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Living with Neuroendocrine Tumors: Assessing Quality of Life (QoL) Through a Mobile Application

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BACKGROUND: The aim was to understand neuroendocrine tumor (NET) patients' QoL through PROMIS-29, symptom tracking and patient journaling via the Carcinoid Health Storylines™ mobile application (app).

METHODS: This 12-week prospective, observational study was conducted among US NET patients recruited through the Carcinoid Cancer Foundation on either lanreotide depot or octreotide LAR via surveys at baseline, week 6, and week 12 with PROMIS-29 and symptom questionnaires at baseline, week 4 & week 8. Patients were asked to monitor symptoms, mood, bowel movement frequency, food, activity and sleep in their app 5x / week. Demographics and medical history were collected at baseline.

RESULTS: Of the 120 NET patients, 78% were female (mean age=57); 76% were gastroenteropancreatic NETs and 88% with metastases. Lanreotide and octreotide use was 41% and 59% respectively. 82% completed ≥ 1 follow-up survey; the most common symptoms at baseline were fatigue (76.7%), diarrhea (62.5%), abdominal discomfort (64.1%) & trouble sleeping (57.5%). The baseline PROMIS-29 assessment revealed high proportions endorsing clinically significant depression (17.7%), anxiety (24.2%), fatigue (58.8%), dissatisfaction with social role (i.e. daily routine, 42.2%), difficulty with physical functioning (i.e. run errands, 16%) and insomnia (34.9%). Thus, 26.9% reported their QoL being poor and yet, a high percentage of patients were hopeful and reported their life as being meaningful (72.3%). Reported symptoms decreased significantly

from initial to subsequent surveys (e.g. 59.3% to 33% for diarrhea; $p=0.002$). App tracking effectively captured variations in reported symptoms and weekly averages correlated well with symptom surveys and PROMIS-29 scores.

CONCLUSION: This study suggests the use of apps for recording daily symptoms in NET patients, with decreased symptom reporting over time perhaps due to reduced recall bias from frequent tracking, or a potential therapeutic effect of journaling. Apps should be developed further to record the experiences and needs of NET patients.