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## Tremor-Related Quality of Life: A Comparison of Essential Tremor vs. Parkinson's Disease Patients

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### Abstract

**Background**—Tremor-related quality of life is a multi-dimensional concept that reflects the physical, emotional and other health effects of tremor. Curiously, tremor-related quality of life has never been directly compared in patients with the two major tremor disorders, essential tremor (ET) and Parkinson's disease (PD). We performed a head-to-head comparison of ET with PD patients.

**Methods**—The Quality of Life in Essential Tremor (QUEST) questionnaire was administered to 103 ET and 103 matched PD patients enrolled in a clinical-epidemiological study in New York.

**Results**—The QUEST total score and QUEST physical subscore were higher in ET than PD patients (both  $p < 0.05$ ). In relative terms, ET patients reported significantly more impairment than PD patients in multiple areas; PD patients reported more impairment than ET patients in one area (all  $p < 0.02$ ). In absolute terms, tremor impacted on many aspects of quality of life in both diseases, including physical and psychosocial, and in one-third or more of PD patients, tremor sometimes, frequently or always interfered with numerous physical activities, including writing, using a typewriter/computer, fixing small things, dressing, eating, and holding reading material.

**Conclusions**—Tremor is a clinical entity that can have numerous effects on patients. While there were relative differences between the two major tremor disorders, ET and PD, in absolute terms, tremor impacted on several domains of quality of life, from physical to psychosocial, in a large proportion of ET and PD patients. Attempts to judge the efficacy of treatments for tremor, whether pharmacological or surgical, should consider its broad impact.

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#### Competing Interests

Dr. Louis has no conflicts of interest and no competing financial interests.

Dr. Machado has no conflicts of interest and no competing financial interests.

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## Keywords

essential tremor; Parkinson's disease; tremor; clinical; quality of life

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## Introduction

Health-related quality of life (HRQoL) is a multi-dimensional concept that includes a number of distinct domains, which are related to physical, mental, emotional and social function. To gauge the effects of chronic illness on quality of life, clinical researchers have used a variety of HRQoL questionnaires.

Essential tremor (ET) is a chronic and progressive neurological disease, eventually impacting numerous aspects of daily function [1, 2]. The Quality of Life in Essential Tremor (QUEST) questionnaire is a specific measure of tremor-related quality of life [3, 4], and its recent introduction has given rise to a growing literature on tremor-related quality of life in ET. Although informative, available studies have a number of limitations, which include the enrollment of surgical patients with significant and disabling tremor whose experiences cannot be extrapolated to most patients with ET [5], the enrollment of very young patients whose age is not typical of ET patients in developed countries [6], and small samples enrolled in specific therapeutic settings (e.g., clinical trials) [7]. QUEST data from several countries, including Spain [3] and India [6], have been published; by contrast, data from patients in the United States are limited [8]. Most important is that, aside from one study in India [6], data on the >30 individual items that richly comprise the QUEST have not been presented in any published study.

Nearly all of the items on the QUEST relate both specifically and explicitly to tremor and its effects on perceived health. Curiously though, the instrument has not been applied to patients with Parkinson's disease (PD), despite the fact that (1) tremor is a hallmark feature of PD, (2) tremor, whether rest, postural or kinetic, occurs in the large majority of PD patients at some point during the illness, (3) and action tremor has been reported in >90% of PD patients [9]. One important caveat; however, is that the psychometric properties of the QUEST have not been assessed in a group of PD patients; hence, assessing these attributes is an important step.

Furthermore, tremor-related quality of life has not been directly compared using the same instrument in the two major tremor disorders, ET and PD. Hence, a head to head comparison has yet to be performed.

The goals of this study were to (1) use the QUEST to present a fine-grained view of tremor-related quality of life in a cohort of patients with ET enrolled in a clinical-epidemiological study in the United States, (2) assess the psychometric properties of the QUEST in PD patients, and (3) directly compare tremor-related quality of life in patients with ET vs. PD.

## Methods

### Participants

Participants were enrolled in a clinical-epidemiological study of movement disorders at the Neurological Institute, Columbia University Medical Center (CUMC) (2009 – 2014) [10, 11]. The study assessed the role of environmental toxins in disease etiology; it also assessed a wide range of clinical features. ET and PD patients seen in the most recent 5 years were identified from a computerized billing database at the Center for Parkinson's Disease and Other Movement Disorders at the Institute. Each patient had received a diagnosis of ET or PD from their treating neurologist at the Institute. One of the authors (E.D.L.) reviewed the office records of identified patients; those with diagnoses of or physical signs consistent with other movement disorders were excluded. During the review, the most recent Hoehn & Yahr score [12] and daily dose (mg) of levodopa were recorded for PD patients.

