Living With Neuroendocrine Tumors: Assessing Quality of Life Through a Mobile Application

Jared Adams, MD, PhD[1]; David Ray, PharmD, MBA[2]; Renee Willmon, MSc[1]; Linda Kaleis, MHI[1]; Anand Gautam, MSc[1]; Sonia Pulgar, MPH[2]; Arvind Dasari, MD[3]

[1]Self Care Catalysts, MaRS Center, Toronto, ON; [2]Ipsen Biopharmaceuticals Inc., Basking Ridge, NJ; [3]MD Anderson Cancer Center, Houston, TX

BACKGROUND

- Neuroendocrine tumors (NETs) are a heterogeneous population of solid tumors that can significantly affect quality of life (QoL) through tumor burden and excess hormone production.
- Commonly reported symptoms include flushing and diarrhea, the true impact on QoL can be far reaching.[1-3]
- Advances in mobile applications (apps) now provide the opportunity to track information, such as symptoms, mood, and medication adherence, in real time.
- The study aim was to understand NET patients' QoL through the PROMIS-29, the EORTC QLQ-c30, daily symptom tracking, and patient journaling via the Carcinoid Health Storylines mobile app.

OBJECTIVES

- To describe the health-related QoL (HRQoL) of patients with NETs treated with somatostatin analogs (SSAs) in the real world using the PROMIS-29 and EORTC QLQ-c30 patient-reported outcome (PRO) measures
- To describe the frequency and severity of symptoms among patients with NETs using daily mobile technology tracking
- To determine how aspects of NET impact daily living among patients in the real world
- To determine the relationship of daily symptom tracking vs. validated QoL surveys
- To qualify, in an exploratory analysis, emotional quality of injection experience using free-text journal entries

METHODS

- This was a prospective, observational study conducted in the US following adult NET patients being treated with a long-acting SSA over the course of 12 weeks.
  - Recruitment via the Carcinoid Cancer Foundation
  - Written informed consent was obtained prior to data collection
- Patients were surveyed at baseline, week 6, and week 12 with the PROMIS-29 and at baseline, week 4 and week 8 using the EORTC QLQ-c30 symptom questionnaire.
  - Surveys were administered through the Carcinoid Health Storylines mobile app.
  - Additional data collected as available: medications, symptoms, mood, free-text journaling, stools, vitals, activity and sleep tracking data
- In an exploratory analysis, journal entries written by patients in the "Thoughts on my therapy" field of the Health Storylines "Treatment Reflections" tool were analyzed qualitatively.
  - Each journal response was stripped of the patient treatment group identifier before coding to identify the themes being discussed.
  - Responses describing the injection experience were assessed in greater detail to determine the emotional quality of each response on a scale of 1 – 5, with 1 being negative and 5 being positive.
  - Patient-adjusted mean scores of emotional quality were then compared within and between treatment groups. Patients were recruited from users of the app and through the Carcinoid Cancer Foundation (mentioned above). It was a convenience sample (non-randomized).

RESULTS

- One hundred twenty SSA patients were recruited for the study; 82 patients completed all assessments.
- Most patients were female (n=95, 79%) and had a gastrointestinal primary tumor (n=73, 61%) (**Table 1**).

Table 1. Baseline Demographics

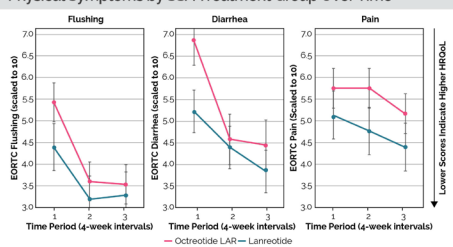
	Total Population		SSA Treatment			
			Octreotide LAR		Lanreotide	
	n	%	n	%	n	%
No. of Patients	120		71		49	
Age, years						
Mean (SD)	56.3 (9.3)		56.5 (9.3)		56.1 (12.6)	
Time since Diagnosis, years						
Mean (SD)	5.9 (4.9)		5.1 (4.5)		5.9 (5.3)	
Sex						
Female	95	79%	57	80%	38	78%
Tumor Site*						
Gastrointestinal	77	64%	43	61%	34	69%
Pancreatic	22	18%	12	17%	10	21%
Lung	9	8%	7	10%	2	4%
Other	15	13%	12	17%	3	6%
Metastatic	105	88%	63	90%	42	86%
Brain Involvement	1	1%	1	1%	0	0
Treated with Chemotherapy	35	29%	19	19%	16	33%
Race						
White	107	89%	63	90%	44	90%
Black	5	4%	3	4%	2	4%
Asian	2	2%	1	1%	1	2%
Hispanic	6	5%	4	6%	2	4%

*3 Octreotide patients reported both pancreatic and gastrointestinal.

