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Factors Affecting Patient Knowledge and Awareness About Neuroendocrine Tumors

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BACKGROUND

Neuroendocrine Tumor (NET) patients are the fastest growing population of cancer patients, hence we wanted to assess if there are gaps in patient knowledge and awareness of their disease. To improve our understanding of the factors affecting patient knowledgeability, we looked at their educational level, satisfaction with educational materials provided at initial diagnosis, other sources used for awareness, and their level of accessibility to education materials about NETs.

METHODS

The Roswell Park NET Biobank has enrolled 154 participants to date and answered questionnaires capturing demographics, patient finances, clinical information, quality of life and access to NET educational materials. Patients were asked to record their responses to the question “How knowledgeable do you feel regarding NETs?” on a 4-point scale: Not at all, Somewhat, Very and Extremely. We combined responses into “low levels” (Not at all/Somewhat) and “high levels” (Very/Extremely) for statistical analysis. We ran multivariable logistic regression models to identify demographic and clinical correlates of patient self-report of NET knowledge levels. These models were adjusted for patient’s age, gender, marital status, education level, comorbidity burden, level of education/counselling provided to patient’s regarding NETs, resources available and their overall level of satisfaction about their accessibility to NET resources. $P < 0.05$ was considered to be statistically significant.

RESULTS

Of the 154 respondents, 123 (79.8%) reported having low levels of knowledge regarding their NET diagnosis. In the multivariable logistic regression model, we found that older patients (OR: 1.06; 95% CI: 1.00 – 1.03) & male gender: (OR: 4.34; 95% CI: 1.18 – 15.92) reported higher levels of knowledge regarding NETs. Those who felt they received adequate education materials/counselling following their initial diagnosis (OR =21.22; 95% CI=4.58, 98.29) and those who self-reported high levels of accessibility to NET resources (OR=11.82; 95% CI=2.50, 55.83) reported higher levels of knowledge regarding NETs. The main areas the respondents felt required improvement are: (1) Education/information about NETs at initial diagnosis (2) Access to more information resources about NETs; (3) Resources to help family and friends understand and cope with a NET diagnosis. The main sources used by respondents were as follows: websites (31.17), educational materials provided by healthcare providers (29.22%) and social media (20.78%).

CONCLUSIONS

Based on our surveys, ~80% of NET patients report low levels of knowledge about NETs, despite using several resources currently available. Efforts to educate newly diagnosed patients and provide information on available NET education resources to patients and their family members are needed.