The CUMC Internal Review Board approved study procedures. Signed informed consent was obtained upon enrollment.

### Study Evaluation

During the in-person assessment, a trained research assistant administered a series of structured questionnaires, which elicited data on (1) demographic variables, (2) general medical health (Cumulative Illness Rating Scale score [13] (range = 0 – 42 [maximum]), total number of prescription medications), (3) disease severity or stage (e.g., duration of symptoms, taking medication to treat tremor [yes vs. no]), and (4) additional variables of interest (e.g., age of tremor onset, family history [first- or second-degree relative] of ET, family history of PD).

The Center for Epidemiological Studies Depression Scale (CESD-10) was administered - a self-report ten-item screening questionnaire for depressive symptoms (range = 0 – 30 [greater depressive symptoms]) [14]. The Essential Tremor Embarrassment Assessment, a 14-item assessment of tremor-related embarrassment (range = 0 – 70 [maximal embarrassment]) [15] was administered to ET patients.

The QUEST was administered [4] to ET and PD patients. In this questionnaire, 30 items are rated on a five-point scale (0 – 4), corresponding to the frequency (never, rarely, sometimes, frequently, always) with which tremor is perceived to currently impact a function or to be associated with various feelings or attitudes [4, 8]. Items are grouped into five domains: physical ( $n = 9$ , e.g., tremor interferes with eating), psychosocial ( $n = 9$ , e.g., tremor interferes with relationships with others), communication ( $n = 3$ , e.g., tremor interferes with ability to communicate), hobbies/leisure ( $n = 3$ , e.g., tremor caused the individual to quit hobbies), and work/finance ( $n = 6$  items) [4]. There are 6 additional items in which tremor is rated in the head, voice and each limb (for each, score 0 – 4), corresponding to the severity of tremor (none, mild, moderate, marked, severe). Four items from the work/finance domain did not apply to the vast majority of our patients, who were elderly, so that in our analyses of the psychometric attributes of QUEST in PD, we used a 26 item version of QUEST that included only the two relevant work/finance items (tremor resulted in early retirement, tremor lead to financial problems/concerns).The psychometric attributes of QUEST in ET

patients have been assessed and most are satisfactory [3, 4]. The psychometric attributes of QUEST have not been assessed in PD, and this was an aim of this study.

A videotaped neurological examination was performed on ET patients. This included one test for postural tremor and five for kinetic tremor (e.g., pouring, drinking) performed with each arm (12 tests total). A neurologist specializing in movement disorders (E.D.L.) used a reliable [16] and valid [17] clinical rating scale, the Washington Heights-Inwood Genetic Study of ET (WHIGET) tremor rating scale, to rate postural and kinetic tremor during each test: (0 – 3). These ratings resulted in a total tremor score (range = 0 – 36) [18].

## Diagnoses

ET diagnoses were re-confirmed (E.D.L.) using the videotaped neurological examination and WHIGET diagnostic criteria (moderate or greater amplitude kinetic tremor [tremor rating  $\geq 2$ ] during three or more tests or a head tremor, in the absence of PD, dystonia or another cause) [19]. The WHIGET diagnostic criteria for ET were developed for a population-based genetic study and, based on data from approximately 2,000 normals (non-diseased controls), these criteria carefully indicate the specific examination maneuvers during which tremor should be present and the severity of tremor that should be evident during these maneuvers. These criteria have been shown to be reliable [16] and valid [18], and are used routinely in Dr. Louis' epidemiological studies of ET [20, 21] and those of other tremor investigators in the US and internationally [22, 23]. The diagnosis of PD was confirmed (E.D.L.) using published diagnostic criteria [24].

## Final Subject Selection

QUEST data were available on all 103 PD patients. These were compared to data on 103 ET patients who were frequency-matched to the PD patients by age and gender.

## Statistical Analyses

Data were analyzed in SPSS (Version 21). Demographic and clinical characteristics of ET and PD patients were compared using chi-square tests, Student's t tests, or Mann-Whitney tests (if the variable was not normally distributed) (Table 1).

