

A general description of cluster headache disorder

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Conceptual paper

Cluster headache disorder is one of three types of Trigeminal Autonomic Cephalalgias or TAC's the other two being Paroxysmal Hemicrania & SUNCT/SUNA (short lasting unilateral neuralgiform headache attacks with conjunctival injection & tearing). All TAC disorders are associated with extreme pain.

Cluster Headaches (CH) affecting approximately 0.1% to 0.3% of the population (about the same as multiple sclerosis) have been given the very serious and profound nickname "Suicide Headaches" for several reasons. The first reason that started the nickname was from Dr. Bayard Taylor Horton's famous description in 1939 who postulated the first theory as to their pathogenesis. Dr. Horton's description explains in his original paper describing the extreme severity of the disorder as "being able to take normal men and force them to attempt or complete suicide".

From Dr. Horton's 1939 paper on cluster headache...

"Our patients were disabled by the disorder and suffered from bouts of pain from two to twenty times a week. They had found no relief from the usual methods of treatment. Their pain was so severe that several of them had to be constantly watched for fear of suicide. Most of them were willing to submit to any kind of operation which might bring relief." Thus the beginning of the name "Suicide Headaches"

There are several descriptions about clusters out there and in many of them are the same exact statements about the disorder that are not entirely accurate. These inaccuracies must be addressed... I have copy & pasted this directly from these descriptions to show the inaccuracies. Without naming these sources which there are several, here is that statement..."Each headache lasts from "30 minutes to 2 hours" and consists of very severe pain on one side of the head, generally in the region of the eye. These daily headaches continue for "4 to 8 weeks" and then disappear for another year or more" Unquote. This is not entirely accurate...

Another example and sometimes the first statement made in these descriptions is, CH was first recognized in 1867 by Von Möllendorff... This is inaccurate... CH was first recognized in 1641 by Dr. Nicolaas Tulp then further more serious documentation and recognition of the disorder and patient group in 1745 by Dr. Gherhardt Van Sweitin.

In response and the proper correction to the above copy & pasted statements... Saying a CH attack cycle lasts from four to eight weeks, then disappears, however a common symptom is misleading and leaves no room to vary which is inaccurate. A CH attack cycle is as different as the individuals that have the disease. More commonly, a cluster attack cycle of varying length commonly lasting from two weeks to six months, followed by a remission period starting the same time the next year, however, may be much longer possibly lasting several years before the next cycle of attacks begins.

CH attack cycles are associated with the episodic form of the disease and a patient can get attacks 334 days a year and still by definition be considered a "Cycle" and also Episodic. There is no average length of an attack cycle as a symptom per say that has no room to vary

many times greatly, only more common symptom descriptions. The chronic form, affecting roughly 15% to 20% of the patient group and is clearly defined as "Going a full year without less than thirty days of relief" however every day year round is not uncommon, anything else is considered episodic...

In response to the statement of length of individual attacks saying an attack lasts from thirty minutes... CH attacks as the diagnostic criteria is written is lasting from fifteen minutes to three hours, rarely much longer and is one of few things about the disorder that must be clear for example just being off by fifteen minutes or more regarding the beginning length of an attack and by saying thirty minutes can instantly point to a different disorder and no longer fit the common correct diagnostic criteria of CH. Attacks can last over three hours, but rarely and if off by over an hour can point to a different disorder again...

Lastly... A phrase heard more frequently all the time that must stop is "Cluster Migraines". There is no such disorder or name or ever has been... We don't know where this first started, but the two are different disorders, although having some similar symptoms, clusters not being one of them. The name was apparently something just made up at the time whenever it was stated then taken as a correct statement... Using this phrase only creates great confusion and is inaccurate. Thank you for understanding the necessity to make these very important corrections.

Day or night cluster attacks can happen with clock like regularity, however, attacks can be triggered by several known outside influences and certain foods such as processed meats with nitrites, fermented foods, alcohol, smoking, strong smells like perfumes or chemical smells, extreme heat or cold, watching TV, turning on an indoor heater, also altitude or a rising and falling barometer may also trigger attacks to name a few.

Cluster Headaches said to affect more men than women (male-to-female ratio may be as much as 5 - 8:1) however, that ratio is constantly changing due to diagnoses being much better these days

as many women had been misdiagnosed with migraine being more common in women than men...

CH is considered a disorder of circadian rhythm and the involvement of the body's circadian clock in the brain, the "Hypothalamus". It is suspected in playing a significant role in the disorder as in studies using PET & MRI imaging has shown involvement with and stimulation of the gray matter of the hypothalamus. The symptoms of CH attacks that happen like clockwork at the same time daily also starting the patients cycle of attacks at the same time from a few months to yearly or every several years at the same time.

