

Spikes & Spasms

The TremorAction.org Newsletter

ET Survey 2009

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Clinical Features of Essential Tremor:

Information from a Internet-Based Survey

"While ET is often noted to be the most common movement disorder, there remain conflicting reports concerning its onset and clinical course. Much of the available data has been obtained from tertiary centers that see severely affected patients or those with unusual features.

This study characterized individuals with ET using an internet-based survey. Subjects were recruited through a link on the Tremor Action Network. The questions were selected to reflect demographics, clinical, and treatment history.

This novel approach may enhance the clinical picture of this disease and serve to identify under-addressed treatment issues. An internet based self-reported survey may provide valuable insight into ET features."

Author: Esther Baldinger, Brooklyn, NY

Session Info: Poster Session I:
Hyperkinetic Disorders

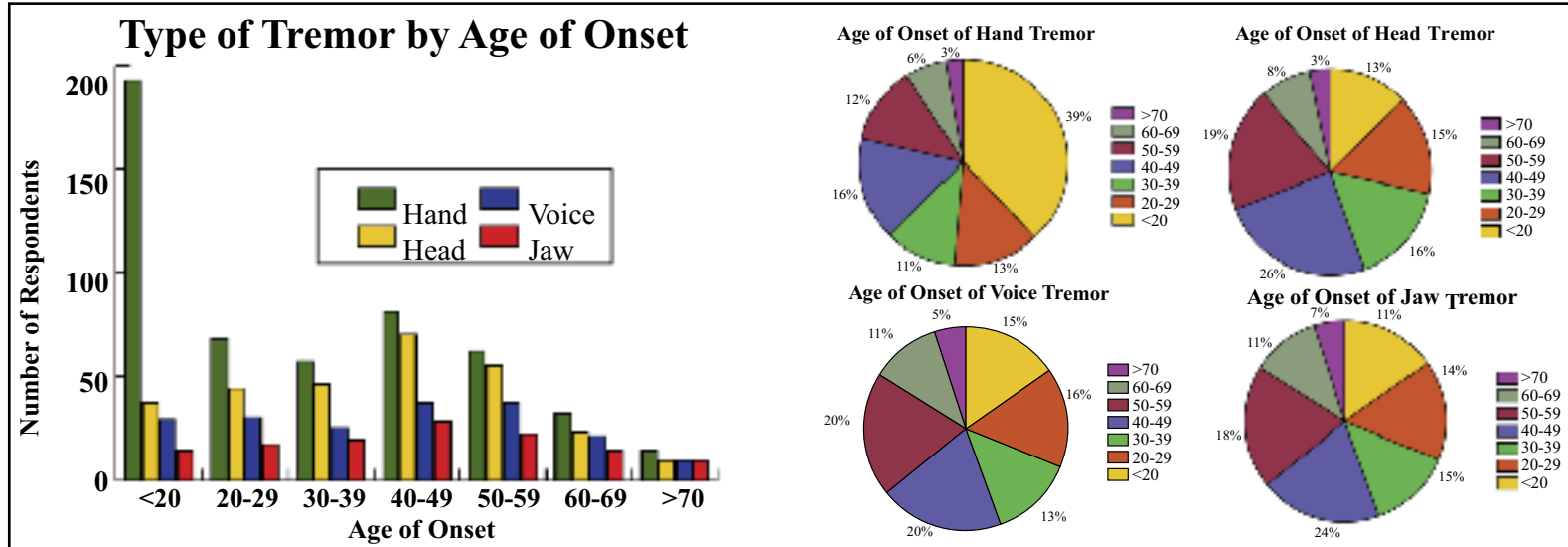
Presentation Time:
Tuesday, April 28, 2009, 7:00 am-10:00 am

Room: 6E

Clinical Features of Essential Tremor: Information From an Internet Based Review

Esther Baldinger, M.D., Dustin Monroe, Matthew Imperioli, Neel Tarneja, Jeff Cloyd, Gracia Mui

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Objective:

To characterize the clinical features of essential tremor (ET) in a non-clinic sample using an internet-based survey.