We evaluated a number of psychometric attributes of the QUEST total score and each of five subscores: (1) *acceptability* (missing data [standard acceptable value <5%], difference between mean and median [standard  $\leq 10\%$  of the maximum possible score], and floor and ceiling effects [maximum acceptable limit 15%]), and (2) *reliability* (internal consistency determined by Cronbach's alpha coefficient [standard value  $\geq 0.70$ ], item-item correlation coefficients using Spearman's rho (values between 0.30 and 0.70 = moderate and values  $>0.70$  = high), and reproducibility [test-retest reliability] using the intraclass correlation coefficient (one-way random-effects model, single measure)[threshold value for groups  $\geq 0.70$ ]) [3]. These analyses (Table 2) were restricted to the 88 PD patients who reported tremor

Rather than selecting only those patients who self-reported tremor, our goal in assessing quality of life was to obtain a global (i.e., broad and all-encompassing) view of PD in all-

comers (i.e., all patients who were encountered). Furthermore, in these and prior analyses, we have found that even among patients who self-report no tremor, there can be mild or intermittent tremor, with associated self-reported changes in tremor-related quality of life on detailed questioning, further justifying our reluctance to attempt to selectively remove some PD patients from the analyses of tremor-related quality of life. Nonetheless, in one analysis, we also reported results after having removed a small number of PD cases who did not report tremor.

QUEST data were compared in ET vs. PD patients either using Mann-Whitney tests (for QUEST total score and each of five QUEST subscores) or a linear-by-linear test of association (for ordinal data on each of the QUEST's 36 self-assessment items) (Table 3). We assessed correlations between the QUEST total score and QUEST physical subscore and several measures of disease severity or duration both in ET and PD patients (Spearman's rho).

## Results

The 103 ET and 103 PD patients were similar in age, gender, race and education (Table 1). The two groups did not differ with respect to Cumulative Illness Rating Scale scores or total number of prescription medications used. As expected, the age of onset was younger and tremor duration was longer in ET than PD, and the two groups differed with respect to the proportion with a family history of ET or PD (Table 1). Interestingly, a marginally higher percentage of PD than ET patients was taking medication to treat tremor (Table 1).

We assessed a number of psychometric attributes of the QUEST total score and each subscore. In terms of acceptability, missing data accounted for <5% of data and the difference between the mean and median value was less than 10% of the maximum possible score for the total QUEST score and three of five QUEST subscores (Table 2). Floor effects were <15% for the total score and two of five subscores. Ceiling effects were very low ( 4.7% for the total score and each subscore). Cronbach's alpha coefficient was uniformly higher than 0.70. Item-item correlation coefficients had a broad range (Table 2); most of these fell in the 0.3 – 0.7 (moderate) range (2/3 for communication subscore, 1/1 for work/finance subscore, 3/3 for the hobbies/leisure subscore, 34/36 for the physical aspects subscore, and 29/36 for the psychosocial aspects subscore). The intraclass correlation coefficient was in the 0.36 – 0.66 range (Table 2).

The QUEST total score (30 items) and QUEST physical subscore were higher in ET than PD patients (Table 3). By contrast, the following QUEST subscores were similar in the two groups: psychosocial, communication, hobbies/leisure, and work/finance (Table 3).

Specific items for which ET patients had more impairment than PD were: my tremor interferes with my ability to write ( $p = 0.001$ ), my tremor interferes with eating ( $p < 0.001$ ), my tremor interferes with drinking ( $p < 0.001$ ), I am embarrassed by my tremor ( $p = 0.01$ ), I use alcohol more frequently than I would like because of my tremor ( $p < 0.001$ ), and I have difficulty concentrating because of my tremor ( $p = 0.025$ ). Self-ratings of tremor severity were higher in ET than PD patients in both arms (both  $p < 0.001$ ) (Table 3).

PD patients had more impairment than ET patients in one area: it is difficult for others to understand my speech because of my tremor ( $p = 0.02$ ) (Table 3). Self-ratings of tremor severity were higher in PD than ET patients in both legs (both  $p < 0.001$ ). The large majority of PD patients reported having tremor (88 of 103 [85.4%]), whereas 15 (14.6%) did not. When we removed these 15 from the analyses, the differences between ET and PD patients persisted.

While there were several *relative* differences in ET vs. PD patients, in *absolute* terms, tremor impacted on numerous aspects of quality of life not only in ET patients but also in PD patients. For example, while nearly one-half (49.4%) of ET patients reported that tremor frequently or always interfered with their ability to write, 38.3% of PD patients reported the same thing. Tremor sometimes, frequently or always interfered with the following physical activities in one-third or more of PD patients: writing, using a typewriter/computer, fixing small things, dressing, eating, and holding reading material (Table 3). Similarly, tremor sometimes, frequently or always resulted in numerous signs of psychosocial stress in 25% or more of PD patients (my tremor makes me feel negative about myself, I am embarrassed about my tremor, I am depressed because of my tremor, I worry about the future, I am nervous or anxious, and I have difficulty concentrating because of my tremor) (Table 3).

