

## Exploring essential tremor: Results from a large online survey

Harsh V. Gupta<sup>a</sup>, Rajesh Pahwa<sup>b</sup>, Phaedra Dowell<sup>c</sup>, Shawn Khosla<sup>d</sup>, Kelly E. Lyons<sup>e,\*</sup>

<sup>a</sup> University of Kansas Medical Center, 3901 Rainbow Blvd, Kansas City, KS 66160, United States

<sup>b</sup> Laverne & Joyce Rider Professor of Neurology, University of Kansas Medical Center, 3599 Rainbow Boulevard, Mailstop 3042, Kansas City, KS 66160, United States

<sup>c</sup> Kansas City VA, 4801 Linwood Blvd, Kansas City, MO 64128, United States

<sup>d</sup> St. Lukes/Des Peres Hospital Family Medicine Residency, 2345 Dougherty Ferry Ave, St. Louis, MO 63139, United States

<sup>e</sup> University of Kansas Medical Center, 3599 Rainbow Boulevard, Mailstop 3042, Kansas City, KS 66160, United States

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### ABSTRACT

**Introduction:** Essential tremor (ET) is one of the most common movement disorders; however, many patients are misdiagnosed and do not receive effective treatment. It is important to better understand the diagnosis, symptoms and treatment patterns to improve care for those with ET.

**Methods:** Persons in the International Essential Tremor Foundation database were invited to complete an online survey, focusing on symptoms, diagnosis, and treatment of ET.

**Results:** The survey was emailed to 19,206 persons, with 2864 (14.9%) respondents. Mean age was 65.4 years, median age of tremor onset was 36–40 years, 61% were women, and 64% had a known family history of tremor. Forty-five percent saw multiple physicians before a diagnosis of ET with 65% being diagnosed by a neurologist. Current care is provided by a neurologist in 42%, a family physician in 26% and 28% do not see a physician for ET. Tremor was most commonly reported in the hands/arms (95%). The most commonly affected daily activities included writing, eating, drinking and carrying. Beta-blockers were the most commonly used treatment (42%); however, 33% had no benefit and 35% discontinued due to side effects. Of note, 33% had never received treatment for their tremor.

**Conclusion:** This survey highlights the need for more effective treatments with greater tolerability. Increased awareness among physicians and patients in the diagnosis and treatment of ET is also warranted, with nearly half the respondents seeing multiple physicians before receiving an ET diagnosis and nearly 30% not seeing a physician and/or not receiving treatment for ET.

### 1. Introduction

Once referred to as “benign essential tremor”, this disease has been shown to be anything but benign for many patients [1]. Essential tremor (ET) patients struggle with disability which includes not only functionality, but also significant social and psychological implications [2,3]. Many patients with ET do not seek medical care and about 30% of patients are initially misdiagnosed with an alternate movement disorder or diagnosed incorrectly with ET [4,5]. For those that do seek treatment, finding an effective treatment that is well tolerated can be a challenge [6]. Therefore, although ET is one of the most common movement disorders, there are multiple gaps in the diagnosis and treatment of this disorder.

To better understand tremor characteristics and other symptoms, as

well as diagnostic and treatment patterns in ET, the International Essential Tremor Foundation (IETF) sent a 21-question survey to their online database. The IETF is a non-profit organization that provides education, awareness, support, and resources for persons with ET ([essentialetremor.org](http://essentialetremor.org)). The goal was to obtain data from a large community sample of patients with ET, in an attempt to better elucidate the current patterns of care and identify areas needing increased awareness among both patients and physicians.

### 2. Methods

A 21-question survey was emailed to 19,206 persons in the IETF online database using Survey Monkey (Table 1). Recipients were asked to complete the survey if they had a diagnosis of ET. The study was

\* Corresponding author at: Parkinson's Disease and Movement Disorder Center, University of Kansas Medical Center, 3599 Rainbow Blvd, MS 3042, Kansas City, KS 66160, United States.

E-mail addresses: [rpahwa@kumc.edu](mailto:rpahwa@kumc.edu) (R. Pahwa), [Phaedra.dowell@va.gov](mailto:Phaedra.dowell@va.gov) (P. Dowell), [Kelly.lyons@att.net](mailto:Kelly.lyons@att.net) (K.E. Lyons).

