European Neuroendocrine Tumor Society (ENETS) 12th Annual Conference; 11-13 March 2015; Barcelona, Spain**

**Base population: All respondents (N = 1928).**

- Most patients (65%) had a caregiver (close family member or friend) who helped them.

**AIMS**

- To assess the patient perspective on NET management and interactions with HCPs.

**METHODS**

From February through May 2014, patients with NETs participated in a 25-minute anonymous global survey that captured the NET patient experience, including perceived benefits of an MDT care approach.

- With the exception of certain demographic information, survey questions were close-ended; participants were provided options from which to choose.

- Patients were divided into two sets: respondents at NET specialist centers (n = 180; 65% female; mean age 56.6 years) and non–specialist centers (n = 1748; 63% female; mean age 55.9 years).

- Data were analyzed at global, regional, and country levels; here, we present results from global data.

- Statistical differences between comparisons were significant at the 95% confidence level.

**RESULTS**

**Demographics**

- A total of 1386 NET patients with NETs were recruited from 124 countries in the Americas, Asia, Europe, and Oceania (Figure 1).

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

**Figure 2. NET specialist center visits. A. Patients who have been to a NET specialist center at least once.**

**Figure 3. HCPs involved in the NET medical team.**

**Figure 4. Tests received for ongoing management of NETs.**

**Figure 5. Topics discussed with NET medical providers.**

**Figure 6. View on relationship with NET medical providers.**

**Figure 7. NET treatment availability.**

**Figure 8. View on NET medical care.**

**Patient views regarding NETs**

- Patients who visited NET specialist centers had more positive feelings regarding NETs than non-specialist center visitors.

**Medical treatments**

- Patients visiting NET specialist centers were more likely than non-specialist center visitors to rate the quality of their NET-related treatments as satisfactory (89 vs 79% on 40 vs 30%).

**LIMITATIONS**

- The NET patient survey has several limitations that may have impacted results.

**REFERENCES**


**ACKNOWLEDGMENTS**

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**Figure 9. Patient feelings regarding NET medical management.**

**Figure 10. Improvements patients believed would help them live better with NETs.**

**CONCLUSIONS**

- The first large, global survey of patients with NETs demonstrated the benefits of an MDT approach to improving physician practices and patient and caregiver interaction and relationships.

- Despite improvements seen with NET care at NET specialist centers, the survey also highlighted significant unmet needs in the management of NETs.

- 40% of patients visiting NET specialist centers did not feel their HCPs worked as a multidisciplinary team.

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- 40% of patients visiting NET specialist centers did not feel their HCPs worked as a multidisciplinary team.

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- While patients typically traveled significantly greater distances to visit NET specialist centers, they were also more likely to be open about their NETs than non–specialist center visitors, including with close friends, relatives, and co-workers/acquaintances.

- A better coordinated/aligned team of NET medical providers differentiated visits to NET specialist centers from visits to non–specialist centers.

- A patient-reported design was employed without independent verification, leading to potential recall bias.

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