Assessment of the Association Between the Burden of Carcinoid Syndrome Symptoms and the Quality of Life Among Patients with Carcinoid Syndrome in the United States Based on the FACT-G Instrument

Lynn Hyunh,1,2,3 Todd Toten,4 Beili Cai,4 Jennifer L. Beaumont,4,5,6 Daniel M. Halperin,6 Maureen P. Neary,7,8 Rachel Bhak,8 Francis Vekeman,9 Mei S. Duh,10 David Cellis11

1Analysis Group, Inc., Boston, MA, USA; 2Novartis Pharmaceuticals Corporation, East Hanover, NJ, USA; 3Department of Medical Social Sciences, Northwestern University Feinberg School of Medicine, Chicago, IL, USA; 4Terasaki Research Institute, Los Angeles, CA, USA; 5Terasaki Research Institute, Los Angeles, CA, USA; 6Department of Gastrointestinal Oncology, The University of Texas MD Anderson Cancer Center, Houston, TX, USA.

Background and Objectives

Carcinoid syndrome (CS) results from secretion of bioactive amines, peptides, and polypeptides by functional neuroendocrine tumors (NETs) of the GI tract. CS symptoms may include diarrhea, flushing, wheezing, flushing and less frequently carcinoid heart disease, diabetes, and psychiatric symptoms. CS symptoms may also be associated with other cancers and may be considered as a result of NET treatments.

Methods

Patients with CS (n = 117) were recruited from the Carcinoid Cancer Awareness Research Network (CCAR; patient advocacy group) for an online, anonymous survey between July 16, 2016, and October 31, 2016. Eligible patients were over 18 years, age; diagnosed with NET by either a medical oncologist or a gastroenterologist; and receiving somatostatin analogs (SSAs) or other medications to control CS symptoms. The primary aim was to describe frequencies and proportions for categorical variables. Multivariable linear regression analysis identified independent associations of CSS with sociodemographic factors, treatment burden, and quality of life. Analysis was performed with R 4.0.2 (R Foundation for Statistical Computing, Vienna, Austria) and non-commercial software.

Statistical Analyses

• FACT-G scores were calculated scores were calculated according to the scoring manual.
• ANOVA and t-tests were used for continuous variables.
• Descriptive analyses assessed patient demographic and CS-related characteristics were made.
• Multivariable linear regression models were used to identify independent associations of CSS with sociodemographic factors, treatment burden, and QoL. Variables with a non-significant effect were removed and the model was re-run.

Results

Demographic and Clinical Characteristics

• The majority of patients were female (67.6%) and Caucasian (91%).
• The mean age was 58.0 years.
• The most frequent reported CSS among the six different symptoms asked in the survey was flushing, followed by diarrhea, wheezing, skin cramping, cyanosis, and peripheral edema.

FACT-G Quality of Life Scores

• The mean total FACT-G score was 65.0 (SD 17.0, range 0–75), and most patients reported being healthy activity levels, with a median of 2 (IQR 1–3).

Carcinoid/NET type

• Among the total sample, the majority of patients had a primary tumor location in the appendix (27.8%), ileum (25.3%), jejunum (19.8%), stomach (13.7%), and lung (13.7%).

Treatment Characteristics

• For CS treatment, the majority of patients (91.2%) were treated with SSAs, followed by surgery (78.0%), CT/RT (40.1%), surgery + CT/RT (26.8%), and surgery + SSAs (16.0%).

• Most patients receiving SSAs through an average number of treatment were able to control the CS burden. However, the most common side effects were diarrhea, flushing, and wheezing.

• Statistically significant associations were noted for P-values < 0.05.

Limitations

• This study was funded by Novartis Pharmaceuticals Corporation. This study was funded by Novartis Pharmaceuticals Corporation.

Conclusions

• The results suggest that controlling CS symptoms may improve QoL. Future studies are needed to explore the impact of CS symptoms on QoL.

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This study was funded by Novartis Pharmaceuticals Corporation.

References

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Figure 1: Categorization of CSS Impact on Quality of Life

- CSS, Carcinoid Syndrome Symptoms;
- Est, (Parameter) Estimate; EWB, Emotional Well-Being; FACT-G, Functional Assessment of Cancer Therapy-General; GH, General Health; PC, Physical Well-Being; QoL, Quality of Life; SWB, Social Well-Being; TPA, Total Patient Assessment; SSA, Somatostatin Analog; VAS, Visual Analog Scale.

Figure 2: Average Number of Bowel Movements and Flushing Episodes per Day in the Past 2 Weeks

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Figure 3: Current Activity Level

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Table 1: Demographic and Clinical Characteristics

- CSS, Carcinoid Syndrome Symptoms; Est, (Parameter) Estimate; EWB, Emotional Well-Being; FACT-G, Functional Assessment of Cancer Therapy-General; GH, General Health; PC, Physical Well-Being; QoL, Quality of Life; SWB, Social Well-Being; TPA, Total Patient Assessment; SSA, Somatostatin Analog; VAS, Visual Analog Scale.

Table 2: NET and CS Treatment Characteristics

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Table 3: Multivariable Predictors of FACT-G Scores: Model 1

- CSS, Carcinoid Syndrome Symptoms; Est, (Parameter) Estimate; EWB, Emotional Well-Being; FACT-G, Functional Assessment of Cancer Therapy-General; GH, General Health; PC, Physical Well-Being; QoL, Quality of Life; SWB, Social Well-Being; TPA, Total Patient Assessment; SSA, Somatostatin Analog; VAS, Visual Analog Scale.

Table 4: Multivariable Predictors of FACT-G Scores: Model 2

- CSS, Carcinoid Syndrome Symptoms; Est, (Parameter) Estimate; EWB, Emotional Well-Being; FACT-G, Functional Assessment of Cancer Therapy-General; GH, General Health; PC, Physical Well-Being; QoL, Quality of Life; SWB, Social Well-Being; TPA, Total Patient Assessment; SSA, Somatostatin Analog; VAS, Visual Analog Scale.

Table 5: Multivariable Predictors of FACT-G Scores: Model 3

- CSS, Carcinoid Syndrome Symptoms; Est, (Parameter) Estimate; EWB, Emotional Well-Being; FACT-G, Functional Assessment of Cancer Therapy-General; GH, General Health; PC, Physical Well-Being; QoL, Quality of Life; SWB, Social Well-Being; TPA, Total Patient Assessment; SSA, Somatostatin Analog; VAS, Visual Analog Scale.

Table 6: Multivariable Predictors of FACT-G Scores: Model 4

- CSS, Carcinoid Syndrome Symptoms; Est, (Parameter) Estimate; EWB, Emotional Well-Being; FACT-G, Functional Assessment of Cancer Therapy-General; GH, General Health; PC, Physical Well-Being; QoL, Quality of Life; SWB, Social Well-Being; TPA, Total Patient Assessment; SSA, Somatostatin Analog; VAS, Visual Analog Scale.