Survey of Challenges in Access to Diagnostics and Treatment for Neuroendocrine Tumor (NET) Patients (SCAN) – Early Diagnosis and Treatment Availability

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INTRODUCTION

• Neuroendocrine tumors (NETs) are rare and complex neoplasms with increasing incidence and prevalence worldwide.1

OBJECTIVE

• SCAN assessed global provision of NET diagnostics and treatment in terms of:
  - Awareness
  - Quality of servicing
  - Availability
  - Affordability

• This analysis focused on early diagnosis and availability of diagnostic and treatment tools in gastroenteropancreatic (GEP) NET patients.

METHODS

• During Sept-Nov 2019, NET patients and healthcare professionals (HCP) completed an online survey
• The survey was disseminated via social media and NET patient groups’ and medical societies’ networks.
• The survey was available in 14 languages: Arabic, Bulgarian, English, German, Dutch/Flemish, French, Japanese, Hindi, Italian, Mandarin (Chinese), Portuguese, Russian, Spanish, and Swahili.

PARTICIPANT CHARACTERISTICS

• There were 1670 GEP-NET patients (female 61% [1012/1670]) from 53 countries across 6 continents.
• Average age was 57 (SD 12) years and patients had a NET diagnosis for a mean of 5 (SD 5) years.
• GEP-NETs were most commonly small intestinal (48% [798/1670]) and pancreatic (29% [488/1670]) (Figure 1).

RESULTS

Misdiagnosis

• Almost half of GEP-NET patients were initially misdiagnosed (44% [727/1670]).
• The top 3 misdiagnoses were gastritis (44% [254/582]), irritable bowel syndrome (44% [254/582]) and anxiety (23% [131/582]).
• Only 18% (134/726) of misdiagnosed patients were diagnosed within 1 year and mean time to diagnosis was 5 (SD 6) years (Figure 2).

Diagnostics and treatment availability

• Biopsy was the most widely diagnostic option (80% [1332/1670]), followed by CT (77% [1293/1670]). Over a third reported specialized diagnostics, such as 68Ga-DOTAM-TATE A PET (39% [657/1670]) and Chromogranin A (CgA: 39% [654/1670]) as unavailable (Figure 3).
• Surgery was a widely available treatment option (81% [1350/1670]). Almost half (45% [746/1670]) stated peptide receptor radionuclide therapy (PRRT) was not available. Somatostatin analogues were available to over two thirds (68% [1131/1670]) (Figure 4).

• More than one-third of GEP-NET patients (38% [638/1670]) were diagnosed with stage IV NETs or metastases at time of diagnosis.
• At diagnosis, 43% (712/1670) of NETs were grade 1, 26% grade 2 (438/1670), 4% grade 3 (74/1670), 3% (52/1670) poorly differentiated, and 24% (394/1670) unknown.

CONCLUSION

• SCAN represents the biggest global compendium of data about NETs extant
• Delayed NET-GEP diagnosis remains a significant challenge and more reliable information on GEP-NETs is needed.
• Key requirements to further drive forward improvements in global NET care include:
  - Increasing the availability of NET diagnostics and treatment, particularly newer, more specialized tools
  - Increasing the number of knowledgeable HCPs, especially gastroenterologists and GPs

REFERENCES


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