Background:

While ET is often noted to be the most common movement disorder, there remain conflicting reports concerning its onset and clinical course. Much of the available data has been obtained from tertiary centers that see severely affected patients or those with unusual features. This study characterized individuals with ET using an internet-based survey. This novel approach may enhance the clinical picture of this disease and serve to identify under-addressed treatment issues.

Design/Methods:

Subjects were recruited through a link on the Tremor Action Network (www.tremoraction.org) Subjects were asked to complete a survey that consisted of 83 multiple choice questions with a fill-in option if none of the choices were sufficient. The questions were selected to reflect demographics, clinical, and treatment history.

Results:

There were a total of 542 survey respondents. Of these, 507 reported hand tremor: 36% with onset under the age of 20 and 48% under the age of 30. Head tremor was present in 284 respondents.

Results continued:

Onset of head tremor was more varied beginning in each decade of life with about 40% of respondents citing onset between 30-59 years of age. Voice tremor occurred in 188 respondents with onset also between the ages of 30-59. Jaw tremor occurred in 98 respondents, most frequently between the ages of 40-60. 68% percent of respondents noted a parent who also had tremor and 30% of respondents noted a sibling who had tremor.

Conclusion:

An internet based self-reported survey may provide valuable insight into ET features. In this sample, contrary to expectations, the onset of hand tremor occurred earlier in life, (under the age of 20) for more than one-third of those affected. Head, voice and jaw tremor onset most frequently occurred at age 40 years or later. Previous studies have suggested a bimodal distribution in the age of tremor onset with peaks in early adulthood and later in life, while other data suggest a late life peak. Current findings indicate the possibility of a larger population of younger adults experiencing tremor onset that may be specific to a tremor site (hand). In this sample there was also a strong familial signal that may support a hereditary link to this early onset group. These and other survey findings warrant further study.

References:

1. Bain PG, Findley LH, Thompson PD, Gresty MA, Rothwell, JC, Harding AE, and Marsden CD. A Study of Hereditary Essential Tremor. *Brain* 1994, 117(4):805-824.
2. Benito LJ. How Common is Essential Tremor? *Neuroepidemiology*, 2009. 32(3): 215-216.
3. Louis ED and Dogu O. Does Age of Onset in Essential Tremor Have a Bimodal Distribution? Data From a Tertiary Referral Setting and a Population- Based Study. *Neuroepidemiology*, 2007. 29:208-212.
4. Louis ED, Frucht SJ, and Rios E. Intention tremor in essential tremor: Prevalence and association with disease duration. *Movements Disorders*, 2009. January 30 Epub.
5. Louis ED, Thawani SP, and Andrews HF. Prevalence of Essential Tremor in a Multiethnic, Community Based Study in Northern Manhattan, NYC, NY. *Neuroepidemiology*, 2009. 32(3):208-214.

Essential Tremor Survey

By Esther Baldinger, MD

Spikes & Spasms Note:

This survey was funded by Tremor Action Network.

Disclaimer: *The results should not be taken as medical advice or endorsement of any specific treatment. Please consult with your medical provider for any discussion or decisions related to your own condition. - Esther Baldinger, M.D.*

Thanks to all of you who responded to the first essential tremor survey. In the three months that the survey has been open, 550 responses have been received! As a qualifier a web site survey is not representative of the general population and can only be the first step to controlled scientific study. While this type of survey can't provide definitive answers, your responses are very valuable in determining future paths for study. We are refining these findings into a shorter and more focused follow-up survey that will be coming soon.

What follows is a summary of the results with a discussion of the answers that I feel are most pertinent.

When asked the age at which you first noticed shaking of your hands:

39% said before the age of 20.

