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Real-World Patient Journey in Extrapulmonary Neuroendocrine Carcinoma (epNEC): Perspectives of Patients from the VOICE Study

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BACKGROUND

Evidence on epNEC patient journey is scarce. This study represents one of the largest efforts to date, comprehensively characterizing the patient journey and unmet needs from the patient perspective.

METHODS

A cross-sectional survey was conducted (Nov 2025 to Feb 2026) of US adults with epNEC recruited via prominent national patient advocacy groups and online panels. Data on diagnosis (dx), treatment (tx), biomarker testing, and unmet needs were analyzed. Health-related quality of life (QoL) was assessed using the Patient-Reported Outcomes Measurement Information System – Global Health (PROMIS-GH-10) and the Work Productivity and Activity Impairment Specific Health Problem (WPAI:SHP).

RESULTS

Among 226 pts (median age 51 years, 67% male, 59% White, 56% employed, 79% gastroenteropancreatic [GEP] NEC, 26% Stage IV). Fatigue (62%) and pain (60%) were the most common symptoms prior to dx. Among symptomatic patients with diagnostic delays (n=28), main reasons for delay were inconclusive test results (46%) and referrals to multiple specialists (39%).

Across first-line (1L) and second-line (2L), primary tx goals for patients were prolonging life, improving QoL and minimizing side effects. 1L tx discussions emphasized efficacy (68%), side effects (61%) and prognosis (53%), while 2L shifted to prognosis (62%), efficacy (61%), and daily life impact (56%). Chemotherapy dominated 1L (73%) while tx was heterogenous in 2L. Although only 66% underwent prior biomarker testing, 94% were willing to undergo testing to inform tx selection.

The top three impacts of receiving dx include relief from identifying symptom cause, emotional distress and positive lifestyle changes. Disease burden was substantial with mean PROMIS-GH-10 Global Physical and Mental Health T-scores of 40.8 and 46.7, both below the general population norm (mean 50; lower T-scores indicate poorer health). Among employed pts, overall work impairment was 63% (absenteeism, 23%; presenteeism, 55%).

CONCLUSIONS

epNEC is characterized by non-specific symptoms, diagnostic delays, evolving tx decisions including biomarker-guided care, and significant impact to QoL and ability to work. Addressing these areas may improve patient-centered care and outcomes.

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