In ET cases, the QUEST Physical subscore was correlated with the total tremor score (Spearman's  $r = 0.43$ ,  $p < 0.001$ ) and tremor duration (Spearman's  $r = 0.20$ ,  $p = 0.05$ ). In PD cases, the QUEST Physical subscore was correlated with daily levodopa dosage (mg) (Spearman's  $r = 0.43$ ,  $p = 0.001$ ), tremor duration (Spearman's  $r = 0.29$ ,  $p = 0.008$ ), but not with Hoehn & Yahr score (Spearman's  $r = 0.12$ ,  $p = 0.42$ ).

## Discussion

We used the QUEST to obtain an in-depth view of tremor-related quality of life in a cohort of patients with ET. Tremor impacted on numerous aspects of quality of life in ET, which was reflected by difficulties in physical, psychosocial, communication, and hobbies/leisure domains. The data indicate that certain physical activities (e.g., eating, writing, drinking) are affected to the greatest degree, but all of the physical activities assessed were associated to some degree with tremor-related difficulty. These included activities such as typing, using a telephone, dressing, brushing teeth, and holding reading material, which were endorsed as frequently or always affected in 28.0%, 13.7%, 28.2%, 17.5%, 9.7% and 15.5% of ET patients, respectively. The broad range of psychosocial items were similarly affected, with tremor interfering with personal relationships, resulting in negative feels of oneself, and feelings of depression and social isolation. A particularly large proportion of ET patients endorsed feelings of embarrassment and anxiety from tremor. We are aware of only one prior study of ET in which detailed, item-by-item QUEST data were presented [6]. That was a study of 50 ET patients in Bangalore, India; however the ET patients were on average 30 years younger than ours (mean age = 40.7 vs. 69.7 years) and mean tremor duration was 8.4 years, compared with 30.9 years in our study. In that study, a significantly lower proportion of ET patients reported the presence of tremor-related physical difficulties (e.g., in their study, 10% of patients reported that tremor interfered with eating [i.e., score  $> 0$ ] whereas in



our study, this value was 84.5%); however, it is of interest that the psychosocial burden of tremor was similar in the two studies [6].

This was the first direct comparison of tremor-related quality of life in patients with the two major tremor disorders, ET vs. PD. In PD, there were clear tremor-related quality of life issues. Indeed, tremor sometimes, frequently or always interfered with the following physical activities in approximately one-third or more of PD patients: writing, using a typewriter/computer, fixing small things, dressing, eating, and holding reading material. Also, there were differences between PD and ET patients. The QUEST total score (30 items) and the QUEST physical subscore were higher in ET than PD patients, and a number of physical and psychosocial items were associated with more impairment in ET than PD patients: tremor interferes with my ability to write ( $p = 0.001$ ), my tremor interferes with eating ( $p < 0.001$ ), my tremor interferes with drinking ( $p < 0.001$ ), I am embarrassed by my tremor ( $p = 0.01$ ), I use alcohol more frequently than I would like because of my tremor ( $p < 0.001$ ), and I have difficulty concentrating because of my tremor ( $p = 0.025$ ). By contrast, PD patients had more impairment than ET patients in one area: it is difficult for others to understand my speech because of my tremor ( $p = 0.02$ ) (Table 3). This was a somewhat curious finding as the two groups rated the severity of their voice tremor similarly (Table 3).

While the discussion of results above considered tremor-related quality of life in a *relative* sense (i.e., ET vs. PD patients), in *absolute* terms, one may see that tremor impacted on numerous measures of quality of life not only in patients with ET but also in those with PD. For example, while nearly one-half (49.4%) of ET patients reported that tremor frequently or always interfered with their ability to write, 38.3% of PD patients reported the same. Tremor sometimes, frequently or always interfered with numerous physical activities in one-third or more of PD patients (Table 3). Similarly, tremor sometimes, frequently or always resulted in psychosocial stress in 25% or more of PD patients (my tremor makes me feel negative about myself, I am embarrassed about my tremor, I am depressed because of my tremor, I worry about the future, I am nervous or anxious, and I have difficulty concentrating because of my tremor) (Table 3).

The QUEST has not previously been administered to PD patients, despite the fact that 29 of 30 items on the QUEST specifically refer to the effects of tremor. One goal of this study was to assess the psychometric properties of the QUEST in such patients. Many of the parameters relating to QUEST were acceptable, with values that were similar to those seen in ET patients [3]. However, as reported in ET, the difference between the mean and median was particularly high for the hobbies/leisure subscore and floor effects were high for the communication, work/finance and hobbies/leisure subscores [3]. As the QUEST was devised for use in ET, some items could be of limited applicability to patients with PD. However, our data indicate that, with the exception of use of alcohol to treat the tremor, all items in the QUEST were endorsed by 20% (and generally many more) of PD patients. The only exception was the work-finance items, which were endorsed by the fewest number of both ET and PD patients. In addition, PD patients may have difficulty disentangling the specific effect of tremor, as opposed to bradykinesia, on some functions (e.g., speech, writing), thereby impacting on the validity of the responses.

