Results From The United States Cluster Headache Survey. Todd D. Rozen[1], MD, Royce S. Fishman[2.] . International Headache Congress, September 2009

Objectives: To present results from the largest survey to date of cluster headache (CH) patients living in the United States

Background: With the support of CH based organizations and the AHS, CH patients were randomly solicited via approximately 9000 emails and internet advertisements to participate in a survey. Only patients who were diagnosed with CH by a neurologist were able to participate.

Methods: Survey consisted of 187 multiple choice and fill in questions and was placed on an Internet website from October 12, 2008 through December 12, 2008. Survey addressed clinical, epidemiologic and economic issues related to CH.

Results: 1134 individuals completed the survey (816 male, 318 female). 868 patients had episodic CH (male: female 2.9:1) while 266 had chronic CH (male:female 1.8:1). Highlights: 71% had their first ever CH at 30 years of age or younger, 35% 20 years of age or younger, while 20% of CCH started after age 40 years vs 10% ECH. Predominant eye color was blue 33%, brown 33% and hazel 21%. Brown eye color was most common in ECH; blue most common in CCH. Diagnosis was typically initially made by a general practitioner or a general (non headache specialist) neurologist. Average time to correct diagnosis was usually either less than 1 year (25%) or 10 years plus (22%). 73% had a smoking history and 72% had at least one parent who smoked while the patient lived with that parent. 45% continued to smoke at the same rate as before CH onset. 16% had never smoked prior to CH onset. 50% stated alcohol triggered a headache while 85% would stop drinking during a CH cycle. Weather changes triggered CH in 36%. 17% had an immediate family member with CH and 52% had a family member with migraine. 55% had thoughts about suicide while 2.2% tried to commit suicide. Depression was the most common comorbid condition occurring in 24% while lung cancer was rare occurring in only 3 patients. Clinically, auras occurred in 21%, almost all lasting less than 25 minutes; lacrimation most common associated symptom 91%, photophobia/phonophobia 45% and nausea 36%. Bilateral pain was rare, but more common in CCH 8.3% vs ECH 1.5%. 50% of the patients would physically hit themselves during a headache. Almost equal distribution of headache onset times during 24-hour day; peak 2:00AM. Most common months to start cycle March, April, September, October. Treatment: Only injectable sumatriptan and oxygen were deemed effective acute treatments, but 52% had never tried injectable sumatriptan and 34% had never tried oxygen. Only 8% had a GON block. Most recognized preventives were deemed ineffective in >70%+ of patients. Verapamil was never tried in 37%, while lithium, valproic acid, gabapentin, methysergide, methylergonovine, and topiramate had not been tried in >70%+. 17% lost their job secondary to CH while 9% had to quit work or go on disability. Almost 50% of survey responders were not currently seeing a neurologist.

Conclusions: In the United States many CH patients are not currently seeing a neurologist, are not being exposed to recognized acute and preventive therapies and are not finding treatment to be effective when prescribed. This is leading to job loss and disability. This survey will help define the clinical description of CH.

Study supported by (if applicable): Unrestricted educational support from Linde Healthcare. The Linde Group; primary and secondary authors received no honoraria.

1. Geisinger Health System, Neurology, Danville, PA, 17822, United States
2. The Linde Group, Linde Healthcare, Hernando, FL, 34442, United States