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Treatment Decision Concerns: A Latent Class Analysis in Young-Onset Neuroendocrine Tumors

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BACKGROUND

With the increasing incidence of neuroendocrine tumors (NETs), patients often face multiple worries about treatment decisions, including side-effects, costs, and disruptions to daily life. This study aimed to identify distinct worry profiles and examine their associations with sociodemographic and clinicopathological factors.

METHODS

Baseline survey data were analyzed from patients, diagnosed between January 2018 and September 2024, in a multi-institutional U.S. cohort study - Neuroendocrine Tumors-Patient Reported Outcomes (NET-PRO), funded by the Patient-Centered Outcomes Research Institute (PCORI). The latent class analysis included five binary indicators reflecting whether participants reported being "at least a little worried" versus "not worried" about the following: (1) treatment side effects, (2) treatment costs, (3) time away from family, (4) time away from work, and (5) transportation to treatment facilities. We selected a three-class model that showed the best statistical fit and clear separation between classes.

Multivariable multinomial logistic regression was used to examine associations between patient characteristics and worry profile membership.

RESULTS

Among 2,198 participants (57.2% female) who completed five worry items, 261 (11.9%) were younger adults (aged 18–39 years at diagnosis). Classes identified were: (1) low-worry (10.8% overall [n=238]; 6.5% younger [n=17] vs 11.4% older adults [n=221]), characterized by consistently low responses across items; (2) moderate-worry (52.6% overall [n=1156]; 34.9% younger [n=91] vs 55.0% older adults [n=1065]), marked by concerns primarily about treatment side-effects (84.8%) and time away from family (58.4%); and (3) high-worry (36.6% overall [n=804]; 58.6% younger [n=153] vs 33.6% older adults [n=651]), characterized by widespread worry across all domains. In multivariable multinomial logistic regression, Being female, having an advanced cancer stage, lower household income, greater distance to treatment, lower perceived quality of care, employer-sponsored or Medicaid coverage, limited health literacy, having carcinoid syndrome, and tumor location in the pancreas, lung, or unknown primary were all significantly associated with higher odds of belonging to the moderate- to high-worry latent classes ($P < 0.05$). The association between advanced disease stage and higher worry was stronger among younger individuals, who had significantly higher odds of belonging to the moderate- to high-worry latent classes compared to older individuals (interaction $P < 0.001$).

CONCLUSIONS

Higher levels of worries about decision-making were associated with key sociodemographic and clinicopathological factors. Younger adults may face unique challenges and greater levels of worry when navigating treatment decisions in the context of advanced disease. Routine assessment of treatment-related worries may facilitate supportive care and help reduce decisional distress in this growing population.

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