P-11

NANETS NETPact Survey on Barriers to Providing Care for Neuroendocrine Cancer: A Dual-Perspective Analysis of Patient and Provider Experiences

Heloisa P. Soares[1], Udhayvir S. Grewal[2], NETPact Committee[3], Jaydira Del Rivero[4]

[1]Huntsman Cancer Institute at University of Utah; [2]Winship Cancer Institute at Emory University School of Medicine; [3]NANETS; [4]Developmental Therapeutics Branch, National Cancer Institute, National Institutes of Health

BACKGROUND

Neuroendocrine Neoplams (NENs) are a heterogeneous group of neoplasms with rising incidence and prevalence in the United States, yet substantial barriers to optimal care persist despite advances in diagnosis and treatment. To better charcterize these barriers, the North American Neuroendocrine Tumor Society (NANETS) NETPact initiative conducted parallel surveys of patients/caregivers and healthcare providers (HCPs) to capture dual perspectives on access and quality of care.

METHODS

Two cross-sectional, web-based surveys were administered as part of the NANETS NETPact patient advocacy initiative. The patient survey collected 181 responses from patients and caregivers affected by NENs, and the provider survey captured 64 responses from multidisciplinary HCPs involved in neuroendocrine neoplasm care. Survey domains included access to specialist care, diagnostic challenges, treatment patterns, financial and insurance barriers, care coordination, clinical trial awareness, and priorities for improvement.

RESULTS

Among patients, 72% reported diagnostic challenges, with 32.8% waiting more than 2 years from symptom onset to diagnosis. Nearly 29% traveled more than 100 miles for specialist care, and 10.8% lacked specialist access entirely. Financial barriers were prevalent, with 47.6% reporting out-of-pocket cost barriers and 72.1% citing travel costs as burdensome. Only 28% reported being informed about clinical trials. Among providers, insurance and reimbursement barriers were rated as the most impactful obstacle (52.9% rating them very or extremely significant), followed by healthcare system fragmentation (67.3% rating moderately to extremely significant) and challenges with clinical trial enrollment (74% encountering these sometimes to always). Both groups identified expanding the workforce of NEN-knowledgeable professionals as the top priority for improvement (75.0% of patients; 66.7% of providers).

CONCLUSIONS

The NANETS NETPact Survey reveals persistent, multilevel barriers to NEN care in the United States, with notable concordance between patient and provider perspectives. These findings support an urgent need for expanded NEN-specific education, improved insurance coverage for diagnostics and therapies, enhanced multidisciplinary care coordination, and increased clinical trial awareness, highlighting actionable opportunities for targeted education and advocacy through NANETS and its NETPact initiative.

ABSTRACT ID #36572