Sensory Neuropathic Symptoms in Postural Tachycardia Syndrome (POTS): Insights from a Cross-Sectional Community-Based Survey

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AIM
Identification of patient-reported sensory symptoms in postural tachycardia syndrome (POTS).

BACKGROUND
POTS is a common form of orthostatic intolerance defined as an increase in heart rate of ≥30 beats per minute (bpm) when moving from a supine to standing position (>20 mmHg drop in systolic blood pressure). Prior literature on POTS has primarily focused on autonomic symptoms. We report on a large survey of POTS patients that suggests sensory neuropathic symptoms are common in this population.

METHODS
• Structured, web-based, REDCap survey
• “Diagnosis and Impact of POTS” study
• Vanderbilt IRB approval
• Survey links posted to Dysautonomia International website & social media
• Parents could complete survey for children <18
• Data collected July 2015 – October 2016
• Cross-sectional analysis

RESULTS
• 4178 individuals with a physician diagnosis of POTS completed the survey
• Individuals from 15 countries participated

• POTS patients were 94% female and 93% Caucasian
• Peak age of onset: 14 years
• Median age of onset: 17 years
• 47% with POTS onset after age 18
• 45% report numbness or tingling of the face (33% and 41%, respectively)
• 81% report burning, numbness or tingling of the hands (32%, 65% and 76%, respectively)
• 75% of patients report burning, numbness or tingling of the feet (40%, 58% and 67%, respectively)

Data on burning sensations in the face was not collected.

Table 1 – Other Symptoms in POTS

<table>
<thead>
<tr>
<th>Symptoms</th>
<th>Percent Total (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difficulty concentrating</td>
<td>94</td>
</tr>
<tr>
<td>Headache</td>
<td>94</td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>97</td>
</tr>
<tr>
<td>Muscle pain</td>
<td>84</td>
</tr>
<tr>
<td>Muscle weakness</td>
<td>83</td>
</tr>
<tr>
<td>Constipation</td>
<td>70</td>
</tr>
<tr>
<td>Diarrhea</td>
<td>69</td>
</tr>
<tr>
<td>Dry mouth</td>
<td>66</td>
</tr>
<tr>
<td>Dry eye</td>
<td>60</td>
</tr>
<tr>
<td>Swallowing problems</td>
<td>57</td>
</tr>
<tr>
<td>Double vision</td>
<td>33</td>
</tr>
<tr>
<td>Difficulty urinating</td>
<td>27</td>
</tr>
</tbody>
</table>

CONCLUSIONS

• POTS is primarily seen in Caucasian females.
• While the peak age of onset is 14, approximately half of POTS cases develop in adulthood.
• Upper limb and facial sensory symptoms and widespread autonomic symptoms are common in POTS. Whether this is due to a non-length dependent polyneuropathy in some patients warrants further research.
• Better recognition of POTS symptoms by neurologists may lead to reduced diagnostic delays and improved care of neurological symptoms in POTS.