

Cluster Headache Patient Survey: 5-MeO-DALT (N,N-diallyl-5 methoxytryptamine)

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Introduction

Cluster headaches are a primary headache disorder characterized by intense unilateral head pain, localized in the supraorbital or suborbital regions. Cluster headache attacks have a very rapid onset (~5 minutes) and generally last from 30 to 90 minutes. The pain of cluster headaches is frequently debilitating, and some patients have been driven to suicide as a means to escape their suffering.

Front-line medications to treat cluster headaches are limited. At present, there are no pharmaceuticals developed specifically to treat cluster headache symptoms. Medical practitioners rely on off-label application of existing medications (including verapamil, topiramate, lithium, and a host of triptans, the most common being sumatriptan) with varying degrees of success.

The lack of reliable medical options, coupled with the excruciating pain of cluster headaches, has led patients to research and develop their own methods of treating their symptoms. In recent years, a number of “alternative” treatments have been adopted by patients seeking more relief than what is available from mainstream medicine.

In early 2014, a small-scale trial was conducted by two cluster headache patients using the novel tryptamine N,N-diallyl-5 methoxytryptamine (hereafter referred to by its common name 5-MeO-DALT) as a preventive treatment for cluster headaches (Post, 2014). The results of this trial demonstrated that 5-MeO-DALT could be extremely effective in preventing cluster headache attacks, meriting further research.

In July of 2014, the information from this study was released to the cluster headache patient community. Many cluster headache patients, especially those already comfortable with self-medication and alternative treatments, began using 5-MeO-DALT as their primary prophylactic treatment. Once the population of patients using 5-MeO-DALT had grown to a significant number, anecdotal evidence suggested that positive results were being obtained, and this survey was implemented in January of 2015 to collect data from this patient group.

Survey Methods

- This survey was open to all cluster headache patients with a valid diagnosis from a medical practitioner. It was controlled to exclude patients without a confirmed diagnosis.
- Survey participants were limited to those actively using 5-MeO-DALT to treat their cluster headache symptoms.
- The survey included both episodic and chronic cluster headache patients.
- The survey was conducted using a web-based survey tool. It was restricted to one entry per unique user, and patient anonymity was verified through SSL encryption. IP addresses were not logged by the survey tool.
- This survey remained open for a period of 90 days, beginning on January 1, 2014 and concluding at midnight on March 31, 2014.
- Survey results have been controlled to include only those respondents who completed the entire survey (a total of 46 patients).

Results Summary

I. Patient Information

There were 33 male cluster headache patients representing 72% of respondents, with 13 female patients comprising the other 28%. The average age of all respondents was 44 years.

Most patients (63%) reported that they had experienced 10 or more years of cluster headaches from the onset of their first attack to present.

Patients were asked to identify the type of medical practitioner responsible for their cluster headache diagnosis. Neurologists specializing in headache disorders was the most prevalent at 41% of diagnoses, followed by General Practitioner (27%) and Neurologist non-specialist (26%).

54% of patients identified as episodic under IHS diagnostic criteria, with 46% being chronic.

II. Treatment History

Patients were asked to report on their use of cluster headache treatments, both prescribed and alternative.

Among mainstream abortive treatments, high-flow oxygen was the most commonly-used (80% of patients), followed by subcutaneous sumatriptan injections (66%) and oral sumatriptan (37%). High-flow oxygen and subcutaneous sumatriptan were ranked as the most effective abortive treatments, with 63% of patients reporting both as being highly effective.

Verapamil or other CCBs ranked as the most commonly-used preventive treatment (85% of patients), with corticosteroids (69%), topiramate (54%), and lithium (38%) comprising the other frequently-used pharmaceutical preventives. The most effective of these treatments was corticosteroids (46%) followed by verapamil or other CCBs (43%).

When asked about alternative treatments used to treat and prevent cluster headache attacks, the most commonly-used among respondents were: Energy drinks/shots containing caffeine and taurine (81%), high-dose melatonin (65%), a vitamin D3-based therapy (63%), psilocybin (56%), d-lysergic acid amide [LSA] (35%), and lysergic acid diethylamide [LSD] (28%). The most effective alternative treatments were reported as being psilocybin and energy drinks (both reported effective by 48% of respondents) and vitamin D3-based therapy (33%).

III. 5-MeO-DALT Treatment and Results

Patients were asked to state the reason(s) they made the decision to use 5-MeO-DALT to treat their cluster headaches. 39% reported negative side effects from previous treatments as their primary reason, and 30% said that their primary treatments eventually lost effectiveness over time.

When treating cluster headache symptoms with 5-MeO-DALT, most patients stayed with the dosage amount (15mg) and timing (every five days) shown to be effective in the original study. 74% of patients remained at the 15mg dosage, and 59% used the five-day dosing schedule.

