Multicenter report of clinical use of a Non-Motor Symptom Questionnaire for craniocervical dystonia: the DNMS Quest

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BACKGROUND

We previously reported the clinical use of a Dystonia Non-Motor Symptom self-completed Questionnaire (DNMS Quest) [1,2], which scores from 0 to 14. In this study, we present data collected in an ongoing multicenter, multilingual validation of the DNMS Quest in consecutive patients with craniocervical dystonia (CCD) attending botulinum toxin clinics at different regional centers in Germany and the UK.

METHODS

In this prospective, one point in time, multicenter study we applied the DNMS Quest with comparator motor scales (TWSTRS, UDRS), established non-motor/quality of life questionnaires (CDQ-24, EQ.5D, MOCA), and the clinical global impression of severity (CGIS) in CCD patients as well as in age and gender matched healthy controls. Demographics are shown in Table 1.

Table 1: Demographics	Patients with cervical dystonia (CD)	Healthy controls	p - value
Patients (Males / Females)	45 (13 / 32)	17 (4 / 13)	0.7
Ethnicity (White / Non White)	45 (45 / 0)	17 (14 / 3)	
Age (Mean ± SD (yrs))	59.20 ± 13.75	57.46 ± 17.04	0.7
Duration of Disease (yrs) (Mean ± SD, range)	13.96 ± 11.46 2.02 – 50.15	-	
Total dose BTX per injection (Mean ± SD Dysport MU)	657.83 ± 358.80 **range?**	-	

Table 2: Motor and Non-Motor Characteristics	Patients with cervical dystonia (CD)	Healthy controls	p-value
TWSTRS	34.58 ± 13.43 9.50 – 65.50		
UDRS	9.62 ± 2.72 1.5 – 14.0		
CGIS	4.38 ± 1.23 2.0 – 7.0	1.0 ± 0.0 1 – 1	<0.001
EQ-5D Graph	63.49 ± 21.10 20.0 – 95.0	69.00 ± 13.12 40.0 – 90.0	0.6
MOCA	27.4 ± 2.33 20.0 – 30.0	27.88 ± 1.90 23.0 – 30.0	0.6
CDQ 24	29.5 ± 17.32 1.0 – 71.0		
DNMSQuest	5.22 ± 2.81 0.0 – 11.0	2.12 ± 1.36 0.0 – 5.0	<0.001