Quality of Life and Symptom Reporting

- Baseline symptom reporting was similar across the EORTC QLQ-c30 and PROMIS-29 questionnaires
  - The most common symptoms reported via the EORTC QLQ-c30 were fatigue (76.7%), diarrhea (62.5%), abdominal discomfort (64.1%), and trouble sleeping (57.5%).
    - Across physical symptoms, scores were often highest at baseline, before decreasing and stabilizing across symptoms (**Figure 1**).

Figure 1. EORTC 4-point Symptom Scale for the 3 Most Common Physical Symptoms by SSA Treatment Group Over Time

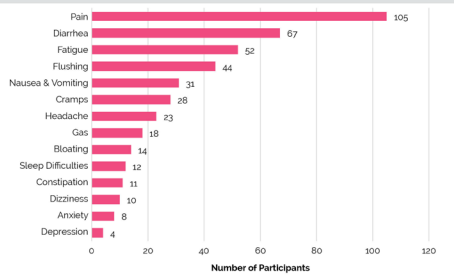


  - PROMIS-29 assessments revealed high proportions of fatigue (58.8%), dissatisfaction with role functioning (42.2%), insomnia (34.9%), anxiety (24.2%), depression (17.7%), difficulty with physical functioning (16.0%).
    - However, a high percentage of patients reported their lives as being meaningful (72.3%).

Daily Symptom Tracking and Intermittent Validated PROs

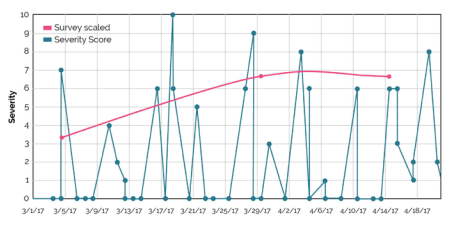
- Of the 120 patients recruited, 105 (88%) patients recorded symptoms in the mobile app (**Figure 2**).

Figure 2. Number of Participants Who Tracked Symptoms in Health Storylines App



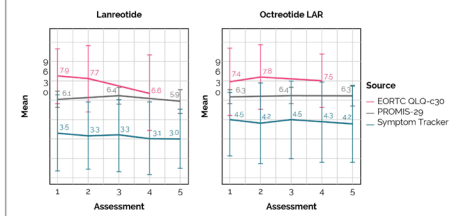
- Daily mobile app symptom tracking captured a wider variation of symptom severity in comparison to cross-sectional PRO assessments.
- In most cases, averaged daily symptom severity resembles corresponding scaled EORTC symptom scores (**Figure 3** and **4**).

Figure 3. Comparison of Diarrhea Severity Tracked by a Single Patient in Health Storylines (blue) vs. Diarrhea Severity Reported in EORTC (red)



- There was a significant correlation between daily diarrhea intensity captured in the app and the PROMIS-29 domains:
  - Anxiety (r=0.32, p=0.02), depression (r=0.4, p=0.003), satisfaction with role (r=−0.44, p=0.001), pain interference with daily living (r=0.39, p=0.005) and fatigue (r=0.49, p<0.001).
- A regression analysis using the PROMIS-29 domains to predict global QoL as measured by the EORTC QLQ-c30 found fatigue (p<0.001), pain (p=0.036), and satisfaction with social role (p=0.001) were statistically significant.

Figure 4. Comparison of PROMIS, EORTC, and Mobile App Fatigue Symptom Assessments



Exploratory Qualitative Analysis of NET Patient Journaling

- Among the 120 patients, 69 patients journaled on their therapy within the mobile app in a total of 1,399 entries (responses per patient; mean=20.3, median=6).
- Effectiveness, side effects, and injection experience were the most common qualitative themes touched on at least once by patients.
- An assessment of the emotional quality of journal entries on injection experience revealed a more negative experience with octreotide compared to lanreotide (2.1 [95% CI: 1.9-2.3] vs. 3.0 [95% CI: 2.5-3.5], p<.001) (**Table 2**).

