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Journal of Neurology & Stroke

Conceptual Paper

Cluster headaches... a deadly situation

Special Issue - 2016

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Received: December 18, 2015 | **Published:** April 04, 2016

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I have devoted my life every day to all who suffer not only with clusters but those who suffer great pain in any form. For Cluster patients I have studied the disease on a daily basis for several years and worked hard to help gain the desperately needed public awareness and respect for what is widely regarded by medical professionals to be the most painful disorder known to medical science, helping save lives and helping folks to gain an education on this severe condition to understand it is not hopeless.

I have the wonderful privilege of being one of the four administrators for the largest chat support group for cluster headache patients in the world on face book with over 5500 patients for some years now. It is a very cool family of patients and supporters of family members who suffer and all helping each other every day around the clock, year round. That's what it's all about… "The Patient" Respect, understanding, caring, love, support, advocacy and education.

It is truly a close family of thousands of patients supporting each other to help get through the days and nights that can be so difficult to do especially if trying to cope alone with this or any disease that causes great pain and/or suffering. Support groups are nothing short of a family that can seriously relate to each other and the mutual struggle trying to cope with this or any severe disease.

This condition that so many have no idea what it really is and just how much incredible brutal pain and suffering over 7 million patients worldwide endure. I have been a cluster headache patient for 43 years since 1973 starting when I was a 14 year old kid… Beginning as a chronic patient and having the chronic form for 40 of those years and three as an episodic patient. I know and understand what this disease is and does and it is horrific beyond imagination. It is absolutely terrifying and devastates patients, family and friends. Besides having the disease for so many years and being involved directly with so many patients every day for years has proven to me that we get a bit different overall picture of this severe condition than does the medical field in many ways, the main one being just daily life and living with the disorder.

To say this is not a deadly disease is just not true and no matter the mechanism of death this disease is so powerful and so excruciatingly painful having multiple daily and or nightly attacks of such violent and unbelievable pain that it leaves many in a very desperate situation. Serious loss of quality of life is what this disease causes in many cases and is also now well known since the last several years to be a major cause of Post Traumatic Stress Disorder (PTSD), also causing severe anxiety, severe sleep deprivation, depression etc…etc…

When when you lose your quality of life not much else matters and especially hard losing it to such powerful, violent, excruciating painful attacks and associated brutal symptoms. Another big contributor is the powerful extent it takes anxiety, filled with the horrible mental and physical anticipation of a coming cycle or coming bad attacks… both keep you seriously on your toes and definitely not in a positive way.

The fact that if this condition was not present no one would lose their life if you take away the disease… That is the bottom line. It has been "Influencing/causing" death for centuries. Countless lives have been lost and continue to be lost at a suicide rate 20 times the national average. The definition of a deadly disease needs to be "any disease that directly causes and or significantly influences death"… directly caused or influenced by the disease itself.

A patient preparing for an oncoming attack that gives you just minutes from no pain to peaking with powerful intensity is the same thing as preparing yourself to have what has been described countless times and I can also completely agree as the very real physical feeling of penetration having an ice pick, knife or hot poker being inserted and severely & repeatedly stabbed through the eye into the brain and out the temple with serious force sometimes lasting up to 3 hours per attack or longer with excruciating, screaming, precise crystal clarity… Over and over and over…

It is absolutely terrifying especially when having consistent bad attacks preparing yourself in anticipation of another bad attack sometimes up to a dozen times a day or waking strait out of sleep multiple times every night into this incredible amount of pain. It "always" leaves the patient with the very real and physical feeling that death or severe damage could only result from so much pain. It literally has you expecting to see blood everywhere… This is absolutely no exaggeration at all.

Getting many "Cluster Headache "10's" are incredibly terrifying and one of the main reasons for the name "Suicide Headaches". It is one of the most common reasons that so many over history have taken their own lives to escape more of these 10's and this incredibly brutal and painful life of daily & nightly multiple attacks.

