

P-11:

Evaluation of the Impact of the Burden of Carcinoid Syndrome Symptoms on Quality of Life Among Treated Patients with Carcinoid Syndrome in the U.S. Based on the PROMIS-29 Instrument

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BACKGROUND: Carcinoid syndrome (CS) results from bioactive amine secretion by functional NET. Common CS symptoms (CSS) include flushing and diarrhea. This study evaluated the impact of the burden of CSS on the quality of life (QoL) among patients with CS using the validated Patient-Reported Outcomes Measurement Information System (PROMIS-29) instrument.

METHODS: CSS patients in the U.S. were recruited via NCAN for an online, anonymous survey between July-October 2016. Adult patients who received either somatostatin analogs (SSA) or non-SSA for CSS control were eligible. The survey consisted of demographic, clinical, QoL, and PROMIS-29 questions. CSS burden was defined by number of CSS experienced. Descriptive and adjusted multivariable regression analyses were performed.

RESULTS: 117 patients (mean age 58 years) completed the survey; average time since CS diagnosis was 7.1 (range: 0.4-27.0) years and duration of SSA treatment was 6.1 (0.3-21.3) years. 98.3% received SSAs in the past month. Patients experienced up to 6 CSS (mean±SD: 3.0±1.1), of which diarrhea (97.4%) and flushing (90.6%) were most common. Mean±SD T-score was

42.1±8.2 for Physical Function (range: 22.9-56.9), which is lower than the general US population (50.0±10.0). Multivariable models showed that additional CSS and requiring any amount of bed rest during the day (compared to normal activity without CSS) resulted in significantly decreased T scores in Physical Function (additional CSS: -1.8, bed rest <50%:-9.8, bed rest ≥50%: -17.3) and Social Role/Activities (additional CSS: -1.6, bed rest <50%: -9.8, bed rest ≥50%:-18.4) and increased Fatigue (additional CSS: +1.8, bed rest <50%: +10.9, bed rest ≥50%: +19.4) (all P<0.05).

Conclusion: Among CS patients primarily treated with SSA, burden of CSS and decreased activity levels were associated with lower QoL. This study suggests that benefits gained by controlling CSS may lead to improvements in QoL. Future studies are needed to assess the possible impact of optimal management of CSS on QoL.