

Baseline Demographics of Neuroendocrine Tumor Patients Presenting to Seven National Comprehensive Cancer Network (NCCN) Institutions: Development of a Multi-Institutional Outcomes Database

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Background: Diagnostic strategies, management paradigms, and clinical outcomes of patients with neuroendocrine tumors (NETs) are diverse and poorly characterized. The National Comprehensive Cancer Network (NCCN) created a comprehensive database to characterize patients treated for NETs at seven participating institutions. Preliminary results from the database are reported.

Methods: Member IRB approval was obtained to identify patients at least 18 years of age presenting to each of seven NCCN institutions between 2004 and 2007 with pathologically confirmed newly or previously diagnosed NETs via hospital medical records. Eligible patients included those with carcinoid (any site); goblet cell or adenocarcinoid; composite carcinoid; poorly differentiated gastrointestinal small cell tumor; pancreatic NET; NET of unknown primary site; pheochromocytoma; and paraganglioma. Baseline demographic characteristics were summarized for this analysis.

Results: Among the 2,798 patients identified with a NET diagnosis, patients most frequently presented with carcinoid tumor (53%), pancreatic NET (26%) and NET of unknown primary site (8%). Median age at diagnosis was 56 (SD=14). Fifty-three percent of patients were female. Most (86%) were Caucasian and 8% were African American. Thirty percent of patients were diagnosed with NET before presenting to the NCCN. Among these, the median time between initial NET diagnosis and presentation to the NCCN was 2 years (SD=6). Significant differences in provider specialty referral patterns were observed between institutions. The institutional point of entry for the majority of patients was medical oncology (institutional range: 17-93%) or surgery (institutional range: 3-62%).

Conclusions: The baseline demographic characteristics of NET patients in this new database are consistent with those previously reported in population-based registries. The database will provide a valuable resource for further exploration of patterns of diagnosis, treatment, and consistency with established guidelines, as well as clinical outcomes in patients with this condition.