

If you want to understand what it really means to live with cluster headache, imagine... fostering empathy through European patients' own stories of their experiences

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Summary

Cluster headache (CH) is arguably the most severe pain condition that afflicts humans. The severity of the pain has earned it the nickname “suicide headache”. Understanding how CH impacts on those who suffer from it is essential, because this understanding creates empathy, which is so valuable to these patients. On the occasion of Cluster Headache Day 2017, we asked CH patients from different European countries to share their experiences, in order to help people to imagine what it means to live with the condition. Here, we look at some extracts from their stories.

These CH patients' direct accounts provide an important illustration of the clinical features and consequences of the disease, helping to contextualise it and its psychological and social consequences. Reports of CH patients' first-person accounts might help to underline the physicians' role and responsibility with regard to the psychological and social consequences of this disease.

KEY WORDS: cluster headache, empathy, narrative medicine.

Cluster headache (CH) is arguably the most severe pain condition that afflicts humans (Nesbitt and Goadsby, 2012). The severity of the pain has earned it the nickname “suicide headache”, and a suicidal risk exists in this condition (Rozen and Fishman, 2012). Like other people suffering from chronic pain, CH patients face a double drama in their lives: first, the disease itself, with its attacks of unbearable pain, and second the difficulty

in obtaining high quality medical care, emotional support, respect and acceptance, or simply in finding someone who understands how devastating this disease can be (Rossi et al., 2017). Thus, the life journey of CH patients can be paved with desperate feelings of loneliness, misunderstanding and mistrust.

Understanding how CH impacts on those who suffer from it is essential, because this understanding creates empathy, which is so valuable to these patients; empathy carries you into another person's world and allows you to understand what someone else is feeling and how they are hurting. It is commonly held that the experience of pain defies language (Smith, 2006). Extending to pain what Elaine Scarry has said about injury, there can be said to exist two important “safeguards” in this regard: “trying to imagine other people better and having laws that are not independent of our imagination”.

On the occasion of the Cluster Headache Day 2017 we asked CH patients from different European countries to share their experiences, in order to help people to imagine what it means to live with the condition. Here are some extracts from their stories:

If you want to understand pain, *imagine...*

“If you want to understand what it really means to live with cluster headache, imagine that a pack of dogs with enormous fangs are tearing you inside your head, tearing off the flesh, crushing everything. Then, a pile of red hot metal passes through your skull, burning the back of your eye and crosses your palate down to your throat. But the most important thing is that, during an attack, the pain moves up to a new dimension. You no longer have a headache, or pain located at a particular site: you are literally plunged into the pain, like in a swimming pool. There is only one thing that remains of you: your agitated lucidity and the pain that invades everything, takes everything. There is nothing but pain. At that point, you would give everything, including your head, your own life, to make it stop...*If you imagine, you'll understand*” (Yves, France).

“If you want to understand what it means to live with cluster headache, imagine that someone is stabbing a knife in your eye and turning it for hours. Imagine the worst pain. Imagine a daily torture, gratuitous, incomprehensible. Imagine yourself suffering alone, terribly. Imagine being a prisoner in a straitjacket of suffering... Imagine the desire to finish, with pain, and the desire to finish ... with yourself. *If you imagine, you will understand*” (Thomas, France).

“If you want to understand what it really means living with cluster headache, imagine how it feels to be sub-

jected to a knife attack on your head, like someone boring a screwdriver into your eye over and over again, sometimes for hours. On a bad day, you suffer up to eight episodes in the space of 24 hours. Not having a normal sleep for days. On a scale of one (no pain) to ten (worst imaginable pain), you rate your pain at eleven and more.

Imagine constantly living in fear, not knowing when the next attack will happen, insisting that your wife leave the room when you get an attack because you don't want her to see you in such pain. Imagine going to bed every night knowing that you will have an attack in less than an hour. *If you did, you would understand* (Richard, The Netherlands).

Comments: CH is traditionally referred to as the most severe pain condition that afflicts humans. The above accounts give this rather elusive standard more meaning ["On a scale of one (no pain) to ten (worst imaginable pain), you rate your pain at eleven and more"]. These first three accounts provide an illustration of the features of CH attacks ("a pile of red hot metal passes through your skull, burning the back of your eye"), and of the way they radiate ("crosses the palate down to your throat"; "a pack of dogs with enormous fangs are tearing you inside your head, tearing off the flesh, crushing everything"). In addition, they illustrate phenomena experienced when the attacks reach their peak. During these moments, the pain seems to reach a "new dimension", monopolising the sufferer's attention and disrupting every single aspect of their lives, thus aggravating the sense of isolation and helplessness.

These moments of pure despair might also be associated with a risk of suicidal behaviour Jurgens, as well summarised by another patient:

"you would give everything, including your head, your own life, to make it stop..", "Imagine the desire to finish, with pain, and the desire to finish ... with yourself", "One night I was alone at home and it was that one black night — deep despair and no one to help me and the window open. I almost did it" (Kalina, France).

In episodic CH, attacks occur once or more daily, followed by a free period lasting several months or years. In the chronic form, CH attacks occur every day for years, sometimes without any remission or with remissions lasting less than one month. Attacks may occur at the same time each day, but the frequency of attacks may change over time. Experience of the alternation between times with and times without attacks, associated with the expectation and fear of the next attack, is well expressed in the accounts.

