Spotlight on Essential Tremor Management and Impact: Results from an Online Survey Capturing HCP and Patient Perspectives of Disease Burden

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Background

Up to 7 million people in the United States may have essential tremor (ET)

Action tremors significantly disrupt daily living for people with ET

Hallmark feature is action tremor that primarily affects the hands

Almost all ET patients suffer from at least one comorbid condition (e.g., depression, anxiety, sleep disorders, cognitive dysfunction)

- ET is characterized by involuntary progressive tremor especially in the hands and upper limbs, with patients experiencing significant disruption to their daily activities, often alongside multiple comorbid conditions.
- Existing treatment options are limited, with high discontinuation rates due to poor tolerability and modest efficacy.
- Importantly, patients experience daily challenges beyond tremor, with significant psychosocial impact.
- Drawing on HCP and patient perspectives, we sought to gain greater understanding of ET, its diagnosis, management and impact.

Survey Conduct

- HCP and patient online surveys were conducted in the US from April to July 2024.
- Only neurologists treating ET, and patients with an ET diagnosis, were eligible to participate.

The Essential Tremor HCP Research

- Fielded at the 2024 American Academy of Neurology (AAN) meeting (Denver, Colorado, April 2024).
- Included 152 neurologists who treat ET in the US, and who were primarily affiliated with academic centers.

The Essential Tremor Patient Research

- Comprised a total of 411 patients who were invited to complete surveys via email communication from June-July 2024.
- Two separate surveys were completed online and included 150 US adults living with ET, and a further 261 US adults living with ET who were pre-screened, but did not qualify, for the Essential3 study.
- Learn more about the Essential3 Study

https://essential3study.com/

Essential Tremor Neurologist Survey

- In the neurologist cohort, the majority reported practicing in academic centers (>75%).
- Approximately 85% of neurologist visits are for patients seeking treatment.
- Neurologists noted their patients' primary challenges as tremor symptoms and impairments in activities of daily living with over 90% of neurologists stating that ET impact on daily living and its symptoms influence their medical treatment decisions.
- Neurologists reported confidence in managing ET; nearly half of whom rarely refer patients for specialist management.

A survey of ~150 US neurologists emphasizes the need for more effective treatments and the importance of patient-physician dialogue in ET

Profound impact on daily activities

Over 90%

of neurologists stated their patients' descriptions of their ET symptoms and impact on daily activities influence treatment decisions

High psychosocial burden

60%

of neurologists reported **mental and emotional challenges** among the top three challenges for their patients with ET

Inadequately managed and undertreated

85%

of neurologist visits are for patients seeking ET treatment

Nearly 50%

of neurologists rarely refer ET patients for specialist management

The Essential Tremor HCP Research was conducted by Fuel Insights (www.fuelinsights.com) in April 2024.

An Urgent Need to Advance Care in ET

- **These findings emphasize the need for more effective, well-tolerated treatments, and the importance of honest physician-patient dialogue in ET.**
- **Notably, these surveys highlight the profound impact on daily activities among patients living with ET and associated widespread psychosocial burden, which we propose may be compounded by a degree of normalization of ET impact.**

Visit praxisessentialtremor.com to learn more and explore community ET stories and resources

Essential Tremor Patient Surveys

- Patient responders across the two separate surveys were generally 30-75 years old who primarily see neurologists and PCPs for their ET management.
- Patient respondents indicated widespread challenges with typical activities of daily living, with up to 80% noting needing to adjust how they complete daily tasks due to their ET symptoms.
- Almost all reported a level of psychosocial impact, with many reporting feeling frustrated, ashamed, worried, sad and hopeless due to their symptoms.
- While treatment regimens are diverse, with many patients on multiple interventions, up to 50% reported they are not currently receiving any treatment.
- Up to 77% of patients reported not feeling their symptoms are manageable with current treatments.

Surveys of >400 ET patients across the US highlight ongoing hidden burden in ET and associated challenges in managing everyday life

Profound impact on daily activities

Up to 80%

reported needing to adjust how they complete daily tasks due to their ET symptoms

Top Challenges

- working / attending social events
- writing
- drinking from a glass

High psychosocial burden

Nearly all patients experience psychosocial burden, with many reporting feeling:

- frustrated
- worried
- sad
- ashamed
- hopeless

Inadequately managed and undertreated

Up to 77%

do not feel their symptoms are manageable with current treatments

Up to 50%

are not receiving treatment

Up to 75%

are not receiving specialist referral for their ET

The Essential Tremor Patient Research was conducted by Fuel Insights (www.fuelinsights.com) from June-July 2024.

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