In ET cases, greater tremor severity and longer tremor duration were association with lower quality of life, although the association with greater tremor severity was the more robust of these two (respective  $r$  values = 0.43 vs. 0.20). This is not surprising as longer tremor duration, in this context, is likely to be no more than an imperfect marker of greater tremor severity. In PD, higher daily dose of levodopa and longer tremor duration were similarly associated with lower quality of life, with the stronger association being with the former (respective  $r$  values = 0.43 vs. 0.29). Here, as well, the dose of levodopa is likely to be a better marker of tremor severity than is tremor duration. These data indicate that as disease progresses, the quality of life in both disorders declines.

The mean CESD-10 score in our PD patients was  $8.6 \pm 5.7$  (median = 8.0). Two prior studies of PD patients of similar age reported CESD-10 scores that were similar to those that we reported (median = 10 in 106 PD patients with a mean age of  $64.6 \pm 9.8$  years, and means =  $6.8 \pm 3.7$  and  $10.3 \pm 5.0$  in two groups of PD patients with respective mean ages of  $72.0 \pm 8.0$  and  $65.3 \pm 8.9$  years) [25, 26]. We know of no prior data derived from the CESD-10 in ET patients.

Data from the current study should be interpreted within the context of several of limitations. First, our study sampled one group of ET and PD cases and it would be valuable to study additional samples of cases. More specifically, the sample of cases was not derived directly from the population. Future studies, of population-based samples, would add to our knowledge of tremor in patients with milder disease. Second, the QUEST was not developed for patients with PD and several of its psychometric properties were of limited acceptability in PD; nonetheless, the same is true of ET. Third, while a videotaped neurological examination in ET patients allowed us to rate the severity of action tremor and assign a total tremor score, the absence of a videotaped neurological examination in PD cases did not allow us to do so for PD patients. Hence, we were not able to correlate QUEST scores in PD cases to the severity of action tremor.

This study had several strengths and unique attributes. First, aside from one study of very young ET patients (mean age = 40.7) in India [6], this is the only study to provide item-by-item data (i.e., > 30 individuals items) to richly detail the effects of tremor on quality of life in ET. It is the only study to do so in US patients and in ET patients with a more typical age (mean age = 69.7). Second, it provides the first data on the psychometric properties of the QUEST in PD, potentially opening the door to the use of the QUEST in PD. Third, it is the only head-to-head comparison of tremor-related quality of life in the two most common tremor disorders – ET and PD.

In summary, tremor is a clinical entity that can have numerous and disparate effects on patients. While there were relative differences between the two major tremor disorders, ET and PD, in absolute terms, tremor impacted on several domains of quality of life, from physical to psychosocial, in a large proportion of patients. Clinicians should perhaps have a lower threshold to offer treatment to their patients with tremor given what may be an under-recognized impact of tremor on quality of life. Also, attempts to judge the efficacy of treatments for tremor, whether pharmacological or surgical, should consider its broad impact.



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- Tremor-related QoL has never been compared in the two major tremor disorders.
- We obtained an in-depth view of tremor-related QoL in ET and PD.
- Tremor broadly impacted all domains of QoL, from physical to psychosocial.
- There were several significant differences between ET and PD patients.
- Attempts to judge treatments for tremor should consider its broad impact on QoL.

