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Commentary

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Why cluster headaches are called "suicide headaches"

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Commentary

In this commentary we will explore the various reasons, cluster headaches are referred to as Suicide Headaches. It is a combination of many reasons, including Dr. Horton's famous description which also is a large reason for the nickname "Suicide Headaches" and the fact that no medication has ever been created to help those who suffer to fight the disease. After reading this description the answer to that question will become very apparent...

This is the description I wrote based on my life as a chronic patient for the most part of 42 years, followed by Wikipedia's well known description.

Many in the medical field have never treated a CH patient so this description will help them or anyone better understand the severity and seriousness of this very powerful and excruciatingly painful disease that lasts a lifetime for so many...

Why cluster headaches are called suicide headaches

It would surprise many to know that the majority of professionals in our medical field has never seen or treated a cluster headache patient. The population prevalence of CH patients is 0.1 to 0.4%. This is considered a rare disease and works out to a minimum of 400,000 sufferers in the U.S and over 7 million worldwide.

We have been told by prominent doctors and neurologists that the average time spent studying cluster headaches in four years of medical school is about 3 hours. More medical classroom education and in depth study is desperately needed. 3 out of 5000 hours for the four years is a mere blip in the semester.

A sense of urgency, when it comes to CH, has been lacking throughout its history. A powerful statement, but all too accurate. When a disease is causing death, no matter the mechanism, urgency needs to be stepped up quickly in order to save a life. For this patient group urgency is long overdue. With awareness and education, conditions are slowly improving.

Countless times patients go to the ER and sit for hours going through attacks. Most ER staff truly has no idea how badly we are suffering. They lack the simplest education and knowledge about this disorder and how to treat it.

Most cluster headache patients stay away from any ER. We all know our attacks can end usually within an hour or two and before we are treated. There is no blood gushing from our bodies to visually indicate our need. We know we are going to get more attacks so going to an ER is practically useless. The only reason we do go is that the incredible pain has become so completely intolerable and unbearable. We are not drug users seeking narcotics, a story I hear all too frequently.

A cluster attack does not always respond well to narcotics. They are not recommended nor needed to stop a CH attack. With that in mind ER's need to realize we are most definitely not after drugs, but only to stop the attack. High flow oxygen, sumatriptan or a few other non narcotic treatments can be used to abort an attack. Narcotics are to be used only if the situation demands and the attending doctor choose to use them.

Cluster headaches are called the "suicide headache" from a long history of patients taking the ultimate step to stop the pain. There are numerous reasons for this which I will explore here. As I mentioned, we rarely go to an ER unless the disease is at its very worse. Being a disease with one of the highest incidence of suicide, it needs to be realized that any CH patient in the ER is a stat situation of having an attack or if the patient is severely depressed. In each case it is always possible that many will be at the point of thinking about or possibly seriously contemplating suicide.

The smallest thing like lack of education, lack of respect, lack of urgency, not believing the patient or accusations of drug seeking and misunderstanding can literally send a patient over the edge and it does happen more than anyone realizes.

It has shown to be practically impossible to truly explain or understand the severity of this pain unless you have the disease or live with someone who does. The actual amount of pain a cluster headache patient goes through, especially when having a bad attack, is beyond description. This is a huge dilemma for us as there is no other pain to compare it to.

It is not a headache in any descriptive sense, but a very powerful, extremely violent, brutally, and traumatic attack that feels physically like you're taking or just took a brutal and cruel beating on the inside of your eye and inside one side of your head. Just like people describe as a beast in your head doing severe physical damage. It is absolutely nothing like any typical headache of any kind. So many have taken their own lives just to escape more of these incredibly violent, powerful and traumatic attacks.

Another misnomer is the phrase "Cluster Migraines" This is a mistaken phrase as there is no such name and may have been confused by some that get clusters of migraines, but the two are completely different disorders and this phrase should never be used as it only creates more confusion.

They say Cluster Headaches is not a deadly disease?? How can anyone possibly make a statement like this when we know for a fact, countless lives have been lost in it? The suicide rate for Cluster headache sufferers is 20 times the national average. I would venture to say countless lives have been lost to this disease over the 374 year history since it was first recognized and who knows how long it truly has been taking lives?

They are called "Suicide Headaches" for a very profound reason. When a disease causes loss of life -no matter how- the fact remains that had this disease not been present no one would lose their life. Death would not be involved or even a factor if you take away the disease... That's the bottom line.

All the pain is on one side of the head temple and back of the neck, sinus pain and swelling, drooping eyelid, facial sweating, in some rarer cases cutaneous allodynia (scalp and facial extreme nerve sensitivity to touch) severe anxiety, fear, PTSD or flashbacks of certain past incredibly traumatic attacks that the patient will never forget.

