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Quality of Life and Care Experiences in a U.S. Multi-Institutional Neuroendocrine Tumor Cohort

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BACKGROUND

Neuroendocrine tumors (NETs) are uncommon, heterogeneous neoplasms associated with prolonged survival and substantial symptom burden. However, patient-reported outcomes (PROs) across NET subtypes remain poorly characterized, particularly in real-world settings.

METHODS

The Neuroendocrine Tumors–Patient Reported Outcomes (NET-PRO) study is a prospective, multi-institutional U.S. cohort funded by the Patient-Centered Outcomes Research Institute (PCORI), conducted across 14 sites. Adults aged ≥18 years with incident small intestinal (SI-NET), pancreatic (pNET), gastroenteropancreatic (GEP), or lung NETs diagnosed from January 2018 through September 2024 were enrolled using a validated EMR-based computable phenotype. Baseline surveys assessed health-related quality of life (HRQoL), symptoms, care experiences, and clinical characteristics using validated instruments. Descriptive statistics and standardized mean differences (SMDs) compared responses by NET site and time since diagnosis.

RESULTS

Among 2,367 participants (mean age 57.8 years; 57.3% female), 1,974 had GEP-NETs (659 SI-NET, 555 pNET) and 393 had lung NETs. Fatigue (mean 33.0), insomnia (32.5), and diarrhea (25.7) were the most burdensome symptoms. Lung NET patients reported worse dyspnea (SMD = 0.58, $p < 0.001$) and lower physical, role, and global QoL scores than those with GEP-NETs. Patients with pNETs reported better functioning and lower symptom burden. Diarrhea worsened over time, especially in SI-NETs. Most rated care highly (75.3%) and reported good coordination, but concerns about treatment side effects (80.4%), costs (60.7%), and travel burden (58.8%) were common.

CONCLUSIONS

This large U.S. cohort highlights substantial, persistent symptom burden among NET patients, with variation by tumor site and disease duration. Findings support longitudinal assessment of HRQoL in this growing patient population.

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