Neuroendocrine tumors (NETs) are rare and complex neoplasms with increasing incidence and prevalence worldwide. The Survey of Challenges in Access to Diagnostics and Treatment for Neuroendocrine Tumor Patients (SCAN) assessed the delivery of healthcare to NET patients around the world.

Scan assessed global delivery of NET healthcare in terms of:

- Awareness
- Quality of servicing
- Availability
- Affordability
- This analysis focused on the NET diagnostic process and the role gastroenterologists play in it.

**INTRODUCTION**

**METHOD**

- During Sept-Nov 2019, NET patients and healthcare professionals (HCPs) completed a self-reported online survey.
- The survey was disseminated via social media and through NET patient groups and medical society 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.
- 2359 NET patients and 436 HCPs from 68 countries responded.

**RESULTS**

**Participant Characteristics:**

- Globally, primary NETs were most often gastroenteropancreatic (GEP; 71%, 1,670/2,359), 10% were lung NETs and 7% were NETs of unknown origin.
- The patient-reported route to correct NET diagnosis included consultations with more than one physician (46%, 1,085/2,359), medical oncologists (40%, 444/2,359), gastroenterologists (39%, 922/2,359) and general practitioners (GPs) or family doctors (39%, 922/2,359).

Every fifth NET patient was diagnosed correctly by a gastroenterologist (20%, 480/2,359).

The subgroup of patients where gastroenterologists suggested diagnostic tests that led to the correct diagnosis (Gastroenterologist Correct Diagnosis - GCD) were GEP NETs in 96% (435/480) of the cases.

**CONCLUSIONS**

- The route to correct NET diagnosis is lengthy, with 5 years of misdiagnosis on average, and detection is often incidental or after many wrong guesses.
- Gastroenterologists play a fundamental role in diagnosing NETs.
- Better knowledge of NET symptoms and appropriate diagnostic tools are instrumental in improving the time to NET diagnosis and ensuring optimal patient outcomes.

**NET Diagnosing, Misdiagnosing and Staging:**

- After initial symptoms and tests, NET was the first diagnosis for 28% of GCD patients (28%, 134/480) vs. 2.7% Global (640/2,359).
- 44% of patients were initially misdiagnosed at least once with other conditions (GCD: 211/480, Global: 1043/2,359).
- Most common misdiagnoses were Gastritis/Other digestive (52%, 110/211), or IBS (42%, 88/211).
- One quarter (GCD 26%, 125/480 vs. global 26%, 613/2359) had their diagnosis made incidentally during testing for another condition.

**Figure 1: Mean time to correct NET diagnosis and proportion of initially misdiagnosed GCDs**

- **Global** GCDs = 44% initially misdiagnosed
- **Mean time to correct diagnosis for misdiagnosed GCD patients** was 4.81 years (mean, SD: 6.8 N=209) vs. 4.75 years globally (mean, SD: 6.1 N=1042).

**NET Diagnostic Process and the Role of Gastrointestinal Gastroenterologists:**

**AIM**

- **Objective:** Determine the global process and the role gastroenterologists play in it.

**METHOD**

- **Survey of NET Patients and HCPs** from 43 countries responded.
- **Participant Characteristics:**
  - **Primary Site:**
    - Small intestine (101)**
    - 228**
    - Gastrointestinal (228)
    - Gastroenterologists (228)
    - Global NET patients
  - **Initial Symptoms:**
    - Pain (64%, 146/228)
    - Bowel obstruction (9%, 21/228)
    - Anemia (21%, 48/228)
  - **Route to Correct NET Diagnosis:**
    - Multidisciplinary team (58%, 133/228)
    - CT scan and colonoscopy (both at 38%, 87/228)
    - S-HIAA in urine and Chromogranin A (CgA) both at 30% (69/228).
  - **PNETs:**
    - Diagnosed most often by biopsy (58%, 133/228), CT scan and colonoscopy (both at 38%, 87/228), S-HIAA in urine and Chromogranin A (CgA) both at 30% (69/228).
  - **Clinical Challenges in NET Diagnosis:**
    - CgA measurements (24%, 54/228)
    - PET scans (21%, 48/228)
    - Chromogranins B (16%, 36/228)
    - S-HIAA (7%, 15/228)
  - **Gastroenterologists Role:**
    - Their role in improving the quality of care for NET patients globally (43%, 435/980).
  - **Impact of Global Guidelines:**
    - These guidelines were instrumental in improving the quality of care for NET patients (43%, 435/980).

**CONCLUSIONS**

- The diagnostic tools that most often led to correct diagnosis for S-NET were biopsy (58%, 133/228), CT scan and colonoscopy (both at 38%, 87/228), S-HIAA in urine and Chromogranin A (CgA) both at 30% (69/228).
- P-NETs were diagnosed most often by biopsy (67%, 64/95), CT scan (47%, 45/95), MRI (35%, 33/95) and endoscopy (28%, 27/95).
- Rectal NETs were diagnosed in 75% of GCD patients via biopsy (30/40).
- NET diagnoses were received most frequently in hospitals without a NET specialist (GCD 38%, 182/480; Global 41%, 967/2359).

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