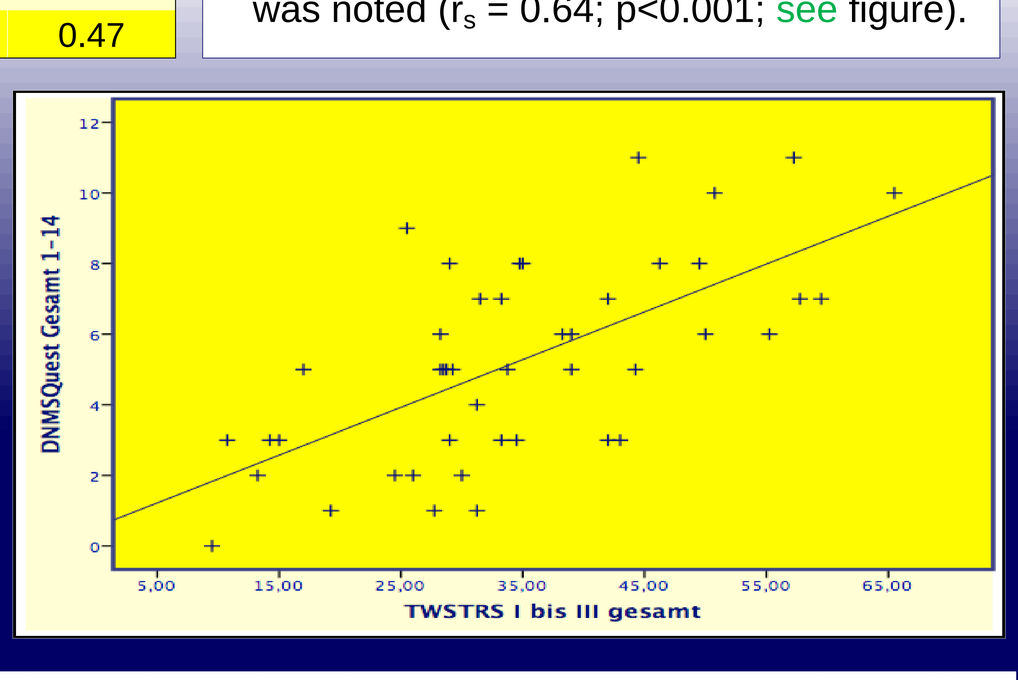
Mean ± standard deviation (SD); Range

Table 3: Dystonia Non Motor Symptom Questionnaire (DNMS Quest)	CD	Controls	p - value
	Pathological answers [%]		
Do you suffer from pain (painful tension) of the body area or near to the body area of your dystonia (without any other condition in this body area that could cause the pain)?	**80.0**	17.6	**< 0.001**
Do you have difficulties falling or staying asleep?	**71.1**	52.9	0.18
Do you suffer from loss of self-confidence due to stigma of visible cervical dystonia?	**55.6**	0.0	**< 0.001**
Does fatigue (tiredness) or lack of energy limit your daytime activities?	**48.9**	35.3	0.34
Do you feel NOT refreshed after an overnight sleep?	**44.4**	35.3	0.52
Do you feel sad or depressed?	**42.4**	23.5	0.17
Do you feel nervous, worried or frightened for no apparent reason?	**40.0**	23.5	0.23
Do you suffer from any walking difficulty or balance problem?	**37.8**	5.9	**0.01**
Do you experience light- headedness or dizziness?	**35.6**	5.9	**0.02**
Does your dystonia affect your vision for instance when your head is turning to one side?	**31.3**	0.0	**< 0.01**
Do you experience unpleasant sensation such as numbness, tingling or pins and needles in the body area or nearby the body area of your dystonia?	**22.2**	5.9	0.13
Do you have flat moods without the normal "highs" and "lows"?	**6.7**	0.0	0.28
Do you have any speech problems?	**2.2**	0.0	0.54
Do you have difficulty while eating such as chewing or swallowing?	**2.2**	5.9	0.47

RESULTS

- 45 patients with cervical dystonia (CD) (32 women); 59.2±13.8 years old (mean ± standard deviation); 14.0±11.5 years of disease duration and 17 healthy controls (13 women; 57.5±17.0 years old) were assessed.
- Motor and Non-Motor characteristics are summarised in table 2.
- Most prevalent dominant NMS in CD, as declared in DNMS Quest, are pain (80%), sleep disturbances (44-71%), loss of confidence (stigma) (56%), fatigue (49%) and mood problems (42%). Occurrence of pain, stigma, dizziness, vision and gait disturbances are significantly higher in patients with CD compared to healthy controls.
- A highly positive correlation of total DNMS Quest and TWSTRS in patients with CD was noted (r_s = 0.64; p<0.001; see figure).

CONCLUSION: NMS are evident in patients with craniocervical dystonia and are often underrecognised. A simple to use self-completed screening tool like the easy to use DNMS Quest is needed to raise awareness for NMS in the context of routine clinical consultations in patients with focal dystonia. Pain, sleep dysfunction, stigma, fatigue and mood problems appear to be dominant issues prompting the need of specific treatment. Also worse motor severity of dystonia seems to be associated with a higher NMS load in CD patients.



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REFERENCES: [1] Naidu Y., Martinez-Martin P., Rizos A., Jost W., Metta V., Warner T., Hulse N., Ashkan K., Ray Chaudhuri K., The development of a non motor scale for cranio−cervical dystonia. Mov Disord 2011: 26 (suppl 2): Abs No: 665. [2] Klingelhoefer L., Warner T., Martino D., Martinez-Martin P., Hulse N., Inniss R., Samuel M., Ray Chaudhuri K., Evaluation of the use of a Dystonia Non Motor Symptom Questionnaire for craniocervical dystonia in the outpatient clinic. Mov Disord 2014: 29 (Suppl 1):1386.