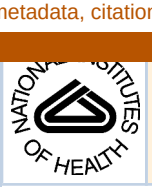

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Embarrassment in Essential Tremor: Prevalence, Clinical Correlates and Therapeutic Implications

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Abstract

Background—Embarrassment is a commonly described feature of essential tremor (ET) but has not been the focus of clinical research.

Objective—To estimate the prevalence, identify susceptible patient groups, and quantify the therapeutic correlates of reported embarrassment.

Methods—106 ET cases from a population-based sample and 349 ET cases from a clinical sample were asked, "Does your tremor often embarrass you?"

Results—In the clinical sample, the prevalence of embarrassment was high (58.2%). Even in those ET cases with no head tremor and mild arm tremor, nearly one-half (29/61 [47.5%]) reported embarrassment. While the prevalence of embarrassment was lower in the population-based sample, it was not negligible (18.9%). Embarrassment was associated with younger age of onset ($p = 0.003$) and women were nearly twice as likely as men to report embarrassment (OR = 1.85, $p = 0.01$). Independent of tremor severity, embarrassment nearly doubled the odds of using tremor medication (OR = 1.86, $p = 0.01$).

Conclusions—Embarrassment may be a source of disability in ET. Even among clinic patients with mild tremor, nearly one-half reported embarrassment. We identified a number of patient characteristics linked to embarrassment. Embarrassment alone (i.e., independent of tremor severity) was responsible for a doubling of tremor medication usage. The majority of clinical trials do not assess the therapeutic effects of medication on embarrassment. These trials may benefit from scaled assessments of level of embarrassment.

Keywords

essential tremor; clinical; embarrassment; treatment

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Introduction

Quality of life issues are now looming large in movement disorders [1], and it is important to understand the impact of disease on quality of life. Embarrassment about tremor is anecdotally well-known to occur in patients with essential tremor (ET) and is likely a prime motivating feature driving treatment and enrollment in clinical trials.

Embarrassment is a unique psychological construct that may be defined as an experience upon having an unacceptable act or condition witnessed by or revealed to others; it is often associated with some amount of loss of honor or dignity. Embarrassment is a source of distress for patients; furthermore, it may result in social handicap and possibly social phobia [2]. Thus, embarrassment itself may be a direct source of disability. It has also been shown that unalleviated embarrassment may remain as an unmet treatment need in many ET patients even after drug therapy has substantially improved their handwriting, drinking, and eating [3]. Hence, understanding embarrassment is important. Despite this, it has not been studied in ET. Little is known of its prevalence or about those patient subgroups who are most susceptible. Furthermore, the relationships between embarrassment, tremor severity and patient motivations to initiate treatment have not been formally quantified.

Our knowledge of embarrassment in ET is mainly anecdotal. The few existing data have been derived from small datasets exclusively from treatment settings. In a study of 18 ET patients attending a treatment center, 8 (44.4%) reported embarrassment, including all patients with head tremor [3]. Of 43 male military veterans seeking treatment for ET, 32 (74.4%) reported embarrassment [4]. In a study of 34 ET patients at a treatment center, “many” complained of embarrassment [5]. Patient susceptibility groups and therapeutic implications of embarrassment have not been assessed in the literature.

We studied embarrassment in ET in order to: (1) estimate its prevalence in two large yet distinct case samples, one from a population (N = 106) and the second from a clinical sample (N = 349). Furthermore, in the clinical sample, we aimed to: (2) establish its clinical correlates (i.e., characterize patient susceptibility groups), and (3) understand and begin to quantify the associations between embarrassment and tremor severity on the one hand and the decision to treat tremor on the other.

Methods

All enrollees signed written informed consent as approved by our institutional ethics board.

