



HHS Public Access

Author manuscript

Narrat Inq Bioeth. Author manuscript; available in PMC 2019 March 15.

Published in final edited form as:

Narrat Inq Bioeth. 2018 ; 8(3): 239–245. doi:10.1353/nib.2018.0073.

On Being the “Right” Kind of Chronic Pain Patient

Caroline J. Huang^{†,*}

[†]Department of Bioethics, National Institutes of Health Clinical Center

Abstract

The intertwined themes that emerge from these passionately told narratives demonstrate how difficult it can be to navigate chronic pain. Many authors describe the labor of living in chronic pain, and several refer to their use of opioid medication as a tool to facilitate participation. The relationship between tolerance, dependence, and addiction is touched on in a handful of narratives, with some authors confronting—and seemingly internalizing—the stigma of addiction in seeking to regulate their opioid use. A related theme is the reduction of opioid medication; a few authors pronounce consensual tapering as beneficial, while others denounce non-consensual tapering as harmful. Most authors also assert their right to make pain management decisions without bureaucratic interference, suggesting that they and other chronic pain patients face reduced access to opioid prescriptions as a result of inappropriately applied governmental guidelines. As richly detailed and informative as these narratives are, they scarcely engage with the reality that chronic pain disproportionately burdens patients who are less privileged in terms of education, race, gender, and class.

Keywords

Chronic Pain; Opioid Medication; Opioid Epidemic; Addiction; Clinical Guidelines; Patient-Clinician Relationship; Health Disparities

Introduction

These twelve narratives illustrate the myriad challenges of striving to be the “right” kind of chronic pain patient during an opioid epidemic. That is, the kind of patient whose pain management choices are considered acceptable to the patient herself; supported by thoughtful clinicians; and understood by family, friends, and colleagues.

In my reading, four intertwined threads emerge in these passionately told stories: the labor of living in chronic pain; the relationship between tolerance, dependence, and addiction; the (non-)consensual reduction of opioid medication; and the right to make pain management decisions without bureaucratic interference. This commentary will discuss each of these

*Correspondence concerning this article should be addressed to Caroline J. Huang, Department of Bioethics, National Institutes of Health Clinical Center, 10 Center Drive, Building 10, Room 1C118, Bethesda, MD 20892, USA, caroline.huang@nih.gov.

Conflicts of Interest.

The author has no conflicts of interest to report in relation to this manuscript.

themes and then close by reflecting on the demographics of the authors, in light of the data on how chronic pain affects Americans.

The Labor of Living in Chronic Pain

Many of the narratives describe how living in chronic pain constrains a person's ability to participate in society, especially absent proper medical and environmental accommodation. For instance, Amy K. succinctly writes, "As a nurse practitioner, I was unable to work due to lifting and mobility restrictions as well as pain. Prior to the Jet Ski accident, I had worked every day since age 15." M. Lucas discusses his efforts to "[control] the chronic pain that makes it hard to participate in the world," including relying on his service dog, Vin. Stowe Locke Teti explains what it was like to spend two years confined to a bed because of pain: "What isolated me most was the destruction of who I thought I was, and how I was now seen; the roles and responsibilities I inhabited and from which I drew strength and purpose were no more." And Samantha René Merriwether argues that society neglects "individuals that should have every right to participate freely" because it is "mainstreamed for those who can walk, talk, eat and sleep with no problems, with no pain."

Though there are no magic bullets for living well (or even adequately) with chronic pain, the authors collectively suggest medical and self-management techniques ranging from procedures and medications to exercise and sleep hygiene. These multimodal techniques align with current best practices for pain management that focus on improving function and quality of life, not eliminating pain (American Academy of Pain Medicine, 2013; Schneiderhan, Clauw, & Schwenk, 2017). Several authors specifically point to opioids as a tool that, when used appropriately, can facilitate their participation. Megan Becker-Leckrone neatly captures this sentiment:

Living in pain is work. Real, material labor; and because the overwhelming majority of us who suffer it still endeavor also to do *other* work in the labor economy—have a job, raise children, or otherwise participate productively in society—opioid medication serves as an essential tool, however limited or imperfect, in getting *both* jobs done.

Becker-Leckrone goes on to explain that her opioid medication "mutes" her pain so that she can think, which is essential to her job as an English professor. Similarly, writer Carlyn Zwarenstein describes how tramadol helps her complete activities of daily living:

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.

A third example comes from K., who notes that methadone provided sufficient relief for her to return full-time as a nurse practitioner and perform basic household tasks.

This view of opioids as a functional aid is commonly espoused in patient testimonials, ranging from carefully reasoned blog posts to desperate comments in all capital letters on news articles (Burge, 2018; Tedeschi, 2017). It also overlaps with a second theme in the narratives: using opioids to facilitate participation is not in itself evidence of addiction.