Table 2. Emotional Quality of Injection Experience Recorded Under "Thoughts on my Therapy" Within the Health Storylines "Treatment Reflections" Tool

	Octreotide LAR n (%)	Lanreotide n (%)	Total N
Responses to "Thoughts on my therapy"			
patients	41 (59)	28 (41)	69
unique responses	1018 (73)	381 (27)	1399
median responses/patient	9	5	6
mean responses/patient	24.83	14	20.28
Unsolicited Comments on Injection Experience			
patients	17 (57)	13 (43)	30
unique responses	102 (73)	37 (27)	139
Emotional Quality of Injection Experience*			
mean (SD)	2.13 (.43)	3.03 (.88)	2.52 (.79)

*1 = Negative | 2 = Somewhat negative | 3 = Neutral | 4 = Somewhat positive | 5 = Positive
†Difference between means, p<.001

Safety

- Safety was not reported as an objective of this study. Adverse events and product complaints were submitted to the manufacturers' Drug Safety Departments. No new safety signals were identified for lanreotide.

CONCLUSIONS

- Patients with NETs experienced a significant physical symptom burden (most commonly pain, diarrhea, fatigue, and flushing) which can be associated with decreased health-related QoL.
- The results suggest the utility of mobile apps for recording daily symptoms in patients with NETs.
- Symptom tracking remained stable throughout, and patient-reported impact and severity of physical symptoms decreased over time. This is perhaps due to reduced recall bias from frequent tracking or a potential therapeutic effect of journaling.
- Apps may help monitor disease and should be further investigated as part of the treatment paradigm.

References

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Conflicts of Interests

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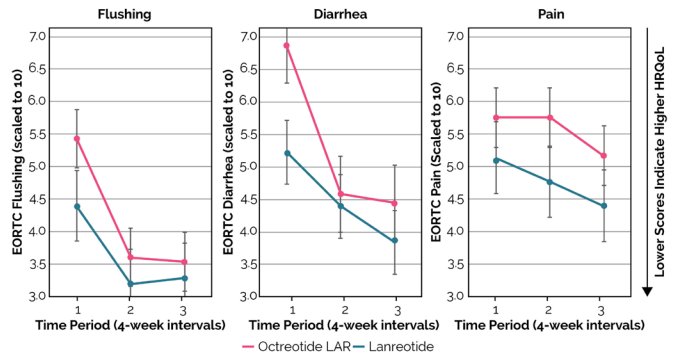

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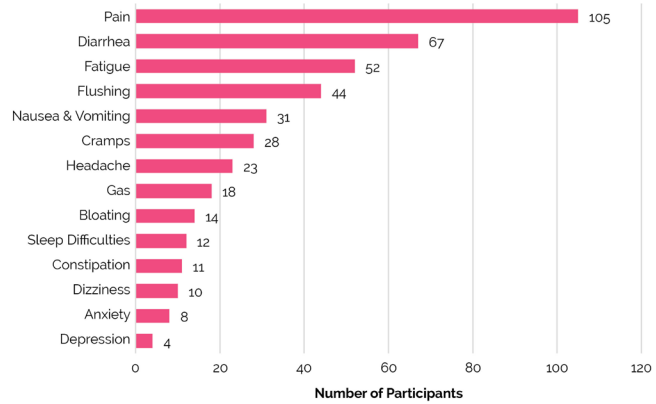

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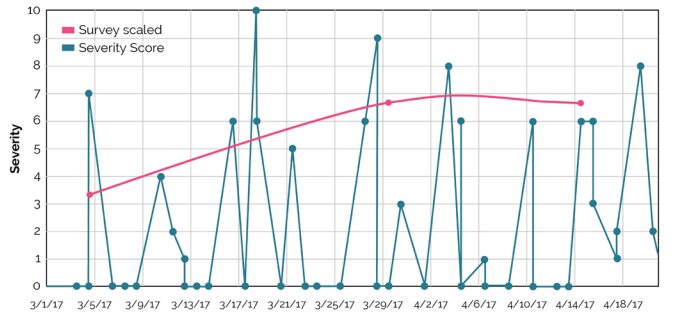

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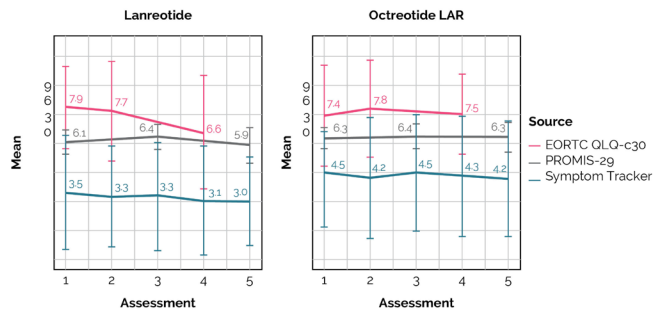

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