Evaluation of the use of a Dystonia Non Motor Symptom Questionnaire (DNMS Quest) for craniocervical dystonia in the outpatient clinic

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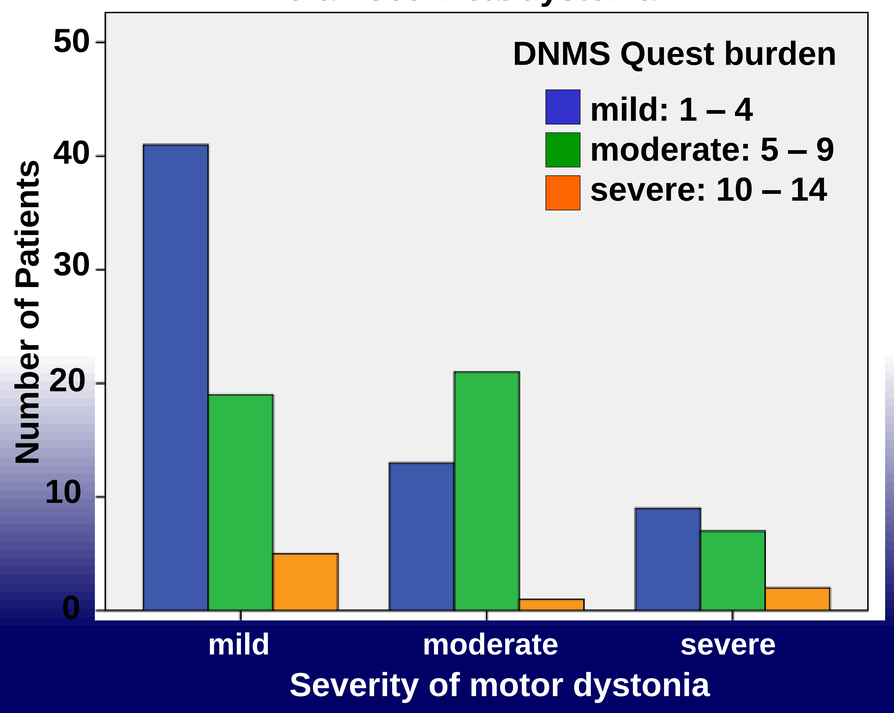
BACKGROUND

Previously we have reported on the development of a Dystonia Non Motor Symptom self completed Questionnaire (DNMS Quest) [1]. In this work we have audited and evaluated the use of this questionnaire in consecutive patients with craniocervical dystonia (CCD) attending botulinum toxin clinics at a regional centre.

METHODS

We prospectively analysed data from 118 patients with craniocervical dystonia which have consecutively completed DNMS Quest and classified the DNMS Quest total score in three severity levels as DNMS burden. We analysed the connection between the DNMS Quest levels and the severity of motor dystonia measured by the Fahn-Marsden Dystonia Scale (FMDS). Patients with generalised dystonia, limb dystonia or undergoing deep brain stimulation were excluded.

Distribution of non motor burden and motor severity in craniocervical dystonia



Dystonia Non Motor Symptom Questionnaire (DNMS Quest)	Pathological answers [%]
Do you suffer from loss of confidence due to stigma of visible head / neck dystonia?	59
Do you have difficulties falling or staying asleep?	58
Does fatigue (tiredness) or lack of energy limit your daytime activities?	49
Do you suffer from any walking difficulty or balance problem?	45
Do you experience light headedness or dizziness?	44
Do you feel refreshed after an overnight sleep?	41
Do you suffer from pain not explained by other conditions?	39
Do you feel nervous, worried or frightened for no apparent reason?	30
Do you feel sad or depressed?	29
Do you experience unpleasant sensation such as numbness, tingling or pins and needles?	29
Does your dystonia affect your vision?	25
Do you have flat moods without the normal "highs" and "lows"?	23
Do you have difficulty while eating such as chewing or swallowing?	23
Do you have any speech problems?	13

RESULTS

In a random consecutive botulinum toxin outpatient population, a total of 118 CCD patients have been audited - cranial (14%) and cervical dystonia (86%). Severity of motor dystonia as rated by FMDS were mild (55%), moderate (30%) and severe (15%). The DNMS Quest scores range from 0 to 14 with arbitrary cut off used for DNMS burden. Severity of NMS burden was mild in 53%, moderate in 40% and severe in 7%. Severe DNMS Quest score was only evident in cervical dystonia (8 patients).

Demographics	No / Mean	% / Range
Patients (Males / Females)	118 (37 / 81)	31% / 69%
Ethnicity (White / Non White)	118 (112 / 6)	95% / 5%
Age (yrs)	60	25 - 85
Duration of Disease (yrs)	11	0 - 44
Botox response (yes / no)	118 (113 / 5)	96% / 4%

CONCLUSIONS: Non motor symptoms are evident in patients with craniocervical dystonia and are often under-recognised. Stigma with secondary isolation, sleep dysfunction and fatigue appear to be dominant issues that need additional support in these patients.

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