"Imagine the fear, spending the time you are pain-free thinking about it coming back. [...] Feel the anger that gnaws at you when you think that this is your only life, the only one you have, and you have to spend it like this, with no chance of retaliating (Emanuele, Italy)."

If you want to understand the way it disrupts life, imagine ...

"If you want to understand what it means living with cluster headache, imagine living with a bull stuck in your head. Imagine not being able to retaliate, to punch him back. Imagine he doesn't spare you anything. Imagine your birthday, Christmas, New Year's Eve, Easter, every kind of holiday spent in fear, thinking he is going to come. He is going to ruin it. Imagine how sad it is to be

happy only for the two of three days of respite it sometimes gives you... Without any reason explaining why it was You, why you deserve it. Bad luck, nothing else. If you can imagine all of this, you can understand me" (Emanuele, Italy).

"Just as my daughter was born, my severe painful headaches returned. For any new mother tiredness is an issue, but if you add eight daily attacks then you are doubly tired. My husband had to work and I was alone with her. I heard my baby cry of hunger but could not feed her when she needed it because I was so debilitated with the awful pain. It was an untenable situation that made me believe I could not be a good mother.

As the years passed everything began to move completely out of my hands. I lost my job and also had to give up my studies. I had no social life. I stopped taking my daughter to day care. My husband had to do everything and every day he could see I was doing nothing more than suffering. It was not just the tremendous pain that was destroying me now. What was killing me was how I had become so useless; someone who was no use for anything; someone not able to care for or devote time to her daughter; someone who was not able to have fun; someone transmitting only sadness. I saw my life falling apart little by little.

My husband changed towards me and, in truth, I did not blame him. My daughter always wanted to be with her father and never with me. Once day I saw my husband walking through the door with my daughter, without me. That was when I decided something had to be done. If you imagine that moment, you will understand" (Bea, Spain).

"A few years ago I had a life — a husband, children, an interesting job and a lovely home. One day my life became a nightmare. I lost everything. I had no life anymore just pain and suffering all the time with just a few hours' relief every day. I couldn't eat, sleep, listen or play with my kids — they were too loud. I couldn't go to the theatre — too loud. I couldn't sleep, couldn't work, I was suffering too much and no one could understand me. I had lost everything" (Kalina, France).

Comments: Chronic attacks have an enormous impact on the personal life of CH patients, including familial and social consequences (Palacios-Ceña et al., 2016). Attacks are so debilitating that patients experience difficulties in their daily activities, as shown by these two accounts from mothers. CH patients are at increased risk of developing depression (Liang et al., 2013). A previous study showed that 96% of patients made lifestyle changes because of their CH attacks (Jensen et al., 2007). An impact on quality of life has also been observed (D'Amico et al., 2002). In Germany, 13% of patients were unable to work (Gaul et al., 2011), and loss of productivity has also been reported (Jürgens et al., 2011). In a Danish study, 30% of CH patients were regularly absent from work (Jensen et al., 2007). A US study estimated that 20% of CH patients had lost jobs as a result of their attacks (Rozen and Fishman, 2012).

If you want to understand about treatment for this condition (and the misunderstanding and helplessness), imagine ...

"I spent a year and a half in hospitals because no one

could say what cluster was ... I spent my time between home and hospitals for a few years, just suffering and nothing else. No one could understand what it was. I was even told by a doctor at one point I had 'psychological problems'!" (Kalina, France).

Comments: Despite the disability caused by CH and the availability of effective treatments, it remains an underdiagnosed and undertreated condition (van Vliet et al., 2003, Voiticovschi-Iosob, 2014). Estimated through a nationwide mailing to general practitioners and neurologists, the median time between the first episode and the diagnosis was three years, and ranged from one week to 48 years (van Vliet et al., 2003). Overall, less than two in five patients will be correctly diagnosed and two in three will never receive an adequate treatment (Voiticovschi-Iosob et al., 2014).

"If you want to understand what it means living with cluster headache you should see my brain. I'm a kind of robot. I'm one of a few patients who had surgery on and in my brain. I can't go through security gates because I set off alarms and it can be dangerous for me. But thanks to this surgery I am still here to explain what it's like to live with cluster headache and fight for others".

Comments: Even in the case of CH diagnosed and treated according to the recommended standards, some cases remain intractable and particularly difficult to manage. The account provided by one patient who has benefited from two different brain stimulation procedures (occipital and deep brain stimulation, "surgery on and in my brain"), in addition to available therapy, highlights the need for continuous medical care and support.

"If you imagine, you'll understand"

Conclusion

From the standard medical perspective, CH is regarded and described as the most severe pain condition that afflicts humans. However, the accounts collected to mark Cluster Headache Day 2017 allow it to be seen from a new and perspective: that of the patients themselves. As these examples show, CH patients' stories provide an illustration of the clinical features and consequences of the disease, helping to contextualise it, and its psychological and social consequences. Reports of CH patients' first-person accounts might help to underline the physicians' role and responsibility with regard to the psychological and social consequences of this disease. In the words of Garden, writing on clinical empathy, "imagining patients' experiences and viewing patients as experts is a critical step in alleviating suffering" (Garden, 2009). Ultimately, striving to achieve an empathic understanding of these first-person witnesses may be a

way of facilitating better understanding of CH patients' needs, and more effective action on their behalf.

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