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

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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 \cite{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 there 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

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

Thank you!