

Efficiency of tryptamines in treating cluster headaches

Conceptual paper

Several different types of Tryptamines have the ability to put cluster headaches into remission for months and in many cases much longer, sometimes lasting years with minimal amounts of medicine to stay CH free, but because of the recreational use associated with these treatments, some call these patients drug seekers.

This is just one of the most extremely cruel and hurtful statements you could possibly say to a cluster headache patient who quite possibly has been searching for years upon years to find “Anything” that will stop the violent and extremely brutal attacks associated with clusters and in a daily struggle that would intimidate anyone. That is the last thing they need to hear.

Unfortunately, I hear these stories on a daily basis and has me fighting for change, understanding and education. I have seen families that have lost children to suicide because of this horrible disease and it tears me apart knowing that tryptamines may have made the difference. Please do not take this perspective any other way than just what I have learned, observed and studied for the last five years every day in being a CH researcher, supporter, advocate also creating this website and one of four administrators for a 5500+ member cluster headache support group, the largest of its kind in the world.

I'm also a 43 year patient of chronic cluster headaches and a retired/disabled ship's captain and commercial fisherman for 35 years. I too, being just another CH patient have the understanding we all share and desperation to see change.

Drug seeking is probably the farthest thing from a CH patient's mind. It's about stopping this incredibly powerful pain and that is the bottom line. It is impossible to try and describe this pain to someone that doesn't have CH and they are so misunderstood because of the word “headache” that even in some cases family members think it's no big deal. I will try and explain something... When having a bad cluster headache attack it will put anyone on their knees screaming in brutal, violent agony, literally wishing desperately to escape their own body and mind.

Just using the cruel stigma of the word “Headache” undermines the suffering beyond imagination. Most all CH patients also battle clinical depression and many with PTSD as a direct result of the incredible terrifying pain and anticipation of an oncoming attack. Flashbacks of past extremely traumatic attacks that can trigger PTSD and severe anxiety along with the hopelessness, frustrations and despair CH can and does cause.

The actual amount needed of these tryptamines to be a therapeutic dose in most cases is a sub-hallucinogenic dose or about half of what is considered a recreational dose as for example with the use of psilocybin. Bottom line, for cluster headache patients these treatments are used to stop the pain and it works close to 90% of the time. “It has nothing to do with recreational use”.

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John Fletcher

President/Founder, Cluster Headache Foundation Inc., USA

Correspondence: John Fletcher, President/Founder Cluster Headache Foundation Inc., USA,
Email clusterheadaches@yahoo.com

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These “Medicines” are very effective at relieving the severe pain and stopping CH in its tracks as well as helping several other severe medical conditions such as clinical depression, PTSD and severe anxiety all symptoms of CH as well.

Putting patients on a role as drug seekers and making it about getting high instead of what is really the issue and that's stopping this horrific pain and suffering is what needs to happen and thankfully since awareness and advocacy of these treatments are now being more widely accepted.

No other known medications, treatments or surgeries come even close to these success rates. However, some other alternative treatments are also more effective than anything offered to CH patients like a long standing proven vitamin D3 anti-inflammatory regimen at 84% efficiency and has been used safely for many years by thousands.

I also believe that D3 therapy is another with huge potential and needs further study and the help needed to mainstream Pete Batcheller's Vitamin D3 Anti- Inflammatory Regimen. The information on this regimen is on www.clusterheadaches.com under treatments and medications.

I continue to read about and talk to patients every day who have spent years on the medication merry go round ending up with nothing working or possibly making the symptoms worse. Personally, it took me 39 years to finally find a treatment to help me in any capacity and it wasn't from my doctor. It was the D3 regimen and tryptamines.

No medication has ever been created to treat CH in the 374 year history of the disorder, so it has been years of experimenting on us using all kinds of different medications including, anti seizure, antipsychotics, antidepressants, neuropathy MEDs, narcotics or opiates, heart and blood pressure meds and steroids are some of the traditional off label medications used to treat the disorder.

The problem is most all have the potential to cause serious side effects or even possibly be harmful. These are the just some of the “preventative” medications, doctors have to fight cluster headaches being that no medication has ever been created for this horrible disease.

The abortive treatments we are being offered are also questionable with the ability to cause serious problems such as triptans causing rebound attacks or “Medication Overuse Headaches” or varying other side effects as it was not created for multiple daily attacks and was created for migraine. Sumatriptan was created for Migraine sufferers and with Migraine Disease not clusters.

Multiple daily powerful attacks are not the case with migraine and because CH is multiple daily attacks and so incredibly painful that it puts serious pressure on the patient to NOT use them to abort an attack. This situation is not uncommon and can lead to excessive overuse that can cause several other serious heart and respiratory issues if exceeding or even using the maximum dose of 12mg daily and using it long term.

These triptans as I mentioned were created for migraine and when the initial studies and trials were done it was never studied and never intended to use the 12mg daily maximum dosage in any consistent long term capacity and has literally been an experiment using it for ECH or CCH when it may be used for months every day at the 12mg maximum with ECH or with CCH which is basically every day year round.

Triptans work very quickly in most cases to abort an attack and when something can stop this kind of pain you know many will be tempted to overuse it and as a result can be a very dangerous situation.

Our #1 abortive treatment, High Flow Oxygen (15 to 40 Lpm) or oxygen period is not recognized by Medicare as a treatment they will cover with the medical insurance they offer leaving so many to suffer greatly without this wonderful “abortive” treatment. Our hospitals don’t in many cases have the protocol of using high flow oxygen to stop a cluster attack and many times we sit for hours in the ER waiting, going through so much pain, far beyond anyone’s realization. In most cases, high flow oxygen is all that is needed to abort an attack and should be part of triage protocol.

It is not uncommon for several of the medication choices we have to possibly make CH worse. More attacks, more frequent attacks and more powerful attacks are the symptoms of Medication Overuse Headaches or rebound attacks and most all medicines used to treat CH have serious side effects potential.

Our doctors are also being forced to experiment in many cases using doses that are very high with some of these medications that are not totally understood how to be using them long term at high doses which is not how they were intended to be used for what they

were created for like Verapamil for example. It is the number one go to preventative medication that doctors use for cluster headaches and is a heart medication that directly affects the heart and lowers your blood pressure.

Doctors are supposed to give the patient an EKG every time the dose is raised by any more than 80mg and the patient is supposed to constantly monitor their blood pressure to be as safe as possible while using this medication. Verapamil can possibly cause heart damage using high doses for long term use and raises the potential to cause even more serious problems. Doses over 700mg daily are not uncommonly used to treat CH and being that it was created as a heart medication never intended to be used at doses this high or higher nor the studies ever done to see the long term effects at doses this high... Use with extreme caution.

Doctors are trying desperately to get some results and relief for their patients. This is the whole point I’m trying to make that our doctors are so limited to what they can use to fight cluster headaches and the many questionable choices they have and a serious reason as to why we so desperately need new, safer and more effective treatments and medications. No medication has ever been created for clusters and a main reason the patient group is in such desperation and continuing suicide rate 20 times the national average.

Having clusters bottom line is about suffering such unimaginable, violent and powerful pain that they are called “Suicide Headaches” for a very profound and serious reason. The medication situation is forcing patients to self treat using alternative treatments by possibly tens of thousands.

I sincerely hope that change is coming sooner than later and believe many share this same point of view and a main reason why I wrote this perspective...

Thank you all for your taking your valuable time to read this and understand just how incredibly painful CH is and the intense frustration that is overly abundant in the CH world...

Acknowledgments

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Conflicts of interests

The authors disclose no conflicts of interest.