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Integrating Patient Reported Outcomes (PROs) in Neuroendocrine Tumors (NETs) Care: An Assessment of Cognitive and Psychological Screening Tools During Follow-Up

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BACKGROUND: An association between neuroendocrine tumors (NETs) and neuropsychological symptoms has been suggested, but objective data is limited. We aimed to assess the burden of neuropsychological symptoms in NETs using validated PROs.

METHODS: We conducted a prospective cohort study of adult patients with WHO grade 1 and 2 bronchopulmonary (BP) and gastro-entero-pancreatic (GEP) NETs followed at a high volume specialized multidisciplinary clinic. The Beck Depression Inventory (BDI-II), Functional Assessment of Cancer Treatment Cognitive domain (FACT-Cog), and EORTC-GEPNET 21 were administered to patients. Patients were also asked about their preference for psycho-social support.

RESULTS: Of 80 patients, 27.5% had BP and 65.2% GEP primary NETs. Metastases were present in 65% and 30% were hormonally active (elevated 24-hour urinary 5-HIAA). No patients had an established cognitive or psychiatric diagnosis. Median time from NETs diagnosis to PROs measure was 82 (IQRL: 64.5-125) months. Using the BDI-II, 16.3% of patients presented mood disturbances, 17.5% signs at or above the level of clinical borderline depression, and 8.8% moderate to severe depression. FACT-Cog assessment revealed
moderate perceived cognitive impairment (median 61, IQR: 50-68, possible range 0 to 72) and considerable reduction in perceived cognitive ability (median 5, IQR: 2-10, possible score 0 to 28). On the EORTC-GEPNET21, social functioning was the most impacted domain (median 16.7, IQRL 8.3-33.3). Gastro-intestinal, endocrine and treatment related symptoms were mildly impacted. Patients preference (very likely/likely to use) for psycho-social support was: social work 23.8%, psychology services 32.6%, psychiatry services 36.2%, and patient support group 36.3%.

**CONCLUSION:** Using validated PROs, one out of 5 patients presented signs of clinical depression and perceived cognitive ability was impaired, during the maintenance phase of care. While symptoms appeared controlled, social functioning was impacted. These results provide insight into the need to routinely screen NETs during follow-up in order to offer support and improve patient-centred longitudinal care.