13.4% ages 20-29

11.6% 30-39

15.3% 40-49

12.4% 50-59

6.4% 60-69

2.9% 70 and above

Slightly more than half (51.4%) of the respondents noticed a hand tremor by the time they reached age 30 and less than 10% of respondents developed a hand tremor after the age of 60. WE MOVE a web site for the "education and awareness for movement disorders" states the mean age of onset of ET to be 45 years. An epidemiological evaluation by Dr. Louis and Dr. Dogu published in 2007, found only 14% of a general population showing tremor

before the age of 30 and 58% later in life. Dr. Bain in a study of ET patients in the United Kingdom in 1994 found the most common age of onset of tremor to be 15 years and if tremor was to develop it did so by the age of 65 years. That study seems closest to our findings. So for people with ET, early onset of hand tremor is to be expected and onset of hand tremor after the age of 60 is infrequent.

About half of the respondents had head tremor. Of those, the onset of head tremor irrespective of whether there was a tremor at another site was:

12.5% under 20 years

15.8% ages 20-29

17.0% ages 30-39

23.4% ages 40-49

19.2% ages 50-59

8.7% ages 60-69

3.4% 70 years and above

Most respondents developed head tremor between the ages of 20 and 60 with the greatest number developing head tremor in their 40's. Young onset, that is under the age of 30 years, occurred in nearly 30% of respondents.

Very few had the onset of head tremor when they were older than 70 years. Most people developed head tremor at the same time or after the onset of their hand tremor. The questions did not separate those people who developed head tremor alone or as the first symptom of ET. This is something that needs to be studied.

Voice tremor was found in 155 people of the group or just over one third.

15.1% under 20

15.6% 20-29

14.0% 30-39

19.0% 40-49

20.1% 50-59

11.2% 60-69

5.0% 70 and above

Current medical literature notes voice tremor beginning after age 50. This survey finds that voice tremor can occur

at any age even in the very young. It appears that the people with voice tremor also have tremor at another site, however, that question was not specifically asked. In addition, many people noted the onset of voice tremor within the same decade as either head or hand tremor, but the order of the onset was not requested and needs to be studied.

Jaw tremor was present in 113 people of the group or slightly less than one fourth.

10.7% under 20

15.0% 20-29

16.8% 30-39

22.1% 40-49

15.9% 50-59

12.4% 60-69

7.1% 70 and above

Jaw tremor has been associated with advanced ET, but our survey shows it can begin at all ages. In an evaluation of jaw tremor in ET patients by Dr. Louis et al in 2006, jaw tremor was associated with older age, more severe action tremor of the arms, and the presence of head and voice tremor. About 20% of people with jaw tremor in our survey appear not to have voice tremor and a smaller number do not have hand tremor. Again this is an area that needs more study.

As expected, tremor interfered with function and caused embarrassment across all ages.

67.6% of all respondents said a relative had tremor. Of those, 33.3% answered father, 34.4% answered mother and 30.3% answered sibling.

93.1% of respondents identified themselves as Caucasian. Nearly every country in Europe was listed as a country of origin of the tremor side of the family with England, Ireland and Germany being cited most often.

There was no relationship between ET and any school subject. Most people's best subject was English and their worst was mathematics. Many people said that they were good at everything, especially spelling (78%), grammar (82%) arithmetic (74%) and reading (88%). Only 38% said they were good at complex math. 41% sing and 35% play a musical instrument.

People with ET do all kinds of work, remarkably including tasks, which require fine and extremely fine hand coordination. 73% said that they were "good with their hands" before the tremor interfered with activities and only 12.3% describe themselves as being "all thumbs." Sadly, a good number of people wrote that they had to

change their work or retire because of tremor. 84% are right-handed. 58% exercise on a regular basis with walking as the exercise of choice for 84% of them.

26% said that they were exposed to chemicals, but no substance or group of substances that were listed stood out as being common to this subgroup of

people with ET.

The great majority of people with ET are non-smokers (83.5%). Of the 16.5% who do smoke, 33% smoke one pack a day or more and the remainder smoke less than one pack. 54% drink alcoholic beverages. 47% answered one drink per day, 33% answered two drinks per day and 20% answered more than two drinks per day. What was not asked was whether alcohol was being used to improve tremor.