Severe anxiety, severe clinical depression and for many Post Traumatic Stress Disorder are a serious factor. For a chronic like myself that means daily attacks (if untreated or unsuccessfully treated) like this and, by definition, over 335 days a year. Every day is the norm. For an episodic, the severe anxiety, fear, depression and terrifying knowledge that a cycle is certainly coming. Never knowing exactly when it will start or end and in some cases it doesn't go from episodic to chronic and back is not uncommon. PTSD is very common among us, each attack compounding the trauma of the previous. We live in terror of such horrific attacks that flashbacks do occur completely and overwhelmingly intensifying the anticipation of coming severe and traumatic attacks.

In other words it literally scares the heck out of you knowing a bad attack is coming... A bad attack is considered worse than a living death by many near death survivors who have CH, myself among them. Not all attacks are the same and some are worse than others, but all are traumatic and far and away from any regular type of headache.

A "Lightning Storm" of unbelievably crisp, brutal pain. It will make your eye feel like it literally will explode out of your head at any time. Comprehension is out the window and being all consumed with violent, excruciating eye, sinus, shoulder, neck, temple and head pain on one side. Then that knife in my eye being pounded in and out through my temple, my right eye watering profusely the whole time feeling like it is being torn or ripped apart violently.

Untreated usually a maximum of an hour but have had attacks over two hours and some over three, but very rarely happens. The average for me is more like about twenty to forty five minutes each. A bad attack will literally make you feel and firmly believe that only serious damage or death could result from so much incredible pain.

Several times over the last 42 years I got into the situation of having rebound attacks known as "Medication Overuse Headache". I would get a dozen or more attacks every day and night. For years of being alone with this disease I did not know that it was the medicine doing this to me and being alone, I just thought my attacks were getting worse as part of the disease symptoms.

It is beyond terrifying having a bad attack and going through the multiple daily attacks day after day, year after year without end. Every single time it is such all consuming, incredibly powerful pain on a level far beyond anything I have ever felt. I am a chronic patient of the disease, having several attacks day and night averaging but varying about 4 to 10 attacks every day year round for most of my life since 1973...

It can put the strongest man on his knees screaming and crying, pulling out hair, smashing his head against the wall or with his fists and during a bad attack, begging for death to just escape this pain and is why many do take their own lives at a rate of 20 times the national average.

When attacks are bad and you are expecting a bad attack, it can send anxiety and fear into a different realm. A bad attack in the upper range of severity, is referred to by many patients as a "10" CH (on a scale of 1 to10) attack. A 10 CH attacks not only scares the patient beyond terrified, but is such an extremely violent and powerful attack that many do succeed in taking their own lives to escape more of these terrifying attacks. This is the main reason they are called suicide headaches.

Either episodic or chronic anticipating a bad attack is an extremely sickening thought, knowing you are going to be brutally assaulted and going to endure pain on a level so violent and so intense that no human should ever have to endure. Ever...

They are extremely disabling and must be treated as any other severely disabling disease that causes death. What most doctors don't realize or anyone for that matter is this pain is so powerful and overwhelming that people do take their own life to escape more attacks. That, usually, but not always, happens as a spur of the moment reaction to the pain of an attack or knowing more bad attacks are coming.

Attacks can completely take away quality of life. Loss of friends, jobs and even family can be very harsh when not understanding what their loved one is going through. When you combine all these things it makes it hard for many to even want to keep going through this insanity... The name "Suicide Headaches" Is very accurate, I see it every day and hear the incredible sadness, depression, desperation of so many begging to be helped.

Treatment by others, including medical staff can be very cruel, adding to the incredible never ending frustration this disease causes. This can lead us to even more severe depression and frustrating despair. When you take all these contributing factors into account and put them together the picture becomes much clearer as to why they are called "Suicide Headaches".

Both chronic and episodic are susceptible to an associated sleep disorder. Most sufferers have the dreaded night attacks that wake you out of a dead sleep straight into excruciating brutal pain, sometimes several times a night. This results in sleep deprivation. Even worse, when attacks are bad, most are terrified to go to sleep or even lay down for fear of the night attacks. Try falling asleep knowing that in 2 hours you are going to be awakened by an ice pick being shoved into your eye.

It is known that laying down during an attack can and in most cases will make the attack worse. Try to stay upright when having an attack.

Attacks can last 3 hours, but 15 minutes to an hour or so is more common. Many get up to or over a dozen attacks a day, but three to eight is average. Being woken out of a dead sleep and straight into incredible pain is common some getting attacks as soon as REM sleep kicks in or within the first hour of sleep. Medication Overuse Headaches or Rebound Headaches can be caused by medicines prescribed for CH such as triptans, NSAIDS, narcotics and several other medicines. Even some of the prescribed treatments can cause this to happen and can make everything far worse.

Over the last several years things got much better and we are getting closer to achieving substantial worldwide awareness. Research is steadily picking up, but have the work still ahead to truly understand the whole disorder.

The Urgency and attention that is desperately needed is starting to step up, but we have quite a ways to go to get to new treatments and ultimately a cure to CH, Migraine and all neurological pain disorders"... John Fletcher

The Well Known Wikipedia description of Cluster Headaches...

