



PROJECT MUSE®

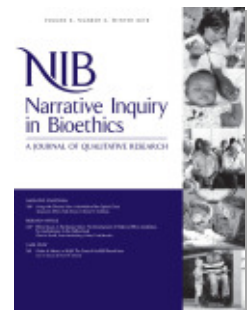
The View from up North

Carlyn Zwarenstein

Narrative Inquiry in Bioethics, Volume 8, Number 3, Winter 2018, pp.
200-202 (Article)

Published by Johns Hopkins University Press

DOI: <https://doi.org/10.1353/nib.2018.0062>



➔ *For additional information about this article*

<https://muse.jhu.edu/article/712004>

walk and notice that when I am not walking, I feel a much higher level of pain. There is also something therapeutic about placing ear buds in my ears and listening to my favorite music while walking. It brings a smile to my face.

Something else I learned at Mayo Clinic Pain Rehabilitation Clinic was Pain Behaviors. These are outward ways of communicating one's pain. For example, some people moan and rub their back to express pain. Others may wear sunglasses to communicate they have a headache. I have learned to stop communicating my pain. The less time I think about communicating my pain, the less I feel the pain. Although I may be experiencing pain, it doesn't help to try to express it to others. That just brings negative attention to myself. Another great tool I learned was sleep hygiene—getting enough rest and doing so on a regular basis. Sleep is vital to my success; therefore, I have to make it a high priority. I have learned how to go to bed at the same time each night and awake the next morning at about the same time. Sleep gives me the needed rest I require each day and it allows my body to recuperate for another day of activity.

My journey with pain and addiction brought me to countless medical professional offices and hospitals. This means I have also met countless medical professionals. It has been my experience that the trust built in the relationship between physician and patient can mean the difference between life and death. At the beginning of my journey I was out to score prescription medications from doctors. Score medications meant lying, misleading, being untrustworthy and manipulation. Unlike that person I once was, I am now honest, upfront, dependable and worthy of a positive relationship with a doctor. I now take my relationships with doctors seriously. These professionals have taken their time to assist me in an honest and professional manner and I owe it to them to be honest and reliable. My sobriety and success in life depends on my being honest and doing and saying what I mean and what my intentions are.

I am now living in recovery from chronic pain, alcohol and opiates. As part of my recovery I attend a 12-step meeting regularly and believe the twelve

steps have assisted me in being successful. The twelve steps gave me a framework to live by and meetings where I could listen and express myself. The twelve-step program has also given me friends that are in some ways like me. I have gained a sponsor, a man I count as a good friend. I am also a sponsor and this has taught me that others teach me just as much as I teach them regardless of who has more time in recovery. I look forward to the meetings at the twelve-step clubhouse, as well as the meetings with my sponsor and sponsee.

My life of chronic pain and addiction was a nightmare eleven years ago. Now I am living a life filled with pride, success, sobriety and quality relationships. I live with pain in a realistic manner and take each day as it comes with the highs and lows of life. I am enjoying each moment for what it is—addiction free.



The View from up North

Carlyn Zwarenstein

As I write this, I shift uncomfortably on my chair. Over and over I pause in my work to painfully stretch. I force my spine, which has lost its natural curves, into triangle pose, a hamstring stretch, warrior pose. I don't feel like a warrior, but more like a martyr at this point, as I am rationing my painkiller medication. As I write this, I am arguing with myself. If I take a dose now, I will have taken my daily max and will not be able to take a dose before bed. I'll be able to work more easily now, but I am more likely than not to wake in the night from pain, unable to find a comfortable position. I put off relief a little longer.

I take a small dose of a mild synthetic opioid several times a day. I use as little as possible to allow periodic relief from pain. Using it sparingly helps to keep my tolerance down and ensures it will continue to work for longer, giving me back my life. So I use this dangerous, addictive drug

just enough to allow me to manage the demands of daily life and the additional demands dictated by *ankylosing spondylitis*, an autoimmune disease that causes chronic inflammation in the spine, is characterized by pain, and is gradually reshaping me into a human question mark.

Not just anyone should use opioids. There's a clear order of operations for doctors to follow, which mine followed to the letter: learn self-management techniques that emphasize behavioural and psychological ways of dealing with pain. Try alternate medications and only move on to a trial of the lowest effective dose of an opioid when the underlying disease (if there is one) is as well-controlled as possible and if other treatments have proven intolerable or ineffective. Use them for as short a time as feasible (my disease is chronic and degenerative so I'm not planning on stopping anytime soon). Complying exactly with best practice, I exercise religiously and take two medications that suppress my overactive immune system. Like opioids, these medications have side effects, potentially waning effectiveness, and unknown or daunting long term effects, including the risk of cancer and early death. With the disease I have, risk is par for the course.

Of course, centuries of writers have described the psychoactive and mood-altering effects of small or large doses, oral or intravenous, of opium, morphine, or heroin. Although I'm just taking a very low, oral dose of the relatively mild opioid *tramadol*, and so don't experience the intensity of an injected heroin high, the prescribed drug does provide the subjective sense of a slightly stronger emotional skin. Temporarily, delicately, it holds back the fears and depression I can otherwise feel, and gives me a feeling of mild euphoria that few long-term pain patients will endorse.

