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Characterizing the Epidemiology and Treatment Patterns of Carcinoid Syndrome Among Neuroendocrine Neoplasms in a Large Population-Based Database

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BACKGROUND

Neuroendocrine neoplasms (NENs) may secrete serotonin and other vasoactive substances causing carcinoid syndrome (CS), which can impair quality of life and reduce survival. Expanding upon prior epidemiological findings, this study characterizes CS at extra-pancreatic NEN diagnosis and its treatment within 1 year after diagnosis.

METHODS

Patients aged ≥65 years with NENs diagnosed between April 2017 and December 2021 and with continuous Medicare coverage were included; pancreatic NENs, small-cell/large-cell neuroendocrine carcinoma, and non-neuroendocrine lung cancer cases were excluded. CS was defined by ≥1 claim for CS or carcinoid heart disease (CHD) or ≥2 claims for diarrhea or flushing 3 months before or 6 months after extra-pancreatic NEN diagnosis. Patient characteristics and treatments were compared between patients with and without CS using chi-square, Fisher exact, and multivariable logistic regression tests. Sensitivity analyses assessed possible coding bias.

RESULTS

Of 8966 patients with extra-pancreatic NENs, 17.4% had CS at NEN diagnosis. The rate of CS among patients with extra-pancreatic NENs was consistent across the study period. Patients with CS were more likely than patients without CS to be female (P=0.001) and to have midgut tumors, regional/distant/unknown stage disease, and grade 2 tumors

(*P*<0.001 for each). Somatostatin receptor ligands (SRLs) were the most common treatment overall, and SRL use was significantly higher among patients with versus without CS (36.1% vs 11.4%; *P*<0.001). Patients with CS also had higher rates of liver-directed surgery (6.0% vs 1.8%; *P*<0.001), liver-directed therapy (4.6% vs 1.8%; *P*<0.001), other therapy (1.7% vs 0.9%; *P*=0.005), radiopharmaceuticals (1.8% vs 0.3%; *P*<0.001), and CHD surgery (1.0% vs <0.1%; *P*<0.001) than patients without CS. Across all tumor grades, patients with CS received more treatments than those without CS.

CONCLUSIONS

Among extra-pancreatic NENs, CS incidence remained steady over time (2017-2021). These findings emphasize the need to characterize the full disease course of NENs and CS at a population level. SRL use was lower than anticipated, suggesting potential barriers to use or misclassification of CS diagnoses due to incorrect coding.

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