Population-based Sample

The Washington Heights-Inwood Genetic Study of Essential Tremor was a family study of ET in the Washington Heights-Inwood community in northern Manhattan, New York. Enrollment was completed in 2000, at which time there were 106 ET cases (59 probands with ET, 33 of their relatives with ET, and 14 affected relatives of control probands). The design of this population-based study has been described in detail elsewhere [6]; in brief, probands with ET age 65 and older were sampled from the Washington Heights-Inwood community and were included if they had a diagnosis of ET. Presence or absence of depression or anxiety was not an enrollment criterion. All cases underwent demographic and medical histories and a videotaped tremor examination, which included one test to assess postural tremor (sustained arm extension) and five tests to assess kinetic tremor (finger-nose-finger, pouring, drinking, using a spoon, drawing spirals)[6]. Each of the six tests was performed with the dominant arm and then the nondominant arm, resulting in 12 tests total. Each videotape was reviewed by a neurologist specializing in movement disorders (E.D.L.) who was blinded to clinical data, and the tremor was rated during each test using a 0 – 3 clinical rating scale. Thereby, each participant

was assigned a total tremor score (range = 0 – 36 maximal tremor). Early in the medical history, all cases were asked, "Does your tremor often embarrass you?"

Clinical Sample

ET cases from the Neurological Institute of New York, Columbia University Medical Center are being enrolled in an ongoing study of the environmental epidemiology of ET (2000 – present); the design of this study has been described in detail previously [7]. Briefly, prior to enrollment, all cases were diagnosed with ET by their neurologist. Presence or absence of depression or anxiety was not an enrollment criterion. After enrollment, all 349 cases underwent a single evaluation that included a series of questionnaires (including a question as to whether they used tremor medications, a tremor disability scale [range = 0 – 100 maximal impairment][8] and Cumulative Illness Rating Scale [CIRS, range = 0 – 42 maximal comorbidity][9]), a performance-based test of function (range = 0 – 100 [maximal difficulty]) [8], and a videotaped tremor examination [7]. Early in the medical history, all cases were asked, "Does your tremor often embarrass you?"

Statistical Analyses

Data for each aim were analyzed in SPSS (Version 15.0). Confidence intervals were computed for several point estimates.

Results

Prevalence of Embarrassment

There were 106 ET cases in the population-based sample (mean ± SD age = 69.8 ± 18.4 years; 63[59.4%] women; age of tremor onset = 56.7 ± 25.6 years; tremor duration = 15.4 ± 18.8 years; total tremor score = 17.6 ± 6.5). Twenty (18.9%) of 106 reported embarrassment (95% CI = 12.6% – 27.4%).

There were 349 ET cases in the clinical sample (age = 67.2 ± 15.3 years; 178[51.0%] women; age of tremor onset = 44.9 ± 22.5 years; tremor duration = 22.6 ± 18.6 years; total tremor score = 18.8 ± 7.2). Compared to the population sample, a larger proportion (203 or 58.2%, 95% CI = 52.9% – 63.2%) reported embarrassment (chi-square = 50.25, $p < 0.001$).

Clinical Correlates of Embarrassment (Clinical Sample)

In univariate analyses, ET cases who reported embarrassment differed from those who did not report embarrassment in demographic factors (younger age, female gender, lower education) and several disease characteristics (younger age of tremor onset, longer tremor duration, family history of ET or tremor, higher total tremor score, greater tremor disability, poorer performance-based test results, voice tremor, and greater medication usage)(Table 1). In multivariate logistic regression analyses, a smaller number of factors emerged that best identified patients who were more susceptible to embarrassment (for final model, $p < 0.001$). In the final model, embarrassment (dependent variable) was associated with female gender (odds ratio [OR] = 1.85, 95% CI = 1.16 – 2.96, $p = 0.01$ [i.e., women were nearly twice as likely as men to be embarrassed, and this was independent of presence or absence of head tremor and arm tremor severity]), younger age of tremor onset (OR = 0.98, 95% CI = 0.97 – 0.99, $p = 0.003$ [i.e., with each 10-year reduction, the odds of embarrassment increased by 20%]), and greater tremor disability scale score (OR = 1.02, 95% CI = 1.01 – 1.03, $p < 0.001$ [i.e., with each 10% increase in the disability scale score, there was a 20% increased odds of embarrassment]).

