



Self-reported side effects in neuroendocrine tumour (NET) patients prescribed somatostatin analogues - the role for specialist dietitians and nurses

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Study Team



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Background

- Often a change in symptoms after starting somatostatin analogues (SSA's).
- In practice side effects experienced by patients are more common than patient information / literature [1,2] suggests.
- Side effects contribute to a large proportion of NET Dietitian and NET Nurse workload.
- It was therefore important to ask patients about their experience whilst taking SSA's.
- Data can be used to help patients and NET units.

Aims



- Assess what symptoms/side effects patients report on SSA's.
- Assess the severity of symptoms/side effects reported by patients whilst on SSA's.
- Produce recommendations on how to deal with symptoms commonly experienced by patients on SSA's.

Method



A survey was posted on social media (twitter), within a closed NET patient support group and an open advocacy site. It was open to anyone worldwide.

Patients were asked 2 questions:

- 1) Which somatostatin analogue they were prescribed
- 2) Rate the severity (0-10) of any symptoms they experience

A list of 11 options was given: constipation, steatorrhoea, diarrhoea, feeling the burden of treatment, vitamin B12 deficiency, hair thinning, nausea, fat soluble vitamin deficiency, weight loss, low glucose level and gallstones.

Results

- Question 1 was answered by 172 patients.
 - Brand of somatostatin analogue taken was 48% Somatuline (lanreotide) autogel v 52% Sandostatin (octreotide) LAR
- Question 2 regarding side effects and severity was answered by 176 patients.

The most common side effect reported was constipation (85%), with 8.6% of these rating the severity 10/10.

Less comparable findings included:

- 68% of patients feel the burden of treatment.
- Over 62% report vitamin B12 deficiency.
- Over half (52%) report a fat soluble vitamin deficiency.

Results

Symptom	Number effected (rating 1-10/10)	Percentage (%) affected (rating 1-10/10)	% effected on Sandostatin (octreotide) LAR Studies [1]	% effected on Somatuline (lanreotide) autogel Studies [2]
Constipation	150	85.22%	≥ 10%	0.1-9.99%
Steatorrhoea	148	84.09%	0.1-9.99%	0.1-9.99%
Diarrhoea	139	78.97%	≥ 10%	≥ 10%
Feeling burden of treatment	119	67.61%	No data	No data
Vitamin B12 deficiency	110	62.50%	No data	No data
Hair thinning	101	57.38%	0.1-9.99%	0.1-9.99%
Nausea	93	52.84%	≥ 10%	0.1-9.99%
Vit A,D,E,K deficiency	91	51.70%	No data	No data
Weight loss	76	43.18%	No data	0.1-9.99%
Low glucose	75	42.61%	0.1-9.99%	0.1-9.99%
Gallstones	29	16.47%	≥ 10%	≥ 10%



Conclusion

- Our results show what problems patients report whilst on SSA's, and how severe these are.
- Constipation, steatorrhoea and diarrhoea during SSA use are the most commonly reported bowel symptoms.
- Symptoms and assumed side effects during SSA use may not have been reported to pharmaceutical companies.

Recommendations

- Adverse events' thought to be linked to SSA's must be reported to the pharmaceutical company.
- NET MDT teams should include at least one NET specialist Dietitian in addition to NET Nurses.
- Stool frequency, consistency and colour must be discussed at appointments. Loose stools and constipation both warrant dietary and lifestyle investigation.
- Trial pancreatic enzyme replacement therapy (PERT) if steatorrhoea or weight loss commences after starting SSA's .

Recommendations

- Consider testing for SIBO/BAM in patients who have diarrhoea or steatorrhoea that has not resolved with anti-diarrhoeal's, PERT, or dietary changes.
- Patients must be screened for malnutrition during all hospital visits.
- Fat soluble vitamins need to be checked before starting somatostatin analogues and ideally every 6-12 months.
- Fat-soluble vitamins need to be supplemented if <200 cm of healthy small bowel remains after resection.

Recommendations



- Vitamin B12 levels should be monitored every 6-12 months.
- Random blood glucose testing?
- Specific direct questions for symptom checking with face to face / QoL questionnaire.
- Offer counselling if the burden of treatment is high.
- NET Resources need to be made available to patients

References



1. Novartis Pharmaceuticals UK Ltd (2015). Sandostatin LAR. *Sandostatin LAR (PIL)*.
2. Ipsen Ltd (2015). Somatuline Autogel 60mg, Somatuline Autogel 90mg, Somatuline Autogel 120mg New device. Summary of Product Characteristics.

Thank you!



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