The most common side effects reported by patients included a feeling of reduced body temperature (41%), and dizziness or nausea (22%). 33% of patients reported no side effects.

When asked what effect 5-MeO-DALT has had on their cluster headaches (given the choices of positive effect, no effect, and negative effect), 87% (40 patients) reported a positive effect, and 13% (six patients) reported no effect. No patients in this survey reported a negative effect on their cluster headaches from 5-MeO-DALT.

Patients were asked to estimate the number of individual cluster headache attacks they experienced per day before treatment with 5-MeO-DALT, and after treatment. Before beginning treatment, 26% averaged five to six attacks per day, and 48% averaged from one to four attacks per day. After treatment with 5-MeO-DALT, 21 patients (46%) reported zero attacks. 17 patients (37%) reported an average of one to two attacks per day.

III. 5-MeO-DALT Treatment and Results (cont.)

When asked to rate the overall effectiveness that 5-MeO-DALT had in reducing the frequency and intensity of their cluster headache attacks, 28 patients (61%) reported a dramatic reduction in frequency or complete elimination of attacks. 27 (59%) reported a dramatic reduction in intensity or complete elimination of pain.

On a gradient scale of 1-10 (1 being no relief, 10 being complete relief), patients were asked to rate the overall relief from cluster headache symptoms they have experienced using 5-MeO-DALT. The highest percentage of patients (35%) selected 10, complete relief. This was followed by a rating of 9 (20%). Patients rating their relief as equal to or greater than 5 (moderate relief) comprised 83% of the respondents (38 patients).

All patients were asked to disclose whether or not they would continue taking 5-MeO-DALT to treat their cluster headache symptoms. 78% indicated that they would definitely continue using 5-MeO-DALT, 15% stated that they were undecided, and 7% indicated they would not continue using 5-MeO-DALT.

Discussion

It is important to note that this treatment method and survey have been conducted entirely by cluster headache patients. With no clinicians or medical researchers involved in this process, certain errors in control, quality of supply, and methods of administration are inevitable. However, the overall results demonstrated by this survey make it clear that 5MeO-DALT has had a dramatic effect in reducing or eliminating the pain of cluster headaches for a large percentage of these patients, well beyond any possible procedural errors or placebo effect.

The glaring lack of viable treatment options for cluster headache patients has created an explosion of “citizen science”, patients researching and experimenting with their own treatments and medications, and serotonergic tryptamines like 5-MeO-DALT are among the primary medications being studied. The internet has provided these patients with access to information and an ability to collaborate that has allowed them to accelerate the pace of research, and drugs like 5-MeO-DALT are the product of this fast-paced search for relief. One of the most common criticisms that can be leveled at this type of citizen science is one of safety. In this light, it is important to understand the nature and severity of cluster headaches. This disorder is accompanied by a level of pain and disruption of daily life that are virtually unequalled by any other pain disorder; cluster headache patients are generally willing to take on a higher degree of risk in order to find relief, as witnessed by the early adoption of tryptamines and other alternative treatments.

The use of 5-MeO-DALT in the treatment of cluster headaches represents an opportunity for a giant leap forward in bringing relief to these patients, who represent an estimated .1% of the total population. Unlike most other serotonergic drugs that have been shown effective in the treatment of cluster headaches, 5-MeO-DALT is currently uncontrolled in the United States. This legal status opens a window of opportunity for advanced research, one that should be capitalized upon immediately before the potential of changing federal regulations stifles the ability to produce and experiment with this important drug.

Participant Narrative

The following comments provided voluntarily by survey participants are included here unedited, except for spelling/grammar when needed to clarify the comment's meaning:

