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

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BACKGROUND

- Neuroendocrine tumors (NETs) are new neoplasms arising from neuroendocrine cells throughout the body.
- Despite a continuously increasing incidence, NETs remain poorly understood among the general public and in the medical community.
- Only a few small (<10) qualitative studies on the NET patient experience have been published.

RESULTS

- The chronic nature and the unpredictable disease course of NETs challenge the coping mechanisms of patients and caregivers.
- Studies in Europe and the United States have shown health-care-related quality of life scores to be significantly lower in patients with NETs compared with the general population.
- In particular, NET-related symptoms, including diarrhea and flushing, were associated with reduced quality of life.

AICN is a network of 17 independent charitable organizations and patient groups from 14 countries around the world. Novartis Pharmaceuticals Corporation collaborated with AICN on an extensive global survey to gather data about the NET patient experience from multiple countries, with the goal of:

- Capturing individual patient experiences of living with NETs in order to understand the ongoing impact of the NET journey and the needs of patients with NETs.
- Highlighting differences and similarities between countries and regions to help improve NET awareness and care.

AIM

To raise awareness of the burden of NETs on patients’ daily lives by tumor location.

METHODS

- From February through May 2014, patients with NET were participated in a 25-minute anonymous online survey that captured the NET patient experience, including disease burden by NET type.
- With the exception of certain demographic information, survey questions were closed-end, participants were provided options to choose from.
- Patients were recruited via use of flyers, Web site posts, e-mails, and social media channels of the INCA member organizations/patient advocacy groups.
- Extensive use of online social media sources through local/regional advocacy groups allowed recruitment of a large number of patients with this rare type of cancer.
- The survey was conducted primarily online and was available in 14 languages: Bulgarian, Dutch, English, French, German, Japanese, Norwegian, and simplified Chinese.
- Paper surveys were developed in several languages and distributed by patient groups and health-care providers (PCPs) towards patients without internet access.
- 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 (p < 0.05) or for elements within the test, statistically significant differences within figures are indicated by *p < 0.05.

This survey was conducted as an equal collaboration between INCA and Novartis, and worked with Novartis’ Hall & Partners, a research organization, formed and analyzed the results.

REFERENCES


CONCLUSIONS

- The first large global NET patient survey demonstrated the considerable impact NETs have on patients’ quality of life and work-related activities, and identified select differences among tumor types.
- Patients experience a wide spectrum of NET-related symptoms and conditions, many of which occurred on a daily or weekly basis.
- NETs have a considerable impact on patients’ personal and work lives.
- Patients with NETs were more likely to report experiencing a large/moderate negative impact on daily life than patients with lung NETs.
- Patients with GI-NETs or pNETs more often made dietary changes than those with lung NETs.
- More patients with GI-NETs or pNETs reported having to stop working due to NETs than patients with lung NETs.
- This survey identified several improvements to enhance the care of patients living with NETs, including increased access to NET-specific medical treatments and learning.

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LIMITATIONS

- This global NET patient survey had several important limitations that may have impacted results.
- A patient-reported design was employed without independent verification, leading to potential recall bias.
- This survey did not obtain standardized, validated quality-of-life assessments.
- Recruitment was conducted primarily through patient advocacy groups (31%) and online sources (31%), which may have resulted in a potentially biased sample not fully representative of the heterogeneous NET patient population.
- Respondents were more likely to be highly engaged and motivated cancer seekers, including female patients and those with a poorer prognosis.

IMPACT OF NETs ON PATIENTS’ LIVES

- Patients with GI-NETs (73%) were significantly more likely than those with lung NETs (50%) or pNETs (59%) to report experiencing a large/moderate negative impact on daily life.
- Patients reported experiencing a wide spectrum of symptoms (29) related to NET location, many of which occurred on a daily or weekly basis.
- Diarrhea was reported more often with GI-NETs (60%) than pNETs (37%) or lung NETs (25%).
- Other NET-related symptoms occurred more often with GI-NETs (40%) than pNETs (32%) or lung NETs (25%).
- Patients associated various conditions as a result of their NETs, mostly GI-NETs, with a similar incidence across tumor types.

Figure 2. NET-related symptoms reported by patients.

Figure 3. Frequency of NET-related symptoms reported by patients.

Figure 4. Conditions occurring as a result of NETs.

Figure 5. Impact of NETs on patients’ daily life and work.

Figure 6. Impact of NETs on patients’ work.

Figure 7. Improvements patients believed would help them live better with NETs.