Also being "In rhythm" or "in tune" with the earth, greatly effected by the seasonal variations and normal weather changes of the seasons of the year as in Fall, Winter, Spring & Summer and the weather and barometric pressure changes being more extreme in the winter (more storms effecting barometric pressure) also summer heat as excessive heat is a known trigger in itself and has shown to have a more influential effect on the disorder as attacks and cycles can be more extreme during these seasons. However... In many ways CH is not a one size fits all disorder and consistently shows we are all a bit different also in treating the disorder with the different off label medications, none ever being created specifically for the disorder do not work for many patients and many times takes trying several different medications before finding one that is effective.

There are two forms of clusters either "Chronic" or "Episodic". The episodic version much more common defined by the patient having cycles of attacks that last varying amounts of time, followed by a remission period that varies in length as well. The episodic form can vary greatly in attack cycle length and remission length, however the length of individual attacks much more clearly defined. The general symptoms and individual attacks are the severe to very severe unilateral orbital, supraorbital and temporal pain lasting from 15-180 minutes and an attack frequency average of two to eight attacks per day however having up to and possibly over a dozen attacks per day is not uncommon. Night time attacks for patients are more common, however, attacks happen day or night. Night time attacks commonly waking the patient from sleep within fifteen minutes to an hour or two with excruciating violent pain.

An average episodic patient may have an attack cycle lasting from two weeks to six months, then a remission period until the same time the following year is common, but as mentioned can vary greatly and some patient cycles can last over six months and remission periods varying from a few months to several years again showing the significant tendency regarding length of attack cycles and remission periods to vary greatly. The patient may also have two or more attack cycles annually. The "Chronic" form (affecting roughly 15 to 20% of patients) is much more clearly defined as "Going a full year without more than thirty days of relief" is the precise definition, anything else is considered episodic.

The disorder can begin at almost any age from infancy to as old as fifty years old or older, but the average is said to be controversially around thirty to forty years old. Once the disorder begins it is common to continue through the patient's life sometimes going from episodic to chronic or chronic to episodic is also not uncommon. These powerful attacks are not something that only happens once or twice or even several times, but multiple daily attacks which is the reason they were named cluster headaches.

Cluster attacks are commonly accompanied by the following autonomic symptoms: Ptosis (drooping eyelid), miosis (pupil constriction), conjunctival injection (redness of the conjunctiva),

excessive lacrimation (watery eye), sinusitis (sinus membrane swelling), rhinorrhea (runny nose), facial blushing, or sweating and less commonly, cutaneous allodynia (extreme head & facial skin sensitivity, painful to the touch). These ipsilateral symptoms (same side) all contributing during an attack.

Secondary effects of the disorder are the inability to organize thoughts and plans, confusion and severe exhaustion in response to such extreme pain and stress. Commonly these symptoms together can be extremely disabling, especially when attacks are bad in the upper range of severity. Patients can get "flashbacks" of past extremely traumatic attacks that will never be forgotten which is a major PTSD factor.

Together, these multiple extreme symptoms can be factors for what we now understand can cause "post traumatic stress disorder" known as PTSD, which is a fairly new understanding with the disorder that is more common than previously understood until the last several years. Patients may adjust their physical or social activities or ask for help to accomplish normal everyday tasks, and may hesitate to schedule plans in reaction to the clock-like regularity of the painful attacks leading to social isolation and commonly, clinical depression.

Less frequently, patients will have an aversion to bright lights and loud noise during an attack. Nausea rarely accompanies a cluster attack, although it has been reported. The neck and shoulders are often very stiff or tender during an attack and into the aftermath of an attack. A less common symptom of jaw or tooth pain sometimes present as a result of the irritation of the lower branch of the trigeminal nerve.

Attacks can and do vary in power and intensity, but all are severe, disabling and extremely painful. The pain of a cluster can go from no pain to full intensity in just minutes and can last up to three hours per attack, however, fifteen minutes to an hour or so is more common. It is rare for a cluster attack to last more than three hours making this symptom good criteria for a correct diagnoses of the disorder vs migraine which rarely lasts less than four hours. Cluster and migraine are two distinctly different disorders, but do have some similar symptoms however it is pretty easy to tell the two apart.

A migraine attack will for most patients cause them to seek a quiet, dark room and isolate, laying down while enduring the severe attacks which can last from four hours to several days. A cluster patient can't sit still and commonly feels the overpowering need to move, become agitated, rock back and forth, pace, scream, cry, curse and thrash out, especially when having a bad attack. Smashing their head on a wall, an object or with a closed fist out of desperation, trying to distract from the pain, bringing the patient to their knees and tearing out hair can be caused by the violent, severe and overpowering pain. A migraine is very different in this regard also making this difference good diagnostic criteria. Migraine and the several different variations are also very painful, brutal and extreme.