More than half (57%) of the group sleeps 7-8 hours most nights, but nearly half (46%) of the respondents said they had some difficulty with sleeping. In the general US population sleep disorders occur in about 1 in 6 people or about 15%. In our survey the reasons for this difficulty were listed as pain, sleep apnea, depression/anxiety, the tremors, medication effects, need to urinate, and

"Slightly more than half (51.4%) of the respondents noticed a hand tremor by the time they reached age 30."

frequently "don't know why." This high rate of sleep disorders is another area that needs further study.

80% like particular foods with vegetables and cheese each getting more than 50% of people citing these as their favorite foods. 54% said they try to avoid sweets.

Allergies were common in the group with 57% saying that they were allergic to substances. Most common was pollen (63%), medications (46%), dust (45%), food (21%), and insect bites (16%). In evaluating the average US population the prevalence of allergies is listed as 9-16%. So the group of people with ET has a much higher rate of allergies. How this relates to ET is an area that needs study.

When asked do you have pain, 61% said yes with the majority having pain in their neck, back and shoulders. 59% said they have headaches now or had them at some time in the past. These numbers are higher than in evaluations of random groups of people, but studies on pain distinguish between acute pain that resolves, occasional pain and chronic pain that is present every day for three months. The questions on pain were too general to be compared with published findings. This needs to be addressed in the future.

Hearing problems were reported by 26% of our group. Hearing problems have been associated with ET. A 2007 study published by Dr. Benito-Leon and colleagues in Spain reported 38.7% of people with ET having hearing loss compared with 29.4% of controls matched for age. A Baylor College of Medicine study found 16.8% of ET patients used hearing aids and that more severe tremor was associated with more severe hearing disability. This survey reveals fewer hearing problems than reported elsewhere perhaps because many of our respondents are younger and have less severe tremor. Whether other studies have over-represented the number of people with ET who have hearing problems is an area for further study.

Balance problems were present in 42% of the group, dizziness in 36% and falling episodes in 19%. These

numbers are large and occurred across all age groups. Many people who had dizziness denied hearing problems. Balance/gait disorder in ET has generally been overlooked in the medical literature. A study by Dr. Stolze and colleagues published in 2001 looked at 25 patients with ET and advanced intention tremor and found abnormalities in gait similar to people with cerebellar disease. People with mild hand tremor or tremor in other sites have not been studied. This is another important area that needs more information.

Vision was reported to be fair, good or excellent in 90% of the group. The sense of smell was fair, good or excellent in 94%. Loss of smell has been reported to be an early indicator of Alzheimer's disease. 88% said they do not have or have not had cancer. Almost one third have high blood pressure and/or high cholesterol, but heart disease was present in only 9% of the group, heart attack in 4%, and stroke in 4%. How these findings relate to ET is unknown. None of the medical literature regarding ET lists rates of heart disease, stroke or cancer in this group. More information is needed.

Thank you for participating in this survey and I hope you will participate again.

About the Author

Esther Baldinger is a practicing neurologist in Brooklyn, New York. She is an associate attending in neurology at the Long Island College Hospital, and an Assistant Clinical Professor of Neurology at SUNY Downstate Medical Center. Dr. Baldinger attended SUNY Downstate Medical College, graduating Magna Cum Laude and AOA in 1977.

Survey of Essential Tremor

By Esther Baldinger, MD

Spikes & Spasms Note:

Dr. Baldinger's Essential Tremor Survey is located online at:

http://www.surveymonkey.com/s.aspx?sm=7yBDntiGTekKkhN6gVvBVg_3d_3d

This online survey is easy to use, and has been designed with the survey participant in mind. Multiple choice questions include Comment fields which allow participants "the Option to add Other choices," and to also make comments.

"Some questions will require only a Yes or No, or straightforward answer, but others will allow you to express your own ideas...No information will be used; shared or published that identifies any individual...Please fill in the survey only once."

Dr. Baldinger's article provides same or similar survey questions for those willing participants who do not own computers or whose computers may not allow them to access an online survey. To participate in the survey offline, please print and complete the questions and then mail to: Esther Baldinger, M.D., 8118 21st Avenue, Brooklyn, NY 11214.