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**Table 1**  
International Essential Tremor Foundation Survey.\*

1. Do you have tremor (shaking) in any part of your body or in your voice? (if no, survey not completed)
2. What year were you born?
3. What is your gender?
4. What type of doctor diagnosed your tremor? (primary/family/internist, neurologist, movement specialist, don't know)
5. How many doctors did you see before your tremor was diagnosed?
6. Which of the following tests were done to help diagnose your tremor? (none, blood, EMG, brain imaging, spine imaging)
7. What type of doctor are you seeing now to treat your tremor?
8. Not included – focused on orthostatic tremor
9. What parts of your body have tremor?
10. Not included – focused on orthostatic tremor
11. Not included – focused on orthostatic tremor
12. Does your tremor affect your walking or balance?
13. Does anyone else in your family have tremor?
14. Does drinking alcohol beverages affect your tremor?
15. At what age did you first notice your tremor? (5 year intervals from 0 to 100)
16. How old were you when you received a diagnosis for your tremor? (5 year intervals)
17. My tremor affects which of the following: (list of ADLs)
18. I am embarrassed by my tremor.
19. I am currently taking the following medications for my tremor:
20. I have taken the following medications for my tremor in the past but had to stop due to side effects:
21. I have taken the following medications for my tremor in the past but had to stop because they did not reduce my tremor.

\*The survey was delivered via email using Survey Monkey. For each question there were various built-in potential responses and respondents selected the responses that were applicable.

reviewed by the University of Kansas Medical Center's Institutional Review Board and it was determined that the study was not reportable as the survey was sent by the IETF, responses were anonymous, and no identifying information was collected. Respondents did not sign consent and they were not compensated for participation. The survey remained active for two weeks.

The survey focused on basic demographics, tremor characteristics and impact, diagnostic process, and treatment experience. Although the email asked that only persons with ET complete the survey, the initial question confirmed the presence of tremor and if absent the survey would not progress and the case was removed. The results are descriptive, as generated by Survey Monkey.

### 3. Results

There were 2864 out of 19,206 persons who responded to the survey within 2 weeks. Sixty-two percent were women and 38% were men. The mean age was 65.4 years.

#### 3.1. Tremor characteristics

The median age at which respondents first noticed tremor was between 36 and 40 years of age (responses were in 5-year increments beginning with 0–5 years and ending with 95–100 years), with onset ranging from 0 to 85 years. The median age at which respondents were diagnosed with ET was 51–55 years. The majority of respondents, 64%, reported a family history of tremor, 25% reported no family history and 11% were not aware of anyone their family with tremor. Tremor was responsive to alcohol in 54%, with 47% reporting a reduction and 7% reporting resolution of tremor with alcohol; 30% do not drink alcohol, 15% reported no effect of alcohol on tremor and 1% reported a worsening of tremor with alcohol.

Ninety-five percent responded that their tremor affects their arms and hands, followed by the head (41%), voice (29%), legs (17%), face (15%), trunk (8%) and tongue (5%). The activities of daily living most impacted by tremor included writing (80%), drinking (68%), eating (67%), holding/carrying items (67%), using scissors/knives/tools

(54%), and typing/computer mouse (54%). Other activities that were impacted in more than 25% of respondents included cooking, brushing teeth, shaving, putting on make-up, putting on watch/jewelry, dressing, holding newspaper/book/cards, and using a telephone. Tremor also impacted the ability to hold a job in preferred field or work fulltime in 15% of respondents. The ability to continue hobbies or play board/card games was impacted in 45% of respondents. Attending social events was also impacted in 42% of respondents. Finally, 17% had difficulty attending appointments such as to the dentist, hairdresser, and eye doctor. In addition, 64% of respondents reported being embarrassed by their tremor and 26% reported an impact on walking and/or balance.

#### 3.2. Diagnostic patterns

The majority of respondents (49%) saw only one physician before being diagnosed with ET; however, 4% saw six or more physicians before being diagnosed (Fig. 1). The diagnosis was made by a neurologist in 65% of respondents; 17% of these neurologists were movement disorder specialists. A primary care physician (PCP)/family doctor diagnosed ET in 25%. The remaining respondents did not know the type of physician or were not officially diagnosed, but had a family history of ET. The majority of respondents were diagnosed without any specific testing, while brain imaging was done in 17%, a blood test was done in 11%, electromyography was done in 10%, and spine imaging was done in 4%. Currently, 42% are seeing a neurologist, of which 19% specialized in movement disorders, and 26% are seeing only their PCP. Interestingly, 28% are not receiving medical care for their tremor.

#### 3.3. Treatment patterns

Beta blockers (42%) and primidone (20%) were the most common medications that respondents were currently taking for ET. These were followed by benzodiazepines (13%), gabapentin (6%), and topiramate (5%). Two percent utilized botulinum toxin, 3% had undergone deep brain stimulation, and 0.4% reported that they have had a thalamotomy. There were 33% of the respondents that had no treatment for their tremor. Respondents were asked to mark each medication that they are currently taking, so we are unable to determine from these data how many were on monotherapy and for those taking multiple medications, which combinations they were taking.