We further stratified ET cases into total tremor score quartiles. Even when we selected ET cases with no head tremor and mild arm tremor (total tremor score in lowest quartile ≤14), nearly one-half (29/61 [47.5%]) reported embarrassment.

Embarrassment, Tremor Severity and Use of Tremor Medication (Clinical Sample)

In univariate analyses, we examined the predictors of current tremor medication use (dependent variable); these were total tremor score, tremor disability scale score, performance-based test score, reported embarrassment and family history (Table 2). In multivariate analyses, two factors emerged, which were associated with an increased odds of using tremor medication: higher total tremor score (OR = 1.04, 95% CI = 1.002 – 1.08, p = 0.04, i.e., with each ten point increase in the total tremor score, the odds of using tremor medication increased by 40%) and reported embarrassment (OR = 1.86, 95% CI = 1.15 – 3.01, p = 0.01, i.e., independent of tremor severity, reported embarrassment was associated with an 86% increased odds of using tremor medication).

Discussion

The prevalence of embarrassment depended on the method of case ascertainment. In a clinical sample, it was a feature of more than one-half (58.2%), though not all, cases. This high prevalence is not surprising in a group of self-referred cases attending a treatment center. Yet even in a population-based sample, while the prevalence was only one-third of that seen in a treatment setting, at 18.9%, it was not negligible.

One limitation of this study is that we assessed embarrassment using a single question; the degree of embarrassment was not graded. Hence, our analyses focused on factors associated with the presence or absence of embarrassment rather than the severity of embarrassment. Within this limited scope, we identified several factors that were associated with embarrassment in initial univariate analyses and, in further multivariate modeling, a smaller number of factors emerged that identified patients who were most susceptible to embarrassment. Of interest is that women were twice as likely as men to report embarrassment, and this was completely independent of presence or absence of head tremor or arm tremor severity. Furthermore, younger age of onset was also associated with increased odds of embarrassment. We had hypothesized the converse (i.e., less embarrassment with more time to come to terms with their condition). Perhaps the presence of tremor at an early age leads to greater sensitization.

While there was an association between embarrassment and tremor severity, our analyses also indicated that embarrassment was not merely a by-product of severe tremor. Even among the subgroup of ET cases who had mild arm tremor and no head tremor, nearly one-half (47.5%) reported embarrassment. These data indicate that embarrassment is an important independent factor to be reckoned with in treatment settings. Indeed, embarrassment was associated with an 86% increased odds of using tremor medication and this was independent of tremor severity.

Embarrassment scales for ET do not exist; however, they would be beneficial in the clinical assessment of patients. Such scales could be adapted from existing literature on the social stigmata of other medical illnesses (e.g., epilepsy, obesity, and stress incontinence).

This study had limitations. If our question had asked whether tremor is “sometimes” rather than “often” embarrassing, prevalence estimates would have been higher. Second, embarrassment was assessed with a single question rather than a series of questions as no such series exist for ET. The use of a single question likely resulted in lower reliability and sensitivity and did not allow for correlations between degree of embarrassment and other clinical correlates. Third, our cases were seen at one time point; it would be useful for future studies

to evaluate changes in embarrassment over time. Finally, additional studies are needed to more fully assess the relationships between embarrassment and other psychosocial issues such as social phobia, depression, anxiety, and health-related quality of life.

In summary, embarrassment may be a source of disability in ET and a barrier to successful treatment (i.e., patients may have remaining embarrassment-related distress despite having a medication-related reduction in tremor amplitude). Even among clinic patients with mild tremor, nearly one-half reported embarrassment. Women and young-onset cases were particularly susceptible. Embarrassment nearly doubled the odds that a patient was taking a tremor medication; interestingly, this was independent of the severity of the tremor. The majority of clinical trials do not assess the therapeutic effects of medication on embarrassment. Clinical trials of ET may wish to provide scaled assessments of level of embarrassment as well as pre-treatment and post-treatment comparisons of these levels.

