Understanding a Rare Disease's Impact on Health Systems: A Population-Based Analysis of Patterns and Drivers of Costs for Neuroendocrine Tumors Costs

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Background: Neuroendocrine tumors (NET) prevalence is increasing. Little is known on resource utilization in NET care. We sought to define patterns of costs in NET management and compare them to a more common malignancy, colon cancer (CC).

Methods: We identified all NET in a cancer registry (2004-2012). They were matched to CC patients (1:3). 2012 CND$ costs were obtained for 4 phases of care around diagnosis: pre-diagnostic (PrDx: -2 years to -181 days), diagnostic (Dx: -180 days to +180 days), post-diagnostic (PDx: +181 days to +3 years) and prolonged post-diagnostic (PPDx: +181 days to +9 years). Mean costs per patient were compared. Costs predictors were analyzed with quantile regression.

Results: 3355 NET were matched to 9320 CC. Mean NET cost was higher in PrDx phase ($5877 Vs $5368; p=0.05), driven by higher non-drug costs including physician encounters, emergency room visits. Mean NET costs were lower in Dx and PDx phases (both p<0.01). In PPDx, drug costs were significantly higher in NET ($26788 Vs $7827; p<0.01), accounting for 41% of costs compared to 16% for CC. CC had a high initial increase in costs, which then decreased PDx. NET had steady increases between each phase, more pronounced in PrDx and PPDx. Older age, lower income, and comorbidities were predictors of higher NET costs in the 4 phases. Gastro-enteric primary site was associated with higher costs in PrDx (parameter estimate – PE $62), and lower costs in Dx (PE $13644). Pancreatic site was associated with higher costs in PDx (PE $3348) and PPDx (PE $1548).

Conclusion: NET cost pattern is unique and differs from CC, with maximal costs during PrDx and PPDx phases. Primary NET site affected costs differently at different time points. Defining these cost patterns now allow for tailoring the use of healthcare resources to tumor type and timing in the patient journey.

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