



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 RS: (motor) disability (feeding, eating, hygiene)
 - Tsui 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

Objective:

- To undertake a clinic based audit of NMS that may be associated with focal dystonia piloted first with cranio-cervical dystonia.
- To develop and validate a specific and holistic patient reported NMS questionnaire for torticollis patients based on audit data.

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.

Dystonia Non Motor Symptom Questionnaire (DNMS Quest)

Name: _____ Age: _____ Date: _____
Centre ID: _____ Male Female

NON-MOVEMENT PROBLEMS IN DYSTONIA

The movement symptoms of Dystonia are well known. However, other problems can sometimes occur as part of the condition or its treatment. It is important that the doctor know about these, particularly if they are troublesome for you.

A range of problems is listed below. Please tick the box 'Yes' if you have experienced it during the past month, if you have not experienced the problem in the past month tick the 'No' box. You should answer 'No' even if you have had the problem in the past but not in the past month.

	Yes	No
1. Do you feel refreshed after an overnight sleep?	<input type="checkbox"/>	<input type="checkbox"/>
2. Do you doze off or fall asleep unintentionally during daytime activities? (For example, during conversation, during mealtimes, or while watching television or reading)	<input type="checkbox"/>	<input type="checkbox"/>
3. Do you have difficulties falling or staying asleep?	<input type="checkbox"/>	<input type="checkbox"/>
4. Does fatigue (tiredness) or lack of energy limit your daytime activities?	<input type="checkbox"/>	<input type="checkbox"/>
6. Do you feel nervous, worried or frightened for no apparent reason?	<input type="checkbox"/>	<input type="checkbox"/>
6. Do you feel sad or depressed?	<input type="checkbox"/>	<input type="checkbox"/>
7. Do you suffer from loss of confidence due to stigma of visible head/neck dystonia?	<input type="checkbox"/>	<input type="checkbox"/>
8. Do you have flat moods without the normal "highs" and "lows"?	<input type="checkbox"/>	<input type="checkbox"/>
9. Do you have difficulty while eating such as chewing or swallowing?	<input type="checkbox"/>	<input type="checkbox"/>
10. Do you dribble saliva during the day?	<input type="checkbox"/>	<input type="checkbox"/>
11. Do you have any speech problems?	<input type="checkbox"/>	<input type="checkbox"/>
12. Do you have problems having sex?	<input type="checkbox"/>	<input type="checkbox"/>
13. Do you suffer from pain not explained by other known conditions?	<input type="checkbox"/>	<input type="checkbox"/>
14. Do you suffer from any walking difficulty?	<input type="checkbox"/>	<input type="checkbox"/>

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 radicular), 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.

Legend: 1a="yes" 0a="no"	
1) Do you feel refreshed after an overnight sleep?	100
2) Do you doze off or fall asleep unintentionally during daytime activities? (For example, during conversation, during mealtimes, or while watching television or reading)	20.0
3) Do you have difficulties falling or staying asleep?	13.3
4) Does fatigue (tiredness) or lack of energy limit your daytime activities?	13.3
5) Do you feel nervous, worried or frightened for no apparent reason?	13.3
6) Do you feel sad or depressed?	46.7
7) Do you suffer from loss of confidence due to stigma of visible head/neck dystonia?	13.3
8) Do you have flat moods without the normal "highs" and "lows"?	13.3
9) Do you have difficulty while eating such as chewing or swallowing?	26.7
10) Do you dribble saliva during the day?	13.3
11) Do you have any speech problems?	13.3
12) Do you have problems having sex?	13.3
13) Do you suffer from pain not explained by other known conditions?	26.7
14) Do you suffer from any walking difficulty?	26.7

Conclusions:

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