**Table 1**

Demographic and clinical characteristics of 103 ET and 103 PD patients

Demographic and Clinical Characteristics	ET (n = 103)	PD (n = 103)	Significance
Age (years)	69.7 ± 12.3	68.3 ± 8.1	p = 0.34 <sup>a</sup>
Female gender	48 (46.6)	41 (39.8)	p = 0.33 <sup>b</sup>
Caucasian race	96 (93.2)	96 (93.2)	p = 1.00 <sup>b</sup>
Education (years)	16.3 ± 2.4	16.5 ± 2.6	p = 0.42 <sup>a</sup>
Tremor duration (years)	30.9 ± 17.3 [29.0]	7.5 ± 5.8 [6.0]	p < 0.001 <sup>c</sup>
Age of tremor onset (years)	39.1 ± 19.3 [41.0]	60.7 ± 9.9 [61.5]	p < 0.001 <sup>c</sup>
Family history of ET	29 (28.2)	12 (11.7)	p = 0.003 <sup>b</sup>
Family history of PD	7 (6.8)	19 (18.4)	p = 0.01 <sup>b</sup>
Cumulative Illness Rating Scale score	7.4 ± 3.6 [7.0]	6.9 ± 3.5 [6.0]	p = 0.33 <sup>c</sup>
Center for Epidemiological Studies Depression Scale -10 score	7.3 ± 5.6 [6.0]	8.6 ± 5.7 [8.0]	p < 0.08 <sup>c</sup>
Essential Tremor Embarrassment Assessment score	25.5 ± 16.2	NA	NA
Total number of prescription medications	5.1 ± 3.3 [5.0]	5.8 ± 3.0 [5.0]	p = 0.14 <sup>c</sup>
Taking medication to treat tremor	57 (55.3)	70 (68.0)	p = 0.06 <sup>b</sup>
Mean daily levodopa dosage (mg)	NA	555 ± 410 [400]	NA
Hoehn & Yahr score	NA		NA
I		48.9%	
II		44.6%	
III – V		6.3%	
Total tremor score on examination	20.5 ± 5.6	NA	NA

All values represent mean ± standard deviation [median] or number (percentage).

NA = not applicable.

<sup>a</sup> Student's t test.

<sup>b</sup> Chi-square test.

<sup>c</sup> Mann-Whitney test.

Table 2  
Psychometric attributes of the QUEST total score and QUEST subscores in 88 PD patients who reported tremor

	Communication Subscore	Work - Finance Subscore	Hobbies - Leisure Subscore	Physical Aspects Subscore	Psychosocial Aspects Subscore	Total Score <sup>1</sup>
Mean	16.3	12.8	25.8	35.3	24.0	27.3
SD	19.9	24.9	35.8	26.5	22.2	21.9
Median	8.3	0.0	0.0	33.3	16.7	22.6
Difference between the mean and median (percentage of maximum possible score)	8.8	12.8	25.8	2.0	7.3	0.7
Observed range	0 - 75.0	0 - 83.3	0 - 100	0 - 100	0 - 86.1	0 - 82.7
Floor Effects (%)	47.7	64.4	54.7	13.3	14.8	5.1
Ceiling Effects (%)	0.0	0.0	4.7	1.1	0.0	0.0
Cronbach's alpha	0.86	0.90	0.83	0.92	0.92	0.95
Item-item correlation <sup>2</sup>	0.59 - 0.87	0.37	0.53 - 0.70	0.35 - 0.78	0.19 - 0.72	0.09 - 0.87
Intraclass Correlation Coefficient	0.66	0.36	0.59	0.48	0.54	0.46

<sup>1</sup> For this analysis, the 26 item QUEST was used.

<sup>2</sup> For this analysis, Spearman's rho was used.

**Table 3**

QUEST Scores, QUEST subscores and QUEST items in 103 ET and 103 PD patients

QUEST Items	ET (n = 103)	PD (n = 103)	Significance
QUEST Physical Subscore	39.0 ± 25.1 [36.1]	30.8 ± 27.1 [27.8]	p = 0.018 <sup>a</sup>
My tremor interferes with my ability to write			p = 0.001 <sup>b</sup>
0	12.6%	36.3%	
1	6.8%	8.8%	
2	31.1%	16.7%	
3	19.4%	16.7%	
4	30.1%	21.6%	
My tremor interferes with my ability to use a typewriter/computer			p = 0.25 <sup>b</sup>
0	29.0%	42.6%	
1	17.0%	10.9%	
2	26.0%	19.8%	
3	14.0%	13.9%	
4	14.0%	12.9%	
My tremor interferes with my ability to use a telephone			p = 0.16 <sup>b</sup>
0	45.1%	56.9%	
1	18.6%	12.7%	
2	22.5%	19.6%	
3	7.8%	7.8%	
4	5.9%	2.9%	
My tremor interferes with my ability to fix small things			p = 0.25 <sup>b</sup>
0	20.4%	33.3%	
1	24.3%	19.6%	
2	27.2%	19.6%	
3	14.6%	13.7%	
4	13.6%	13.7%	
My tremor interferes with dressing			p = 0.08 <sup>b</sup>
0	42.7%	33.0%	
1	20.4%	18.4%	
2	19.4%	25.2%	
3	11.7%	12.6%	
4	5.8%	10.7%	
My tremor interferes with brushing/flossing my teeth			p = 0.12 <sup>b</sup>
0	64.1%	50.0%	
1	15.5%	23.5%	
2	10.7%	14.7%	



