

Commentary

Learning to let go: My experience with Chronic Pain Stockholm Syndrome

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Editor's note: This commentary includes material adapted from R. Gulak's reflections on his experience with chronic pain and Chronic Pain Stockholm Syndrome which were previously posted online (People in Pain Network: Living with Pain Stories, www.pipain.com/living-with-pain-stories, 4/7/2014). - DL

Introduction

Children and adolescents referred for treatment to a tertiary care pain management program have typically lived with pain for several years, and pain has interfered significantly with their normal daily lives and development. In some more difficult to treat cases, their whole identity has been taken over by pain, suffering, disability, and the pursuit of a solution to the pain. The following is the narrative of a young man who benefitted from working with the Complex Pain Service team at BC Children's Hospital in Vancouver, British Columbia during his adolescence. It is based on his personal experience and insight. He introduces the concept of Chronic Pain Stockholm Syndrome (CPSS), analogous to Stockholm Syndrome, a psychological phenomenon that can occur in some individuals who are taken hostage, wherein victims inadvertently develop positive feelings towards captors, and come to identify with their captors' cause as a way of dealing with the trauma. He shares strategies intended to help children and adolescents avoid succumbing to CPSS and learn to let go of chronic pain.

Learning to let go

It's Grade 11, chronic pain year seven and counting. My average day consists of: wake up in excruciating pain; drag my uncooperative body to

school, usually missing first period; intermittently pass out, waking in puddles of my own drool multiple times a day and sometimes even talking in my sleep much to the amusement of other students; leave in the early afternoon thanks to a spare block, and head home; stare at my computer screen, not actually doing anything for several hours; collapse on my bed and stare at the ceiling for hours unable to sleep; rinse and repeat.

Worse than the pain, however, are the psychological ramifications long-term pain is having on my mind. I have nothing in the external world from which to draw a sense of satisfaction. And in the midst of this suffering a deadlier symptom is emerging, one that I seem to share with many other sufferers of chronic pain but only few seem to talk about. I'm deriving a sense of pleasure from my pain.

The tendrils of chronic pain have rooted so deeply in my personality that they have incubated a feeling of pride for my continued suffering. Later in life I defined this phenomenon as Chronic Pain Stockholm Syndrome (CPSS), as I've spent many years reverse engineering my own process of how I not only dug myself out of that horrible time of my life, but how I figured out how to want to get better. My hope is that by raising awareness of this behavior, chronic pain sufferers unaware they are feeling this will be better equipped to stop

identifying with their pain, and to truly want to create change in their lives.

I've spoken with many chronic pain sufferers, and when I share my experience with CPSS I find that, more often than not, they too admit to having had the same feelings at some point. So, if it's so common, why is no one talking about it? Stigma. Chronic pain sufferers are in a constant battle to prove their symptoms to those around them. It is not an option to express how sometimes you feel so attached to it that not only do you feel you can never have a life without pain, but that when you do occasionally indulge in thoughts of a pain-free life they actually terrify you. This is because loss of pain becomes loss of identity, which feels like death.

Based on primarily personal experience, cross-referenced with other chronic pain sufferers, I've pieced together how I believe this develops in the mind:

- Chronic pain reduces quality of life, and as its reach grows your previous identity recedes.
- You begin to forget what it felt like to live a pain-free life, and your past life starts feeling more like a hazy dream.
- Your pain has now taken root. It has reached critical mass and is now almost indistinguishable from you.
- Feeling unable to accomplish things in the outside world, you begin to look for positivity internally in the only thing you can, your pain.
- In a bizarre twist of traumatic bonding, you now wear your pain like a badge of honor, and you enjoy telling your pain story to others. Each additional year of pain is another year you endured it.
- You have hot-wired a reward system shortcut in your brain. It's now easier to feel good about being in pain than it is to want to improve your life.
- You stop looking up new ways to get better, you become comfortable.
- In this state, recovery is virtually impossible without first removing these habits from your mind.

Reversing this process is challenging for many reasons, because once your CPSS is at this point there is no cold turkey option to suddenly start

thinking positively. The only way through it is the same way you got there: incremental change.

The first step in breaking the spell, is simple to start but difficult to master. You must become aware that your pain has infiltrated your personality and is doing it so well that you did not even realize it wasn't you. And from there accepting this truth for what it is, that you are not your pain. The CPSS habits your mind has formed can only function while you are unaware of them. Once you have begun to disassociate yourself from your pain, the control it exerts over your well-being will diminish rapidly.

To accurately track your progress, keep a physical or digital log. Chart your progress and track your mental and physical health. It doesn't have to be complicated. For example, each day write the following in a journal:

Mood Rating from 1 (*Good*), 2 (*Medium*), to 3 (*Bad*)

Pain Rating from 1 (*Good*), 2 (*Medium*), to 3 (*Bad*)

You can break this up in to as many chunks as you'd like to track. For instance, brain fog, fatigue and so on. It would probably also be good to jot down a few sentences about your day, but that isn't absolutely necessary. I use a journal app on my smart phone that reminds me at 10 p.m. every day to write in it. Don't sweat it if you can't get to it every day, but try. Once you have a few of these steps under your belt, press on with your recovery. I won't write about pacing in much detail here as there are far better resources already available for that than I could ever hope to write. But keep going, roll with the bad days and you will see improvement.

Moving forward with a chronic pain recovery can appear like a catch 22 to someone who is only starting their own. You need energy to exercise, but you'll only get that energy once you start exercising. The key here is to stop thinking and start doing. Schedule two to three blocks of manageable exercise per week, and stick to it until it becomes routine. That is what you're after. This is a marathon, not a sprint. You have to form good habits if you want to improve.

Burn whatever fuel you have. In my case the only energizing feeling I had when I started was rage, pure unbridled frustration about the path my life had taken. I used that fuel to give me what I needed in order to get through the beginning stages of my recovery. Once I had several accomplishments under my belt, I had access to much cleaner-burning fuel, such as the satisfaction of having succeeded at something combined with recognition of my friends and family seeing my improvements.

Chronic pain management has improved dramatically, as more and more doctors are receiving the training and resources to effectively assist people with a wide variety of chronic pain conditions. But you are the only person able to directly influence your pain. Do not become sympathetic to your captors; do not let pain tell you what your life's limits are. Bite the hand that feeds, honestly assess your feelings, and then work hard to create the life you want.

Conclusion

This narrative has the potential to be a powerful clinical tool in treating recalcitrant chronic pain in children and adolescents. By sharing it with their patients, psychologists and other pediatric pain

specialists can facilitate an open dialogue about potential psychological obstacles to treatment success, despite best efforts to change. Theoretical explanations for CPSS vary based on psychological orientations (e.g. psychodynamic, behavioral, cognitive), but across theories, the term can offer a useful metaphorical framework for understanding the chronic pain experience. The fact that the author is a young adult who has learned to live successfully with pain may be the main source of its credibility for children and adolescents with chronic pain. As a young adult, despite continued pain, the author enjoys a successful business career and volunteers as a facilitator of a community support group for youth with chronic pain.

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