Essential Tremor (ET) is a common problem, but many of the features of this disorder remain unknown. If more was understood about ET then ideally better treatments could be made available and the issues of slowing or stopping progression could be addressed.

A very important question is whether all ET patients have the same disease. Three genes (so far) have been associated with ET, but there is no information about whether people with one type of ET-gene look or act differently from those with another ET-gene. Does race or ethnicity play any role? In addition, we do not know if substances in the diet or environment can produce ET or influence progression. Do lifestyle choices like work, hobbies, sports, and even sleep make a difference?

"A very important question is whether all ET patients have the same disease."

What follows is a survey to help learn more about ET. It may be the first of many if the information leads to more questions and new ideas. Some questions will require only a yes or no, or straightforward answer, but others will allow you to express your own ideas. A summary of the results will be published in this newsletter. No information will be used; shared or published that identifies any individual. Your candor is appreciated. Please fill in the survey only once.

We are still recruiting patients for the study of the effect of Riboflavin on ET. Please contact me (Esther Baldinger, M.D.) at (718) 232-1570 if you can make four visits to Brooklyn, New York.

Thanks for participating.
Esther Baldinger, M.D.

1. How old were you when you first noticed shaking of your hands?

2. How old were you when you first noticed shaking of your head? Voice? Jaw?
3. At what age did the tremor interfere with daily activities, or cause embarrassment?
4. Does anyone else in your family have tremor? If yes who? What country did they come from? What is your ethnic or racial background?
5. How far did you go in school?
6. While you were in school what was your best subject? What was your worst? Do you sing or play a musical instrument?
7. Are you good at spelling, grammar, arithmetic, complex math, and reading?
8. What kind of work do you do now or if retired what did you do? If you had different jobs you can list them. Have you been exposed to any chemicals? If so, list them.
9. What do you like to do for fun? List sports, hobbies or whatever you like to do.
10. List a task that you find particularly easy.
11. Consider yourself before the tremor interfered with activities. Some people would describe themselves as "having all thumbs" are you one of those or would you say you were "good with your hands?"
12. Are you left or right handed or use both?
13. Do you exercise on a regular basis? What kind of exercise do you do?
14. Do you smoke? If yes how much daily? Do you drink alcohol? If yes how much daily?
15. How many hours do you sleep? Do you have a problem sleeping? If yes describe.
16. Do you have a food you really like and often eat? What foods do you try to avoid?
17. Do you have allergies? If yes, list allergies such as medications, foods, pollen, dust, insect bites or others.
18. Do you have pain? Where? What is the cause of your pain?
19. Do you get headaches now or did you at some time in your life? Were you diagnosed with migraine?
20. Do you have motion sickness? As a passenger can you read in a moving car?

21. Do you have hearing problems? Can you listen while on the phone with either ear?
22. Do you have balance problems? Do you get dizzy? Have you fallen? Describe your symptoms and the length of time you have had them.
23. How is your vision? If you have had visual symptoms, describe them and the length of time you have had them.
24. Would you describe your sense of smell as good or poor and if changed when did that occur?
25. Do you have or did you have cancer? If yes where? Did any treatment received for the cancer effect your tremor? If yes in what way? Did anyone in your family have cancer and where?
26. Do you suffer from high blood pressure? High cholesterol? Heart disease? Have you suffered a stroke, or heart attack? How have these conditions influenced your tremor?
27. List any other diseases you suffer from.
28. List the medications you take.
29. List the Vitamins you take.
30. Have your tried Riboflavin for ET? If yes have you noticed any benefit?

About the Author

Esther Baldinger is a practicing neurologist in Brooklyn, New York. She is an Associate attending in neurology at the Long Island College Hospital, and an Assistant Clinical Professor of Neurology at SUNY Downstate Medical Center. Dr. Baldinger attended SUNY Downstate Medical College, graduating Magna Cum Laude and AOA in 1977.

Dr. Baldinger's Essential Tremor Survey is located online at:

http://www.surveymonkey.com/s.aspx?sm=7yBDntiGTekKhkN6gVvBVg_3d_3d