A defining difference between CH & Migraine is the severity of the actual pain in which CH is a more violent pain but being a different disease, some migraine symptoms like the severe nausea and vision problems not associated with CH are extremely brutal and disabling symptoms and migraine is also extremely painful... Both disorders are just horrible. No doubt both needing more serious research. We here at CHF also want to help with migraine as well as all the disabling neurological pain disorders and future research...

CH is considered by medical professionals around the world as the most painful disorder known to medical science. The anticipation of a coming bad attack can be an extremely sickening and terrifying

thought filled with severe anxiety and fear as all patients absolutely dread the anticipation of an oncoming bad attack. Knowing the violent and traumatic attack is on its way and many times, if no abortive treatment there will be most likely nothing you can do to stop it or change that reality and a direct cause and contributing factor to the high suicide rate.

The disorder can cause loss of jobs, friends and even family members can be very harsh when not understanding what their loved one is going through directly caused by the trivializing word "Headache". Clusters are about as far from that descriptive word as one can possibly get and the powerful stigmas, misunderstandings and misconceptions it has caused. It has had a powerful direct impact and effect on individual patients and the overall disorder causing a serious lack of respect, urgency and a long and profound 374 year history of lack of appreciation of the severity of the incredible pain involved. However, that is getting better because of many patient advocates and organizations having a direct impact on public awareness, but we still have a long way to go to eliminate the stigmas and misconceptions about the disorder.

Professor of Clinical Neurology, Prof. Peter Goadsby at the University of California, San Francisco and Kings College in the U.K. considered by many in the field as one of the leading neurologists and researchers in the world on the disorder has commented: "Cluster headache is probably the worst pain that humans experience. I know that is quite a strong remark to make, but if you ask a cluster headache patient if they have had a worse experience, they will universally say they have not".

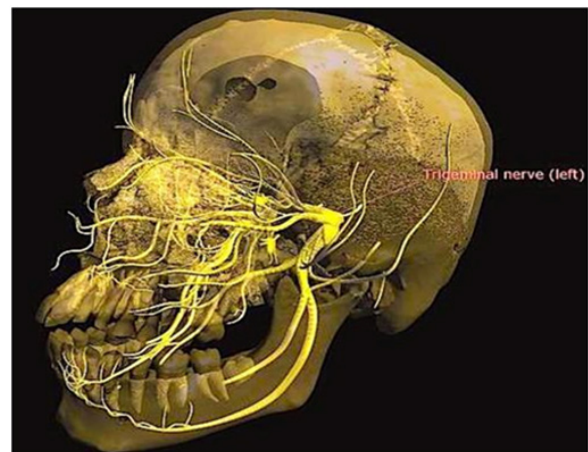
"Women with cluster headache will tell you that an attack is worse than giving birth. Therefore, you can imagine that these people give birth without anesthetic, two to eight times a day, for six, eight, or ten weeks, and then have a break. "More painful than a gun shot, knifing, broken or shattered bones, kidney stones or having a limb amputated without anesthetic". These comparisons from Prof. Goadsby are meant in the true sense of the statements coming directly from patients that have had these different and extreme scenarios. The serious reality that when having the chronic form of the disorder a patient will go over 335 days a year two to eight attacks every day on average for many years is common...

Countless lives have been lost to this disorder around the world over history and continues to do so today at a suicide rate 20 times the national average, however CH has actually been controversially addressed as "not a deadly disease". A Neurological Disorder,

Disease, Syndrome, Condition or Affliction...All are correct. By way of good information and education, it can change how anyone views this disorder and bring the serious public awareness and realization to our overall medical community that CH is far more severe and far more serious than it has been treated throughout history.

This disorder is certainly not just a headache and in our opinion needs to be respectfully considered much more seriously as a disease that does indeed take lives and has for centuries. The long overdue respect that the disorder and patients must have in order to get more scientific studies and research started and going on a consistent basis to try and finally understand this extreme form of Trigeminal Autonomic Cephalalgia which to this day is still a mystery.

More direct medical research and medicinal studies and trials going to finally better understand the entire disorder and to create new, highly effective medicines and or treatments specifically to treat the disorder or ultimately to cure it. No medication or treatment has ever been created to help this patient group of well over 400,000 in the U.S and over 7 million worldwide to endure this very difficult life filled with attacks of extreme, brutal and violent pain called Cluster Headache Disorder.



Acknowledgments

None.

Conflicts of interest

None.