- *Miracle*
- *This is by far the best treatment I've ever used in 20 years of being episodic. Currently I'm out of a cycle but occasionally I will get a shadow, when I do I take 15mg and I'm good, no shadows whatsoever. This last cycle was the absolute worst I've ever experienced and was truly contemplating suicide. Thanks to this incredible 5meo-dalt my life has changed.*
- *Only one dose into it, so feel free to discard.*
- *15mg was too high to start with. Had sweats, heavy limbs for first hour. Had trouble turning brain off to sleep. Wanted melatonin which I have used for 10 years. Minor CH during the first night. Felt precursors build then just prior to the CH it felt like a bubble burst and then CH gone. Slapback the following morning of first dose. None on second dose. (3/28/15)*
- *I was toward the end of my headache cycle when I took my first dose. It did give me relief. I took 5 more doses ever 5 days, and 1 more after 7 days for a total of 7. It has been 33 days since my last dose. All pain free! Historically my pain free period is 6 to 16 months. I prefer to not take doses during this time, but I will try 5-MeO-DALT when my next headache cycle starts.*
- *I had to use mushrooms every two weeks and was still getting shadows. After one dose of 5-meo-dalt i was shadow free for a month. After second dose no shadowing yet. Going on three months.*
- *Third time I felt somewhat of a(not unpleasant) buzz- over in a couple hours, as promised. But that hit at the top of a mountain was pretty intense. It happened I got the flu with bad headache a few days later, I was sick for 10 days, so I couldn't think of dosing. Pain level of clusters was 5-6 , cycle ended a couple weeks later. But, although I said above my average pain level was 7-8, I really don't have an average- I never know. O2 has been a pretty good abortive for me but it's not very portable! several questions an tihs survey I would have prefered to answer "none of the above":#20, #16 for two. Thanks,*
- *To have or get 5-MeO-Dalt will be difficult in Future.*
- *I switched preventive treatment from mushrooms to 5-MeO-DALT; that is the reason I had no attacks previous first dose of it. - It seems to as effective as mushrooms for prevention. - I came to prefer the HCL (Salt) form of 5-MeO-DALT; it allows to be easily dissolved in H2O which makes storage and dosing super easy for me. - I would suggest studies/tests with water solutions of it in nasal spray for aborting attacks. (worked like a charm or magical spell for a clusterhead I did suggest it to)*

- *I get short few minute spikes and shadows that go away before I realize it with no treatment given for them*
- *My attacks are down to ONE EVERY EVENING. Down significantly in frequency and down dramatically in intensity. I believe this treatment needs to be shared with every sufferer.*
- *My decision to use 5 MeO Dalt while NOT in cycle was due to constant shadowing. Three weeks in, I am only experiencing random jolts and minimum shadowing. I will continue the process until I reach a status completely free of any CH activity.*
- *DALT is life changing. Nothing has given me the peace of mind and comfort DALT has, ever.*
- *Amazing treatment!*
- *I prevented a whole episode 2014 using 5-meo-Dalt. I was busting with psilocybin every two weeks for two months to prevent increasing shadows, two 15mg doses of 5-meo-Dalt stopped the shadowing completely and haven't had to bust since. Psilocybing was keeping the episode away, but i had to repeat the dose every two weeks.*
- *Nothing all good. No attacks today. :)*
- *This chemical treatment is the answer I have been looking for for 5 years when no doctor could tell me what the answer was*
- *great job! thank you for doing this important work! I tried my best, my english is not too good. after beeing in 5MD i have some sharp strong side pain (?) goes away in about 2 minutes. this comes several times a day after takeing 5MD. Never had this with shrooms. so this is not working so great than psilocybin for me :(but aborts well the big ch:s*
- *The does taken seems high but tried first with 25mg but continued to have ch attacks. Side effects at 50mg Still quite manageable, little hard to concentrate.*
- *Only 4 does in, the first 2 doses didn't work too well and had gotten some really bad CHs for days after. These last 2 doses have been more promising. However, after the first dose, I went on a prednisone cycle to maybe try and ease my body on using the DALT. So, maybe another good question to eventually ask is "Are you taking any other medications while taking the DALT?"*
- *Polices saliva test shows positive for amphetamine/methamphetamine. Causes for me similar CH attacks as pseudoephedrine does.*

- *This has been the most effective treatment I have used. Minimal side effects and a very mild drug. Two hours and I barely notice anything. Psilocyben has become difficult to use because of the frequency in which I need to bust, and the side effect of chronic pain in my body during the trip. Also inconsistencies in effectiveness each bust. I have tried most preventatives minus lithium with none of them working. 5-Meo-DALT has truly been a life saver.*
- *Well, I didn't get the capsules. I just got the 15mg scoop, and the 5-MeO-Dalt and basically the first time put it under my tongue. It made it numb, tasted kinda ick, but worked fine. The second dose I swallowed with water. Tongue still went numb, and I felt a bit more drunk. But it was also okay. As long as it helps the hits, I don't see the need for putting it in a capsule. Works just fine without. I'm not squeamish.*
- *Zero anxiety. Zero planning for treatment dosages. Prior to 5-MeO DALT treatment my anxiety levels were very high. I've been able to take the 5-MeO DALT treatment (without having to set aside hours while involved in a hallucinogenic state) participate in life AND be completely pain free.*
- *I'm a French user, among others, DALT since August 2014 with excellent results. The main problem is the dosage that was rough at first, then I bought a scale. I find that the DALT works as well as psilocybin, but much less well and as fast as LSD. I could not keep taking LSD as often, it had become too restrictive, then the DALT is my savior! Thank you so much*
- *Best part about this treatment is it works , no tripping ,minor side effects (cold fingers and toes) Inexpensive and easy to administer*

The author and participants in this study in no way condone the use, procurement, or production of any illegal substances for the treatment of cluster headache symptoms.

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References

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