As well, of course, as holding back grinding spine pain. The latter benefit is visible to anyone: without the drug, I can't stop moving. I'm unable to stand in one place for more than a minute or two without discomfort, I need to stretch constantly to relieve pain and stiffness in my spine and other joints, I can't sit down without gradually increasing pain. While exhaustion is a constant problem that constant motion exacerbates, I wake frequently at

night, unable to find a position in which to sleep without pain. In pain, I get quiet and tense, focusing intently on my breathing as a pain management technique, excluding the outside world, which includes work, domestic responsibilities, and my two children.

I can easily live without pain relief for short periods (as two unmedicated labours as well as my current rationing of pain medication attest); however, when pain is unrelieved for long stretches of time, mental pain management techniques prove inadequate. Without pain treatment or adequate control of the underlying inflammation (an endless balancing act as an anti-inflammatory burns a hole in my esophagus, a biologic medication makes my hair fall out and stops working, a low dose of a chemotherapy drug gives me dizzy spells and stomach cramps), I inevitably become depressed, desperate and, ultimately, despite my ardent desire to live fully, suicidal. Pain becomes the dominant feature of my life. It is the sense of wasted opportunity, rather than the quality of pain itself, that pushes me to nervous breakdown over and over.

Within an hour of taking a dose of tramadol, I am able to sit down without pain, without fidgeting. No longer needing to focus on my breath or on mindfully observing the texture of pain in order to get through it, I can attend to the world around me, follow a conversation, wash the dishes, bend down to pick things up, walk my children to school or sit with them to watch a movie. I can work. I can finish this essay and still make dinner.

After six years of daily use, I don't show any of the symptoms of either dependence (physical dependence and creeping tolerance both being features of opioids, not bugs, as they say) or addiction—unless writing a book about it counts (*Opium Eater: The New Confessions* was published in 2016, and goes into more detail on all of this).

It has been strange to watch, from over here in Toronto, the American response to what is invariably described as a crisis or epidemic of opioid addiction and overdose. From the relative safety of the less draconian, more thoughtful and individualized response to over prescription and overdose here in Canada, I watch pain patients reduced to

desperation by a dramatic swing of the pendulum from over prescription of opioids where they were not warranted, to under prescription for patients in the same vulnerable minority in which I fall. I'm protected, yet very aware of the fragility of my situation. On Twitter and on Internet message boards, patients whose conditions and lives have been stabilized for years through use of opioid medications have been reporting abrupt and forced tapers. A rash of suicides and threats of further suicides has alarmed even addiction medicine doctors, leading to nuanced but decidedly minority criticism from a small group of physicians with no ties to the pharmaceutical industry. They criticize insurance companies for incentivizing rapid reductions to an arbitrary morphine equivalent, and over-zealous advocates who have weaponized voluntary guidelines to reduce over prescription into a mandate to censure doctors whose chronic patients do better with opioids than without.

One shift in policy, or even one change of heart on the part of my doctor, and I would be quickly dealing not just with withdrawal symptoms (perhaps) but with more existential pain of trying to live without the daily, short-term pain relief that opioids have provided me for six years. During those six years, opioids have allowed me to reclaim swathes of my life that my degenerative spine disease had taken from me: travel, watching movies, earning a living, washing the dishes, enjoying a meal with friends. Pain control isn't just about my *joie de vivre*: it directly affects my income, how many hours I can work, my ability to care for my children, my ability to do the exercise that eases stiffness (and pain) in my joints. Adequate pain control lowers my risk of dying of overdose of an illicitly obtained alternative—a permanent solution to what can indeed be a permanent problem of pain, or an attempt to regain lost function in my life. The available non-opioid alternatives have already proven to be too harmful in my case, which is representative of a significant minority of pain patients.

Opioids should, of course, be prescribed only as a treatment where alternatives have been thoroughly tried and found intolerable. In that situation, though, which is my situation, the intention is to take them for as long as I continue to suffer from

a degenerative spine disease characterized fundamentally by stiffness and pain. At the same time, the nature of opioids requires that I carefully ration the drugs, denying myself excessive or constant relief, in order to prevent them from losing effectiveness over time, and to minimize my risk of developing a range of unpleasant possible side effects. This means that I take, as I should, the lowest *effective* dose (and often somewhat less than that). This is all good practice. There are other risk management strategies including rotating to low doses of a different opioid to prevent excessive tolerance, and to supplement low doses of an opioid with low doses of a different drug to reduce side effects and risks of both. The greatest risk management technique is open and regular communication between a patient and her primary healthcare provider and a shared focus on maximizing function and quality of life in accordance with the patient's own values and goals.

All of medicine involves careful, individualized weighing of risks versus benefits. This is particularly true in the case of intractable pain. The "opioid crisis" turned several years ago from primarily an issue of over prescription to primarily an issue of illicit drug poisoning. Meanwhile, prescription opioid policy remains stuck in the past and is increasingly founded on selective use of evidence dictated by a moralistic attitude around pain and drug use. I can only hope that Canada continues to strike a reasonable balance, better educating patients and doctors about the significant risks of opioids while protecting those of us for whom risk management, not taper, remains the best approach.



Perception Versus Reality in a Brain Addicted to Opioids

Anonymous One

My story begins 8 years ago on Labor Day weekend. I had just begun a new job and all the new employees had gotten together for some drinks and a night out on the