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.

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).

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.