QUEST Items	ET (n = 103)	PD (n = 103)	Significance
3	5.8%	4.9%	
4	3.9%	6.9%	
<b>My tremor interferes with eating</b>			
0	16.5%	46.6%	p < 0.001 <sup>b</sup>
1	19.4%	17.5%	
2	33.0%	24.3%	
3	13.6%	6.8%	
4	17.5%	4.9%	
<b>My tremor interferes with drinking</b>			
0	13.6%	54.4%	p < 0.001 <sup>b</sup>
1	17.5%	15.5%	
2	34.0%	18.4%	
3	16.5%	4.9%	
4	18.4%	6.8%	
<b>My tremor interferes with reading/holding reading material</b>			
0	38.8%	51.5%	p = 0.31 <sup>b</sup>
1	23.3%	14.6%	
2	22.3%	15.5%	
3	5.8%	13.6%	
4	9.7%	4.9%	
<b>QUEST Psychosocial Subscore</b>			
	22.0 ± 19.8 [19.4]	21.4 ± 21.9 [13.9]	p = 0.49 <sup>a</sup>
<b>My tremor interferes with my relationships with others</b>			
0	73.8%	69.9%	p = 0.51 <sup>b</sup>
1	11.7%	13.6%	
2	9.7%	10.7%	
3	3.9%	2.9%	
4	1.0%	2.9%	
<b>My tremor makes me feel negative about myself</b>			
0	40.2%	47.6%	p = 0.51 <sup>b</sup>
1	23.5%	22.3%	
2	21.6%	19.4%	
3	5.9%	4.9%	
4	8.8%	5.8%	
<b>I am embarrassed about my tremor</b>			
0	33.0%	48.5%	p = 0.01 <sup>b</sup>
1	16.5%	18.4%	
2	25.2%	17.5%	

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QUEST Items	ET (n = 103)	PD (n = 103)	Significance
3	16.5%	10.7%	
4	8.7%	4.9%	
I am depressed because of my tremor			p = 0.47 <sup>b</sup>
0	57.3%	52.4%	
1	21.6%	20.4%	
2	13.6%	19.4%	
3	4.9%	4.9%	
4	2.9%	2.9%	
I feel isolated or lonely because of my tremor			p = 0.07 <sup>b</sup>
0	78.6%	68.0%	
1	8.7%	15.5%	
2	10.7%	9.7%	
3	1.9%	2.9%	
4	0.0%	3.9%	
I worry about the future			p = 0.08 <sup>b</sup>
0	48.5%	40.2%	
1	21.4%	16.7%	
2	16.5%	23.5%	
3	5.8%	6.9%	
4	7.8%	12.7%	
I am nervous or anxious			p = 0.25 <sup>b</sup>
0	33.0%	35.0%	
1	14.6%	23.3%	
2	28.2%	25.2%	
3	17.5%	9.7%	
4	6.8%	6.8%	
I use alcohol more frequently than I would like because of my tremor			p < 0.001 <sup>b</sup>
0	70.9%	90.3%	
1	6.8%	4.9%	
2	15.5%	4.9%	
3	1.0%	0.0%	
4	5.8%	0.0%	
I have difficulty concentrating because of my tremor			p = 0.025 <sup>b</sup>
0	70.9%	59.2%	
1	13.6%	11.7%	
2	10.7%	18.4%	
3	2.9%	5.8%	

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QUEST Items	ET (n = 103)	PD (n = 103)	Significance
4	1.9%	4.9%	
QUEST Communication Subscore	10.2 ± 16.9 [0.0]	14.2 ± 19.3 [0.0]	p = 0.16 <sup>a</sup>
My tremor interferes with my ability to communicate with others			p = 0.70 <sup>b</sup>
0	68.0%	64.1%	
1	15.5%	16.5%	
2	11.7%	15.5%	
3	3.9%	3.9%	
4	1.0%	0.0%	
My tremor interferes with my ability to maintain conversations			p = 0.10 <sup>b</sup>
0	73.8%	65.0%	
1	14.6%	13.6%	
2	8.7%	17.5%	
3	2.9%	3.9%	
4	0.0%	0.0%	
It is difficult for others to understand my speech because of my tremor			p = 0.02 <sup>b</sup>
0	82.5%	67.0%	
1	9.7%	16.5%	
2	6.8%	14.6%	
3	0.0%	1.9%	
4	1.0%	0.0%	
QUEST Hobbies/Leisure Subscore	18.4 ± 33.0 [0.0]	22.4 ± 34.3 [0.0]	p = 0.37 <sup>a</sup>
I have lost interest in my hobbies because of my tremor			p = 0.79 <sup>b</sup>
0	69.3%	68.0%	
1	8.9%	6.8%	
2	9.9%	14.6%	
3	6.9%	4.9%	
4	5.0%	5.8%	
I have quit some of my hobbies because of my tremor			p = 0.24 <sup>b</sup>
0	78.6%	71.3%	
1	0.0%	0.0%	
2	0.0%	0.0%	
3	0.0%	0.0%	
4	21.4%	28.7%	
I have had to change or develop new hobbies because of my tremor			p = 0.64 <sup>b</sup>
0	82.0%	79.4%	

