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## **Unawareness of Head Tremor in Essential Tremor: A Study of Three Samples of Essential Tremor Patients**

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## Keywords

essential tremor; head tremor; awareness

Patients with Huntington disease may be unaware of their chorea and patients with Parkinson disease often do not recognize or endorse their medication-induced dyskinesias. 1, 2 Head tremor occurs in essential tremor (ET), <sup>3</sup>, <sup>4</sup> yet patients in our experience are often unaware of it. While this phenomenon is anecdotally noted, it has not been formally documented or studied systematically.

To broadly sample ET in different settings, we selected cases from three settings: a tertiaryreferral center (largest sample),<sup>5</sup> a population-based study in Manhattan,<sup>6</sup> and a brain repository. As expected, cases differed in several respects (Table). Using the same clinical questionnaire, each case was asked whether he/she sometimes has a head tremor. A 20 minute videotaped tremor examination was performed, which included assessments of arm and head tremors (including sitting facing the camera, sustained phonation, reading aloud, finger-nosefinger maneuver, drinking, using a spoon, stand facing camera, and walking). The videotape was reviewed (E.D.L.); arm tremors were rated using a 0-3 scale. Head tremor was rated as absent (0), mild or equivocal (1), intermittent yet clearly present (2), moderate (3), or severe **(4)**.

In the tertiary-referral center, 119/320 (37.2%) ET cases had head tremor on examination (≥ 1); 46/119 (38.7%) did not report having head tremor. Most false negatives asked the interviewer, "do you see a head tremor now?" When told "yes", they uniformly commented that they were unaware of this (e.g., "I don't notice it"). By contrast to head tremor, of 298 ET cases with dominant hand tremor while writing on examination (rating  $\geq 1$ ), only 60 (20.1%) did not report having hand tremor while writing (OR 0.40, 95% CI 0.25 – 0.64; i.e., ET cases were 2.5 times less likely to report head tremor than handwriting tremor). Patients may underreport tremor because of embarrassment; however, when we restricted analyses to 129 ET cases who reported that they were not embarrassed by tremor, 21/43 (48.8%) with head tremor did not report their head tremor. When we restricted analyses to 78 ET cases who had moderate or severe head tremor on examination, approximately one-quarter (18/78 [23.1%]) did not

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report head tremor (as compared to only 12/150 [8.0%] cases with moderate to severe handwriting tremor who did not report their handwriting tremor, OR 3.45,95% CI 1.56-7.61). Based on these findings, we consider that failure to report head tremor was not merely due to having mild head tremor.

In the population-based sample, 13/106 (12.3%) cases had head tremor on examination; 7/13 (53.8%) did not report having head tremor. In the brain repository, 92/170 (54.1%) cases had head tremor on examination, but 30/92 (32.6%) did not report having head tremor.

In each setting, one-third to one-half of ET cases did not report the presence of head tremor. These same cases were two to three times more likely to report their hand tremor than their head tremor. One possibility is ET cases failed to report head tremor because they were poor historians or were embarrassed. However, they reported hand tremor with reasonably high validity and, among those who were unembarrassed by their tremor, nearly one-half did not report their head tremor. A second consideration is cognitive impairment. This is unlikely; in our largest sample (tertiary-referral clinic), cases with cognitive impairment (Telephone Interview for Cognitive Status<sup>9</sup> <31) were excluded. Third, even when head tremor impedes a skilled task (e.g., while shaving), patients are often unsure whether this is due to shaky hands or a shaky head. A final possibility is that cases were actually unaware of their head tremor. Indeed, when their tremor was pointed out to them, false negatives uniformly stated that they were unaware of it. A lack of internal feedback about a movement may lessen self-awareness of that movement. <sup>1,2</sup> Whether, from a proprioceptive vantage point, patients have a subjective experience of head tremor, is not clear. For example, with some types of oscillatory cranial movements (e.g., patients with congenital nystagmus, who rarely experience oscillopsia 10) perceptual stability (i.e., lack of awareness of nystagmus) may be achieved through a reduced sensitivity to the motion or the use of other signals to cancel the effects of the movements (i.e., a spatial constancy feedback loop). 11 Whether a similar mechanism is operative in ET cases with head tremor deserves future investigation.

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**Table**Demographic and clinical features of ET cases in each of the three ET case samples

TERTIARY-REFERRAL CENTER (N = 320)	
Age in years	$67.4 \pm 15.2$
Women	165 (51.6%)
White race	301 (94.1%)
Total tremor score	$18.9 \pm 7.3$
Tremor duration in years	$22.9 \pm 18.7$
POPULATION-BASED STUDY (N = 106)	
Age in years	$69.8 \pm 18.4$
Women	63 (59.4%)
White race	42 (39.6%)
Total tremor score	$17.6 \pm 6.5$
Tremor duration in years	$17.4 \pm 19.7$
BRAIN REPOSITORY (N = 170)	
Age in years	$74.5 \pm 9.5$
Women	102 (60.0%)
White race	170 (100%)
Total tremor score	$22.3 \pm 6.9$
Tremor duration in years	$39.2 \pm 20.2$

Values are means  $\pm$  SD and number (percentages)