Although beta-blockers were the most commonly used medications for ET, 35% of patients had to discontinue due to side effects and another 34% due to lack of benefit. Similarly, 23% discontinued primidone due to side effects and 18% due to no benefit. This discontinuation pattern also occurred with benzodiazepines, gabapentin and topiramate (Fig. 2).

### 4. Discussion

This IETF survey was conducted to gain information about ET symptoms, issues related to diagnosis, and treatment patterns from a large community population of persons with ET. There were 2864 responses from persons who were either diagnosed with ET or were not diagnosed but had a family history of tremor. The responses related to tremor were similar to previous publications with nearly all respondents reporting hand tremor, and fewer reporting head, voice, legs, face, tongue and trunk tremor [7]. The functional disability leading to difficulties with nearly all basic activities of daily living was also reported [8]. Psychological implications were identified, with respondents reporting difficulties maintaining employment, hobbies and social interactions and a majority reporting embarrassment as a significant impact of ET [9,10]. As previously reported, the majority of ET respondents (54%) had a reduction in tremor with alcohol [11] and family history was reported in 64% of respondents [12]. Although there are inherent concerns with large, self-report, survey studies, these consistencies with the ET literature help to lend credence to the findings.

This survey highlighted concerns regarding the diagnostic process. In

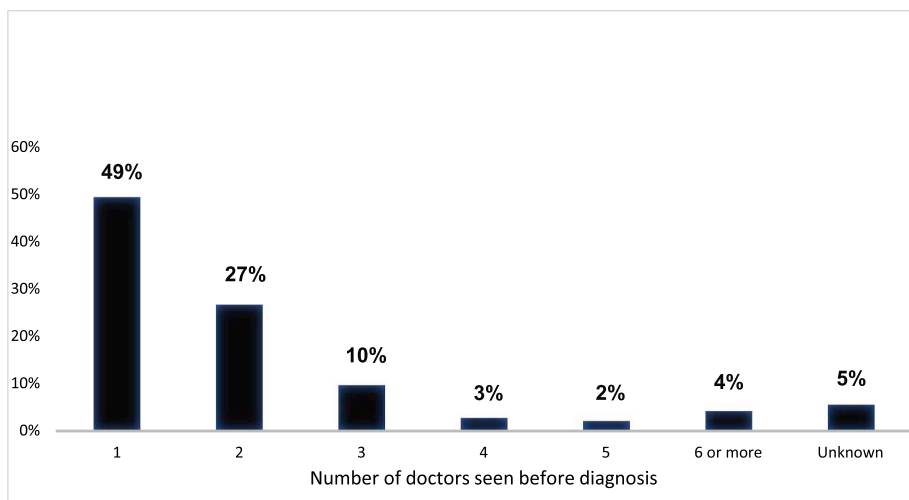


Fig. 1. Number of doctors seen prior to final diagnosis (percentage of patients).

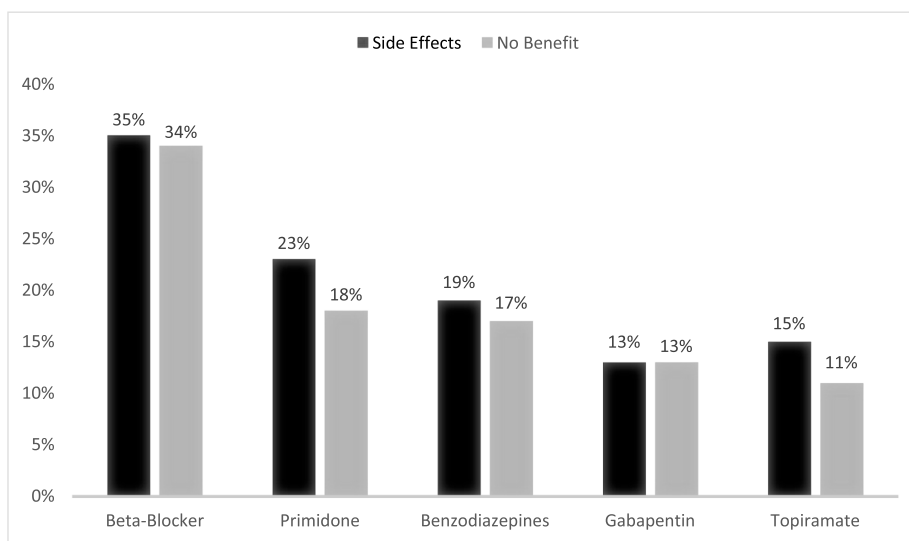


Fig. 2. Percentages of survey respondents that discontinued tremor medications secondary to side effects or lack of benefit.

