THE DEVELOPMENT OF A NON-MOTOR QUESTIONNAIRE FOR CRANIO-CERVICAL DYSTONIA

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Background:
• The occurrence of a range of non-motor symptoms (NMS) associated with the various types of adult onset cranio-cervical dystonia such as torticollis (CT) and dystonia are under-recognised and under-reported.
• Currently available scales for assessment of dystonia include:
  - Jankovic Rating Scale (Blepharospasm)
  - Burke-Fahn-Marsden Dystonia Rating Scale: (motor)
  - TAU scale for cervical dystonia:
  - TWSTRS: pain/ADL
  - Writers cramp rating scale
  - Cranio-cervical dystonia questionnaire CDQ-24: (reading/TV, leisure, pain, social events, social isolation, anxiety, depression)

There are no holistic scales addressing NMS in dystonia apart from those addressed in CDQ-24

Conclusions:
1. The proposed NMS questionnaire for CT will address NMS that are not addressed in currently available tools and validate a specific and holistic patient reported NMS questionnaire for torticollis patients based on audit data.

Objective:
• To undertake a clinic based audit of NMS that may be associated with focal dystonia piloted first with cranio-cervical dystonia.

Method:
• CT patients were recruited from dystonia clinics at Kings and satellite centres.
• NMS data was collected using a structured audit based questionnaire based on clinical experience and a sleep audit study (Metta et al. 2009).
• A range of NMS were recorded as declared by the patients using the framework of the PD NMS scale.

Results:
• 100 CT cases audited and non motor items of flagged up was recorded.
• The items are: 1) Sleep, 2) Pain, 3) Spasms during sleep, 4) low mood, 5) social isolation, 6) balance problems, 7) swallowing problems, 8) dribbling of saliva, 9) fatigue, 10) sexual difficulties.
• Sleep dysfunction (insomnia), pain (dystonic local pain and radical), fatigue and low mood were most prevalent in patient reported symptoms.
• Based on these items a proposed holistic dystonia NMS questionnaire has been developed.

Table 1 shows the results when the Dystonia NMS Questionnaire was piloted on 15 CD patients.

<table>
<thead>
<tr>
<th>Item</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you feel refreshed after an overnight sleep?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Do you doze off or fall asleep unintentionally during daytime activities?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you have difficulty getting up in the morning?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Do you have difficulty sleeping?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you suffer from head pain for no apparent reason?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you suffer from headache for no apparent reason?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you suffer from pain not explained by other known conditions?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you suffer from neck pain not explained by other known conditions?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 1 shows the results when the Dysotonia NMS Questionnaire was piloted on 15 CD patients.

Conclusions:
1. The proposed NMS questionnaire for CT will address NMS that are not addressed in currently available tools and CDQ-24. 2. The proposed Dystonia NMSQuest will empower patients with CT to disclose NMS to clinicians. 3. This may help better recognition and characterisation of NMS such as pain, sleep disturbance, depression and fatigue in CT. 4. The dystonia NMSQuest will help development of a 1-grade rating NMS scale which could be used in clinical trials and also to monitor effects of therapy with botulinum toxin.