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Health-related Quality of Life of Patients with Neuroendocrine Tumor Compared to the United States General Population

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Background: Health-related quality of life (HRQL) can be disrupted in patients with chronic illnesses such as cancer. The study evaluated the HRQL burden of patients with neuroendocrine tumor (NET), testing the hypothesis that NET patients have reduced HRQL compared to the general United States population.

Methods: NET patients were invited via email to participate in an online, anonymous survey. This survey consisted of a brief set of demographic and disease-related items, the RAND-36 and the PROMIS-29, the latter two of which are standardized measures of HRQL with general population normative values available for comparison. Norm-based scores were calculated for all subscales, such that a score of 50 represents the mean of the general population (standard deviation=10). For the anxiety and fatigue subscale, higher scores (> 50) represent worse outcome. Results are presented as means and 95% confidence intervals.

Results: Data collection is currently ongoing but at the time of this writing 565 eligible participants have completed the survey. Demographics: 66% were female, 91% white, 3% Hispanic, 40% 60 years or older. 25% require some amount of bed rest during the day, 35% have diarrhea and 51% experienced at least one flushing episode in the past two weeks. NET patients demonstrated worse HRQL scores compared to the general population mean of 50 on all subscales of the RAND-36 and PROMIS-29. For example, mean scores (95% confidence interval) in NET patients were: physical function = 45.2 (44.4-46.0); anxiety = 54.2 (53.4-55.0); fatigue = 54.7 (53.8-55.6); and general health = 40.0 (39.0-41.0).

Conclusion: In this preliminary evaluation of the survey results, NET patients reported worse HRQL outcomes compared to the general population on all subscales of the RAND-36 and PROMIS-29. Symptom management and/or psychosocial interventions may be warranted to ease the HRQL burden experienced by patients with NETs.