The pain may be very sharp, may cause pain in and around the eye area, and may be a pain within the back of the eye. The pain of cluster headaches is markedly greater than other headache conditions, including severe migraines; experts have suggested that it may be the most painful condition known to medical science. Female patients have reported it as being more severe than childbirth. Dr. Peter Goadsby, Professor of Clinical Neurology at the University of California, San Francisco and in the U.K. a leading researcher on the condition 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 once or twice a day, for six, eight, or ten weeks at a time, and then have a break or if chronic over 335 days a year without relief.

"More painful than a gun shot, knifing, broken or shattered bones, kidney stones, renal colic or having a limb amputated without anesthetic" That is meant in the true sense of the statement from Prof. Goadsby. A bad cluster headache attack is absolutely horrific and completely terrifying to the patient.

The pain is lancinating or boring/drilling in quality, and is located behind the eye (per orbital) or in the temple, sometimes radiating to the neck or shoulder. Analogies frequently used to describe the pain are a red-hot poker inserted into the eye, A knife being pounded in and out of the eye or a spike penetrating from the top of the head, behind one eye, radiating down to the neck.

The condition was originally named Horton's Cephalalgia after Dr. B.T Horton, who postulated the first theory as to their pathogenesis. His original paper describes the severity of the headaches as being able to take normal men and force them to attempt or complete suicide. From 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 operation which might bring relief."

Thus, cluster headaches are also known by the nickname "suicide headaches." The cardinal symptoms of the cluster headache attack are the severe or very severe unilateral orbital, supraorbital and/or temporal pain lasting 15-180 minutes, if untreated, and the attack frequency of one to 24 attacks in 48 hours. The headache is accompanied by at least one of the following autonomic symptoms: ptosis (drooping eyelid), miosis (pupil constriction) conjunctival injection (redness of the conjunctiva), lacrimation (tearing), rhinorrhea (runny nose), and, less commonly, facial blushing, swelling, or sweating, all appearing on the same side of the head as the pain.

The attack is also associated with extreme restlessness, the sufferer often pacing the room or rocking back and forth. Less frequently, he or she will have an aversion to bright lights and loud noise during the attack. Nausea rarely accompanies a cluster headache, though it has been reported. The neck is often stiff or tender in the aftermath of a headache, with jaw or tooth pain sometimes present. Some sufferers report feeling as though their nose is stopped up and that they are unable to breathe out of one of their nostrils.

These are the basic symptoms of an average attack, but many times these symptoms can be just beyond brutal and beyond the ability of the patient to cope or comprehend and attacks so terrifying that once you have had it for most patients PTSD kicks right in with the anticipation of the trauma of another bad attack. Some patients have reported that passing out due to the extreme pain is not uncommon.

Secondary effects are inability to organize thoughts and plans, exhaustion (in response to such extreme stress, the body shuts down and only wants to sleep/repair), and severe depression. Patients tend to absolutely dread facing another headache, may adjust their physical activities or ask help to accomplish normal tasks, and may hesitate to schedule plans in reaction to the clock-like regularity of the pain schedule leading to social isolation.

Cluster headaches are occasionally referred to as "alarm clock headaches" because of their ability to wake a person from sleep and because of the regularity of their timing: both the individual attacks and the clusters themselves can have a metronomic regularity; attacks striking at a precise time of day each morning or night is typical, even precisely at the same time a week later.

The clusters tend to follow daylight saving time changes and happen more often in spring and fall equinox. This has prompted researchers to speculate an involvement of the brain's "biological clock" or circadian rhythm. In episodic cluster headaches, these attacks occur once or more daily, often at the same times each day, for a period of several weeks, followed by a headache-free period lasting weeks, months, or years.

Approximately 15 to 25% percent of cluster headache sufferers are chronic; they can experience multiple headaches every day for years. Cluster headaches occurring in two or more cluster periods lasting from 7 to 365 days with a pain-free remission of one month or longer between the clusters are considered episodic.

If the attacks occur for more than a year without a pain-free remission of at least one month, the condition is considered chronic. Chronic clusters run continuously without any "remission" periods between cycles. The condition may change from chronic to episodic and from episodic to chronic.

This description is an older one and however accurate, it does not mention what we know now and that's beside the association of clinical depression is the association of severe PTSD that accompanies this disease for many sufferers, not all but it depends on the severity of the disease for each person.

Cluster Headaches have been greatly overlooked and underfunded throughout history because of the word "Headache". Using the word "Headache" can be extremely misleading when it comes to the extreme severity of this very powerful and extremely painful disease and greatly undermines and trivializes the suffering beyond imagination.

In many cases it leaves sufferers in a severe case of neglect, misunderstanding, desperation, severely depressed, enduring

incredible pain and suffering for a lifetime for many. Definitely a serious contributor to the name "Suicide Headaches" or "The Suicide Disease".

Thank you for taking the time to read and understand this serious situation. I hope this description of Cluster Headaches has shed some light to a very desperate situation of millions suffering "The Most Painful Disorder Known To Medical Science" without a single medicine created to help...

Ackowledgments

None.

Conflicts of interst

None.