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Table 1

Clinical features of ET cases who report embarrassment s vs. ET cases who do not report embarrassment

	ET cases who reported embarrassment (n = 203)	ET cases who did not report embarrassment (n = 146)	Significance (p value)
Age in years	65.5 ± 16.2	69.5 ± 13.8	0.02[a]
Female Gender	115 (56.7%)	63 (43.2%)	0.01[b] OR = 1.7 (1.1 – 2.7)
White Race	188 (92.6%)	140 (95.9%)	0.20[b]
Education (years)	14.7 ± 3.8	15.5 ± 3.9	0.050[a]
Age of tremor onset in years	40.8 ± 22.9 (n = 198)	50.4 ± 20.8	<0.001[a]
Tremor duration in years	25.2 ± 18.9 (n = 198)	19.1 ± 17.6	0.003[a]
First- or second-degree relative with ET or tremor	138 (68.0%)	80 (54.8%)	0.01[b] OR = 1.8 (1.1 – 2.7)
Currently takes daily medication for tremor	112 (55.2%)	56 (38.4%)	0.002[b] OR = 2.0 (1.3 – 3.1)
Total tremor score	19.9 ± 7.5	17.4 ± 6.4	0.001[a]
Tremor disability scale score	59.0 ± 28.6 (n = 202)	41.1 ± 27.6 (n = 140)	<0.001[a]
Performance-based test score*	34.3 ± 22.2 (n = 116)	26.2 ± 19.3 (n = 75)	0.01[a]
CIRS score	5.6 ± 3.7	5.5 ± 3.6 (n = 141)	0.76[a]
Head tremor by history	78 (38.6%) (n = 202)	44 (30.3%) (n = 145)	0.11[b] OR = 1.4 (0.92 – 2.3)
Head tremor on exam	83 (40.9%)	50 (34.2%)	0.21[b]
Voice tremor by history	49 (24.1%)	15 (10.3%)	0.001[b] OR = 2.8 (1.5 – 5.2)
Voice tremor on exam	71 (35.3%) (n = 201)	38 (26.2%) (n = 145)	0.07[b] OR = 1.5 (0.96 – 2.5)

Values represent mean ± standard deviation or number (percentage). For some items, there were missing data and sample size is provided in parentheses (e.g., n = 198).

* Performance-based test score was performed as part of a sub-study.

OR = odds ratio with 95% confidence intervals.

[a] t test

[b] Chi-square test

CIRS = Cumulative Illness Rating Scale.

Table 2

Odds of using a tremor medication

Factors	**OR (95% CI), p value univariate analysis***
Age in years	1.01 (0.995 – 1.02), p = 0.24
Gender	0.88 (0.58 – 1.35), p = 0.57
White Race	0.96 (0.69 – 1.34), p = 0.79
Education (years)	0.98 (0.93 – 1.03), p = 0.44
Age of tremor onset in years	1.001 (0.99 – 1.01), p = 0.82
Tremor duration in years	1.004 (0.99 – 1.02), p = 0.46
First- or second-degree relative with ET or tremor	1.64 (1.06 – 2.55), p = 0.03
Total tremor score	1.05 (1.01 – 1.08), p = 0.005
Tremor disability scale score	1.01 (1.005 – 1.02), p = 0.001
Performance-based test score	1.02 (1.002 – 1.03), p = 0.02
CIRS score	1.05 (0.99 – 1.12), p = 0.09
Head tremor by history	1.22 (0.79 – 1.90), p = 0.38
Head tremor on exam	1.27 (0.83 – 1.96), p = 0.27
Voice tremor by history	1.38 (0.80 – 2.38), p = 0.25
Voice tremor on exam	1.46 (0.93 – 2.31), p = 0.10
Reported embarrassment	1.98 (1.28 – 3.05), p = 0.002

*dependent variable = current use of a tremor medication.

CIRS = Cumulative Illness Rating Scale.