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## Symptom Burden at the End of Life for Neuroendocrine Tumors: A Population-Based Analysis of Patient-Reported Outcomes

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**BACKGROUND:** How to best support neuroendocrine tumor (NET) patients remains unclear. While the peri-diagnostic period has been investigated, there is no data regarding symptoms at the end of life, when suboptimal symptom control may be particularly burdensome. This study examined symptom trajectories and factors associated with high symptom burden in NET at the end of life.

**METHODS:** We conducted a population-based retrospective cohort study of NET diagnosed from 2004-2015, who died between 2007-2016. Prospectively collected patient-reported Edmonton Symptom Assessment System scores were linked to provincial datasets. Moderate-to-severe symptom scores in 6 months prior to death were presented by 2-week intervals. Multivariable Poisson regression identified factors associated with moderate-to-severe symptoms scores.

**RESULTS:** Among 677 decedents, 2,579 symptom assessments prior to death were analyzed. Overall, moderate-to-severe scores were most commonly reported for tiredness (86%), wellbeing (81%), lack of appetite (75%), and drowsiness (68%) at any time. This proportion changed over time, progressively increasing closer to death: 56.8% to 83.9% tiredness, 50.5% to 73.1% wellbeing, 40.9% to 80.6% lack of appetite, and 41.5% to 68.8% drowsiness. The increase was steeper in the 8 weeks before death for lack of appetite, drowsiness, and shortness of breath. On multivariate analyses, the risk of moderate-to-severe symptoms was significantly higher in the last 2 months prior to death and with



shorter survival from diagnosis (<6 months). Women reported a higher burden of anxiety, nausea, and pain than men. There was no association between symptom burden and age or primary tumor site.

**CONCLUSION:** NET patients suffer a high symptom burden at the end of life, not previously described. The proportion of moderate-to-severe symptoms increases steeply as death nears, highlighting an opportunity for improved management. Combined with identified factors associated with moderate-to-severe symptom, this information is important to improve patient-centred and personalized supportive care for NET at the end of life.