this sample 46% of respondents saw at least 2 and up to 6 physicians before getting a diagnosis of ET. In addition, 36% reported that they received diagnostic testing which is not required since the gold standard for the diagnosis of ET is a thorough history and physical examination. Finally, nearly one third of respondents were not followed by a healthcare professional for their ET. It is unclear if this is because their tremor is not bothersome, they have a family history of tremor and don't feel they need to see a physician, or they aren't aware that their tremor can be treated. In fact, only 19% of this population sees a movement disorder specialist for their tremor. This is somewhat surprising given that this is a population that has done some degree of research into ET, in order to have been included in the IETF database. These points all highlight the need for increased education and awareness of the diagnostic process for both patients and throughout the healthcare system, to reduce stress, frustration and costs for those with ET.

The need for better tolerated and more effective pharmacological treatments for ET is also apparent from this survey. According to the AAN Guidelines [13,14], both propranolol and primidone have Level A evidence and are recommended for the treatment of ET. These medications are reported to be effective in approximately 50% of the patients, but are associated with side effects such as cognitive difficulty, sedation, and depression [15]. This is consistent with the survey in that 35%

reported discontinuing beta-blockers secondary to side effects and 33% discontinued due to lack of benefit. Similarly, 20% of respondents reported discontinuing primidone secondary to side effects and 17% reported that it did not reduce their tremor. In addition, only 3% of the respondents had deep brain stimulation and less than 1% had thalamotomy. More surprisingly, one third of the respondents were receiving no treatment for their tremor, which for some may be due to that fact that tremor is not bothersome, but may also be related to a lack of awareness of potentially effective treatment options for ET.

There are several limitations of this report. There are inherent concerns with mass-mailed survey data such as lack of confirmation of diagnosis for the respondents, inability to conduct detailed analyses of responses, and inability to collect or further confirm reasons for the given responses. In addition, the sample is biased towards individuals who have reached out to the IETF and may not be generalizable to the general population of ET patients. In contrast, this methodology allows for a large number of responses in a relatively short period of time to identify potential gaps in the diagnosis and treatment of ET. This method also allows for participation from persons in the community, that may not have been accessed in a typical research setting. Given that many of the findings are consistent with the current literature, this survey provides evidence for the need for increased education and awareness

regarding the diagnosis and treatment of ET as well as the need for additional treatment options that are well-tolerated and effective in controlling tremor.

## 5. Conclusion

This survey highlights the challenges faced by patients with ET, from initial misdiagnoses to a variety of disabilities to inadequate treatment. Given the prevalence of ET, these findings confirm that it is vital that additional education and research is devoted to improving the accuracy of the diagnosis of ET and developing additional treatment options.

## Declaration of interest

Dr. Gupta, Dr. Dowell and Dr. Khosla have nothing to disclose.

Dr. Lyons is a consultant for Abbott and Sage and is President of the International Essential Tremor Foundation.

Dr. Pahwa serves as a consultant for Abbott, AbbVie, ACADIA, Acorda, Adamas, Amneal, CalaHealth, Global Kinetics, Impel, Jazz, Neuropharma, Kyowa, Lundbeck, Mitsubishi, Neurocrine, Orbis Bioscience, PhotoPharmics, Prilenia, Sage, Sunovion, Teva Neuroscience and US World Meds. He receives research support from Abbott, AbbVie, Addex, Biogen, Biohaven, Boston Scientific, Bukwang, Cerevance, Cerevel, Global Kinetics, Impax, Lilly, MJFF, Neurocrine, Neuroderm, Neuraly, Parkinson's Foundation, Pharma 2B, PSG, Roche, SIS, Sun Pharma, Sunovion, Theravance.

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## CRediT authorship contribution statement

**Harsh V. Gupta:** Writing - review & editing. **Rajesh Pahwa:** Conceptualization, Methodology, Investigation, Writing - review & editing, Funding acquisition. **Phaedra Dowell:** Writing - original draft, Writing - review & editing, Visualization. **Shawn Khosla:** Writing - original draft, Writing - review & editing. **Kelly E. Lyons:**

Conceptualization, Methodology, Formal analysis, Investigation, Writing - review & editing, Supervision, Project administration, Funding acquisition.

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