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QUEST Items	ET (n = 103)	PD (n = 103)	Significance
1	0.0%	0.0%	
2	0.0%	0.0%	
3	0.0%	0.0%	
4	18.0%	20.6%	
QUEST Work/Finance Subscore	7.9 ± 15.1 [0.0]	10.6 ± 23.0 [0.0]	p = 0.32 <sup>a</sup>
I have had to change jobs because of my tremor			p = 0.12 <sup>b</sup>
0	88.3%	82.4%	
1	5.2%	2.7%	
2	1.3%	1.4%	
3	0.0%	1.4%	
4	5.2%	12.2%	
I am working only part-time because of my tremor			p = 0.59 <sup>b</sup>
0	94.2%	91.8%	
1	0.0%	0.0%	
2	0.0%	0.0%	
3	0.0%	0.0%	
4	5.8%	8.2%	
My tremor interferes with my job/profession			p = 0.49 <sup>b</sup>
0	54.9%	63.5%	
1	11.3%	5.4%	
2	18.3%	17.6%	
3	7.0%	6.8%	
4	8.5%	6.8%	
I had to retire or take early retirement because of my tremor			p = 0.06 <sup>b</sup>
0	91.2%	82.4%	
1	0.0%	0.0%	
2	0.0%	0.0%	
3	0.0%	0.0%	
4	8.8%	17.6%	
I have to use special aids/accommodations to continue my job			p = 0.07 <sup>b</sup>
0	92.0%	78.1%	
1	1.3%	6.8%	
2	4.0%	9.6%	
3	0.0%	1.4%	
4	2.7%	4.1%	
My tremor has led to financial problems/concerns			p = 0.11 <sup>b</sup>

QUEST Items	ET (n = 103)	PD (n = 103)	Significance
0	88.2%	77.5%	
1	3.9%	7.8%	
2	2.9%	6.9%	
3	1.0%	2.0%	
4	3.9%	5.9%	
<b>QUEST Total Score</b>			
26 Items	25.3 ± 19.1 [19.2]	23.7 ± 22.0 [17.3]	p = 0.23 <i>a</i>
30 Items	19.0 ± 16.2 [14.6]	14.8 ± 18.2 [6.7]	p = 0.015 <i>a</i>
<b>Rate the severity of your head tremor</b>			
0	67.6%	78.4%	p = 0.076 <i>b</i>
1	25.5%	17.6%	
2	5.9%	3.9%	
3	1.0%	0.0%	
4	0.0%	0.0%	
<b>Rate the severity of your voice tremor</b>			
0	69.6%	62.7%	p = 0.55 <i>b</i>
1	17.6%	26.5%	
2	9.8%	6.9%	
3	2.9%	2.9%	
4	0.0%	1.0%	
<b>Rate the severity of your right arm/hand tremor</b>			
0	10.8%	41.2%	p < 0.001 <i>b</i>
1	27.6%	25.5%	
2	52.0%	24.5%	
3	11.8%	4.9%	
4	7.8%	3.9%	
<b>Rate the severity of your left arm/hand tremor</b>			
0	11.9%	39.6%	p < 0.001 <i>b</i>
1	22.8%	27.7%	
2	48.5%	23.8%	
3	8.9%	3.0%	
4	7.9%	5.9%	
<b>Rate the severity of your right leg/foot tremor</b>			
0	91.2%	54.9%	p < 0.001 <i>b</i>
1	4.9%	24.5%	
2	2.9%	14.7%	
3	0.0%	3.9%	

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QUEST Items	ET (n = 103)	PD (n = 103)	Significance
4	1.0%	2.0%	
Rate the severity of your left leg/foot tremor			p < 0.001 <sup>b</sup>
0	90.2%	54.5%	
1	6.9%	23.8%	
2	2.0%	14.9%	
3	0.0%	5.9%	
4	1.0%	1.0%	

For rows that present quantitative data, these are mean ± standard deviation [median].

For some cells, there were missing data on up to 5% of patients.

<sup>a</sup> Mann-Whitney test.

<sup>b</sup> Linear-by-linear association test.

For rows that present quality of life data, 0 = never, 1 = rarely, 2 = sometimes, 3 = frequently, 4 = always.

For rows that present tremor severity data, 0 = none, 1 = mild, 2 = moderate, 3 = marked, 4 = severe.

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