

Satisfaction survey of administration modes for long-acting somatostatin analog therapy in patients with neuroendocrine tumors: Results of cognitive interviews with US-based patients and nurses

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BACKGROUND

- Somatostatin analogs (SSAs), long-acting octreotide or lanreotide depot, are recommended for advanced unresectable gastroenteropancreatic neuroendocrine tumors (GEP-NETs).¹ In addition to treatment of underlying cancer, patients with carcinoid syndrome (CS) receive SSAs to control associated symptoms.¹
- Given long therapy duration and differences in administration routes, it is important to understand patients' injection experiences and factors that impact satisfaction.
- A questionnaire was developed to measure patient satisfaction, convenience, sequelae, and other experiences related to their most recent injection.
- We report qualitative findings for the development of a survey on patient satisfaction with SSA treatment. The final, quantitative, longitudinal, web-based survey will be administered in 2019 to 200 patients with NET in the United States (US) who are being treated with a long-acting (LA) SSA.

OBJECTIVE

- The aim of the cognitive interviews with patients and nurses was to evaluate a draft patient survey and identify and/or expand upon concepts potentially relevant for the measurement of patient satisfaction with LA SSA injections.

METHODS

- The draft survey was designed by researchers, medical experts, and The Carcinoid Cancer Foundation² to describe patient satisfaction with LA SSA injection focusing on differences in route of administration.
- A convenience sample of participants was identified, contacted, and recruited by the Carcinoid Cancer Foundation.
- Using a semistructured guide, 1-hour concept elicitation and cognitive pretesting interviews were conducted with 8 patients with NET and 2 nurses with LA SSA injection experience (Table 1 shows participant eligibility criteria).
 - The purpose of the interviews was to evaluate the content and refine wording and response options to be relevant to the target population.
 - Standard "think aloud" procedures were used with directed probes to delve further into the question/answer process.
 - Participants interpreted the items (paraphrasing key sentences in the participants' own words) and what they thought about suggested responses and scales.

Table 1. Participant Eligibility Criteria

Inclusion Criteria	Patients	Nurses
US resident	✓	✓
18 years of age or older	✓	✓
Self-reported physician diagnosis of a NET	✓	N/A
Self-report of experience receiving an injection of either LA formulation of octreotide or lanreotide for the treatment of their NET or to treat symptoms of CS	✓	N/A
Self-report of experience injecting LA octreotide and/or lanreotide	N/A	✓
Able and willing to provide verbal informed consent	✓	✓
Able to complete the surveys in English during a telephone interview	✓	✓

CS = carcinoid syndrome; LA = long-acting; N/A = not applicable; NET = neuroendocrine tumor.

RESULTS

Patient (n = 8) and Nurse (n = 2) Characteristics

- Eight patients with a self-reported physician diagnosis of a NET with or without CS and who were receiving or recently received a LA SSA injection were interviewed. Patient characteristics at the time of the interview are listed in Table 2.
- Five patients reported current treatment with LA lanreotide and 3 with LA octreotide; 2 patients reported experience with both injection types. Seven patients were female, and most reported a primary NET in the small intestine (n = 5; 62.5%).
- Both nurses reported 8 to 13 years of experience injecting both LA somatostatin analogs, worked in academic settings, and are active with patient advocacy.
- Participants also described their general experiences with the disease.
- In general, the questionnaire items and response options were well understood. The resulting survey questionnaire will be fielded in a larger sample in 2019.

Table 2. Patient Characteristics (N = 8)

Characteristic	Patients (N = 8)
Self-reported physician diagnosis (n)	
NET only	4
NET with symptomatic CS	4
Type of LA SSA injection currently receiving (n)	
Lanreotide	5
Octreotide	3
Experience receiving lanreotide and octreotide (n)	
Both	2
Primary location of NET (n)	
Small intestine (small bowel, duodenum, jejunum, ileum)	5
Lung	2
Pancreas	1
Gender	
Female	7
Male	1
Time since diagnosis of NET (n)	
0-5 years	1
6-10 years	3
11-15 years	2
16-20 years	2
Frequency of injection (n)	
Every 2 weeks	1
Every 4 weeks or 28 days	6
Every 4-5 weeks	1

CS = carcinoid syndrome; LA = long-acting; NET = neuroendocrine tumor; SSA = somatostatin analog.

PATIENT FEEDBACK

Training or administration inconsistencies:

Patients felt additional LA SSA injection training for nurses was needed.

- Most patients expressed confidence in their "usual" or familiar injection nurse (e.g., minimal or familiar/expected pain/discomfort) and were skeptical of unfamiliar nurses and their knowledge of the injection technique.

Noted issues raised by patients included the following:

Inconsistencies between pinching versus flattening the skin

Lack of nurse experience with giving the injections

Inconsistencies between rubbing versus pressing on the injection site after the injection

Nurse anxiety about giving the injections

Inconsistent body positions are suggested by nurses for the injection

Patients experience multiple needle sticks because the needle gets clogged

Need to locate an area without scar tissue for the injection

Patient-driven discomfort alleviation tactics:

Several patients described pre- and/or post-injection actions taken to alleviate mental and/or physical discomfort (e.g., anxiety, soreness, pain) associated with injections:

- Topical anesthetic on injection site before injection or ice cubes/hot pad on injection site
- Allowing alcohol-wiped skin to dry before the injection so that alcohol is not pushed into the skin, causing pain
- Acetaminophen or naproxen
- Acupuncture
- Cannabis
- Lying prostrate on the table with toes inward to relax hip/buttocks

NURSE FEEDBACK

The nurses described the injection preparation processes at their clinics. Some clinic decision-making factors in prescribing LA octreotide versus LA lanreotide included:

- Patient body mass index (the octreotide needle is long but sometimes not long enough for larger patients, in which case they may go with lanreotide)^a
- Patient experience with side effects; those with more diarrhea may be prescribed LA octreotide

Noted reasons raised by nurses for injection preparation times:

Need to bring both injections to room temperature. To shorten patient wait time, some nurses can set out medications on the counter prior to patient arrival.

Medical record review requires time (e.g., dose confirmation, allergy check).

Timing the octreotide saturation correctly before the liquid crystallizes and clogs the needle.

"Somatuline does not require much prep time."

One nurse will swap out the octreotide needle from the kit and use the original gauge needle to avoid the clogging.

Nurses raised the following points regarding injection education:

- One nurse noted that the octreotide manufacturer sent a training person and provided a model that lights up if you hit the right area for injection.
- The other nurse noted that they have "figured it out" and established protocol efficiencies with the other two nurses at the infusion center. New nurses are trained on the same process. Also, teaching videos are available, and the training for octreotide has evolved with the kit change.

^aRoutes of administration are different among LA octreotide (intra-muscular) and LA lanreotide (deep subcutaneous).

CONCLUSIONS

- Results of the cognitive debriefing interviews found that the questionnaire was well understood and captured relevant concepts related to SSA injection.
- Concepts related to SSA injection of importance to patients with NET included nurse training and familiarity with the injection process, proper preparation and administration, and differences in patient demographics.
- Caution must be taken in generalizing results from a small sample size.
- The larger patient survey will provide broader insight into the SSA injection experienced by patients with NET.

REFERENCES

- National Comprehensive Cancer Network. NCCN clinical practice guidelines in oncology. Neuroendocrine tumors version 2. 2018.
- Carcinoid Cancer Foundation. <https://www.carcinoid.org/>.

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