It is an attack of pure excruciating, violent and traumatic one sided head, eye, temple, sinus, neck & shoulder pain all being extremely painful and traumatic along with even more scary and painful symptoms during an attack such as the severe anxiety and heart palpitations being very common.

Lightning-Thunder"A Lightning Storm" of violent crisp pain so intense that there is nothing to compare it to. It is death without dying. A bad attack considered a "10" which would be far beyond a normal pain scale and can take the strongest man, put him on the floor screaming, crying, smashing his head against a wall or with closed fist. Also not uncommon to lose consciousness.

A "10" attack is considered worse than living death by many near death survivors who have CH, myself among them. Having a 10 is absolutely terrifying and words just can not describe this amount of pain. Personally it makes me feel like having my eye and head brutally assaulted by something evil wielding a knife. Like being repeatedly stabbed with great force through the eye into the brain and my eye has burst or has been severely damaged and the right side of my head beaten to a bloody pulp caused by such violent pain… Every time… A routine of pure anxiety filled dread.

One thing that bothers all CH patients is the given name of a headache, the same for Migraine patients or any of the severe and disabling primary headache disorders. Calling this pain an "ache" is as far from the meaning of the word as you can possibly get. It is a violently brutal assault of incredible intensity. It is nothing like the word headache implies in any descriptive sense.

This is one of those diseases that has been so misunderstood over history that in our past Clusters were sometimes confused and thought to be a mental disease/disorder and in some extreme situations would take patients and lock them up in mental institutions mistaken for mental health problems because of the patient screaming day and night from multiple attacks and so much pain. I am so glad we are mostly passed that, but believe it or not it still happens and I have seen it and know of at least one patient now that was institutionalized because of a severe case of CCH (Chronic Cluster Headaches). Due to a correct diagnoses they recently let him out :)

Doctors are forced to use off-label medicines created for other diseases like epilepsy, neuropathy, anxiety, high blood pressure, depressive disorders, anti convulsants etc. All with questionable success rates and serious side effect potential as none were ever created specifically for CH and in many cases do not work leaving patients to try multiple different medications in hopes of finding one that will bring some relief and not always successfully. It is not uncommon for some medications to make attacks even worse such as some that can cause MOH or Medication Overuse Headache also called rebound attacks which can happen using medications even at prescribed doses, a potentially horrible and scary situation.

Cluster Headaches do not respond the same or very well to traditional pain medications like narcotics or opioids and are not recommended and can actually make things far worse in several ways. Patients are going to alternative treatments, possibly by the tens of thousands because of the desperately needed "Hope" that several of these treatments can bring as many patients do achieve great relief or complete remission from using them… This is the reality and what the situation has come to up to this point. Many advancements in the history of this disease such as effective alternative treatments were researched and brought forth by the patients themselves out of pure desperation while searching to find anything that can stop this powerful condition and brutal attacks.

A very, very frustrating and scary situation for all patients, but most all are so far beyond desperation that they would be willing to try practically "Anything" to stop this insanity as I hear it daily that some patients after years of searching still have found nothing that stops this, personally took me 37 years to find my first relief and that was temporary. In writing this I have meant no disrespect at all to the medical field only bringing awareness and hoping to show how desperately we need to have the first medicines created specifically to fight and endure this disease or ultimately the dream of a cure. We do have some promising future possibilities that will most definitely need more research funding such as CGRP & Genetic research.

As patients we desperately need to stop this incredible pain and life of excruciating agony. Due to continuing and historical lack of funding the necessary research, we still do not fully understand its cause or causes and no medicine has yet been specifically created to help relieve the most severe pain a human can experience and associated powerful symptoms of this devastating condition making this a very serious and potentially deadly situation…

Acknowledgments

None.

Conflicts of interests

The authors disclose no conflicts of interest.

Citation: Fletcher J. Cluster headaches... a deadly situation. *J Neurol Stroke.* 2016;4(5):1–6. DOI: 10.15406/jnsk.2016.04.00141