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Patterns of Symptoms Burden in Neuroendocrine Tumors: A Population-Based Analysis of Patient-Reported Outcomes

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BACKGROUND: How to best support neuroendocrine tumors (NETs) patients remains unclear. Improving symptom management and quality of life requires an understanding of the symptoms experienced by patients. Validated assessments of symptom trajectories over the course of disease is lacking. This study examined patterns and risk factors of symptoms burden over time in NETs, using patient-reported outcome tool.

METHODS: A population-based retrospective observational cohort study of all NETs diagnosed from 2004-2015 who survived at least 1 year, was conducted. Prospectively collected patient-reported Edmonton Symptom Assessment System scores were linked to provincial administrative healthcare datasets. Moderate-to-severe symptom scores were presented graphically for both the first year and the first 5 years following diagnosis. Multivariable Poisson regression was used to identify factors associated with moderate-to-severe symptoms scores during the first year after diagnosis.

RESULTS: Among 2,721 included patients, 7,719 symptom assessments were recorded during the first 5 years after diagnosis. Moderate-to-severe scores were most often reported for tiredness (40-51%), wellbeing (37-49%), and anxiety

(30-40%). The proportion of moderate-to-severe symptoms was stable over time, with 10% reduction within 6 months of diagnosis for anxiety followed by stability, and below 5% changes for other symptoms. Similar patterns were observed for the first year after diagnosis. Primary tumor site, metastatic disease, younger age, higher comorbidity burden, lower socio-economic status, and receipt of therapy within 30 days of assessment, were independently associated with higher risk of elevated symptom burden.

CONCLUSION: NETs patients have a high prevalence of moderate-to-severe patient-reported symptoms, which does not change over 5 years after diagnosis. Patients remain at risk of prolonged high symptoms burden following diagnosis, highlighting potential unmet needs to be addressed. Combined with identified patient and disease factors associated with moderate-to-severe symptom scores, this information is important to support the design of symptom management strategies to improve patient-centred care for NETs.