<u>Oxygen and Cluster Headache: Results from the United States Cluster</u> <u>Headache Survey</u>. Todd D. Rozen¹, MD, Royce S. Fishman². International Headache Congress, September 2009

Objectives: To present results from the largest survey ever done of cluster headache (CH) patients living in the United States concerning the use of Oxygen (O2) as an acute treatment

Background: CH patients were randomly solicited via approximately 9,000 emails and internet advertisements. Only patients who were diagnosed by a neurologist were able to participate.

Methods: Total survey consisted of 187 multiple choice questions of which 84 questions dealt with oxygen use, efficacy and economics. Survey was placed on an Internet website from October 12, 2008 through December 12, 2008.

Results: 1134 individuals completed the survey (816 male, 318 female). 868 patients had episodic CH while 266 had chronic CH. 93% were aware of O2 being an acute therapy. 34% had never tried O2. 70% stated O2 was effective (ECH >CCH 72% vs 61%). 50% had tried O2 alone to abort CH, but only 25% were currently using O2 as a sole abortive > 80% of the time. 44% had to first suggest O2 therapy to their physicians to get it prescribed. There was an equal distribution (28% each) of physician type (general practitioner, general neurologist, headache specialist) who initially prescribed O2. Reasons why a physician would not prescribe O2 included: did not know that O2 was used for CH 32%, did not believe it worked 44% and stated medical literature not convincing 16%. Patient or physician had to submit medical literature 44% of the time to get reimbursement for O2. Only 64% of insurers covered O2 for CH. 50% of those using O2 never received training on proper use of O2 cylinder equipment or mask. 45% had to find a source to buy O2 on their own. On oxygen prescriptions only 45% specified a flow rate, 50% stated CH as diagnosis and 28% indicated a specific mask type. 12% of CH patients had used welders O2 (non-prescription, less expensive) stating economic reasons including having no insurance. Oxygen delivery systems: 11% using nasal cannula, 29% standard mask, while 47% high concentration non-rebreather mask. Initial flow rates prescribed: 23% 7 lpm, 51% 8-12 lpm, 18% 13-15 lpm, 8% 16-25 lpm. During therapy 41% start and 34% end using 7-10 lpm, 17% start and 14% end using 11-12 lpm, 28% start and 34% end using 13-15 lpm, 7% start and 10% end at 16-20 lpm and 6% start and 8% end at 21-25 lpm. O2 aborted a CH completely in less than 15 minutes for 36%, 16-30 minutes 30%, while taking > 45 minutes in 22%. Of those using O2 plus another abortive agent, 38% administer the other abortive before, 6% after starting O2, while 56% only administer if O2 did not work.

Conclusions: In the United States despite the obstacles of getting O2 prescribed, covered by insurance, finding an O2 source and having no instruction on how to use it, O2 still remains a viable treatment option for CH patients. A significant portion of CH patients find O2 to be an effective acute therapy although many need to increase the flow rate of O2 during an acute attack and very few use O2 as sole therapy to treat most of their attacks. From this survey physicians and CH patients need more education on the use and prescribing of O2 for CH while headache specialists need to better recognize what CH patients are actually doing with O2 therapy at their homes.

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