The Relationship between Tolerance, Dependence, and Addiction

Several authors touch on the relationship between tolerance, dependence, and addiction, which is sometimes confused in public policy and discourse. Per the National Institute on Drug Abuse (NIDA), *tolerance* refers to the body requiring more of a substance to achieve a certain effect after repeated use; *dependence* refers to the body adapting to the presence of a drug and experiencing withdrawal symptoms if drug use suddenly stops; and *addiction* is “compulsive drug use despite harmful consequences” that may be accompanied by tolerance and withdrawal (NIDA, 2018). Understandably, chronic pain patients may be sensitive to having the tolerance and dependence that can result from long-term opioid therapy conflated with and stigmatized as addiction.

Patients themselves often confront—and sometimes internalize—the stigma of addiction in seeking to regulate their opioid use. Amber Milliken, for instance, portrays herself as alternating between “a masochistic drill sergeant” and “a desperate seeker of relief” when it came to her pain medications: “I permitted myself drugged reprieve, but only after I let myself sufficiently suffer, living the societal argument of blame on the drug-seeker and stigma of a potential addict.” Teti describes how he sought to limit his opioid intake to retain control over his identity:

Reducing opioid use was empowering, despite the increased pain... I wasn't in school, or able to work, to contribute. Tapering off of opioids was something I *could* do; it gave me the agency I sought in a situation where I otherwise had almost none. Standing up to severe pain became a metric of self-worth.

Similarly, Zwarenstein discusses how she chooses relief during waking hours *or* relief during rest, explaining that she uses opioid medication sparingly to “keep [her] tolerance down.”

Taking a broader view, K. sums up her frustration by comparing how society differentially regards treatments for chronic pain and high blood pressure:

Chronic pain patients are not addicted—they are dependent on a medication in order to function and contribute to society. I am also dependent on 2 anti-hypertensives. I rely on aspirin for its anti-platelet properties. Would anyone ever imagine taking those treatments away because I am dependent on them? No.

While K.'s point about not inferring addiction from dependence is well taken, there are, of course, some patients who struggle, or have struggled with, both chronic pain and opioid use disorders (OUDs). Two such narratives are included in this issue: Ken Start and an anonymous healthcare professional describe themselves as addicts who are now in recovery. Importantly, neither Start nor the anonymous contributor had to choose between treating addiction and managing pain, as both found relief through non-opioid sources. Similarly, no

chronic pain patient using opioids without symptoms of an OUD should be forced to choose between preventing addiction and managing pain.

Furthermore, it is not the intention of the vast majority of people with chronic pain to use opioids for anything other than increased quality of life, nor is it the intention of people with OUDs to keep people with chronic pain from accessing medications. These narratives collectively underscore the need for better individualized management and understanding of chronic pain—and relatedly, OUDs—that does not blame patients or reflexively treat opioid use as morally inferior to non-use.

Reduction of Opioid Medication

Another closely related theme is the reduction of opioid medication, suggested to—and in some cases, forced upon—chronic pain patients as a way to treat or prevent addiction. Start describes his experience at an inpatient pain rehabilitation clinic:

[I]t was decided that my medications would be decreased and my internal dilaudid pain pump would be turned off. As an addict, this was a terrifying thought. However, after speaking with the medical professionals I had built a trust with, I agreed to go through with their plan.

Notably, Start begins by saying the taper was *decided* for him, but he then writes that he *agreed* with their plan before it began. He is not explicit about whether his continued treatment was contingent upon his agreement, which would have denied him a meaningful choice. At the end of his piece, though, Start expresses pride in his sobriety from both alcohol and opiates. The anonymous health-care professional, also grateful to be in recovery, goes a step further in recommending that fellow chronic pain patients consider bringing up tapering to their clinicians:

I would tell others with chronic pain that opioids are almost never the appropriate long-term solution for pain. These should only be considered as a last resort when all other options have failed, for terminally ill patients, and for very short-term use after procedures. If you're on high doses of opioids and you're not getting any benefit, discuss doing a taper with your PCP or ask them to send you to a specialist who can do this.

On the opposite end of the spectrum, Meredith Lawrence starkly outlines the worst-case scenario for non-consensual opioid limitation: suicide. She describes the additional pain, indignities, and hopelessness her husband Jay experienced when his clinician unilaterally reduced his morphine dose from 120mg to 90mg. As Lawrence tells it, Jay's story illustrates the need for a precision often lacking in pain medicine: There can be a substantial "difference ... between three pills and four pills on a chronic pain patient's quality of life." She also quotes Jay as saying, "I will not live like this." A case report in a 2014 issue of *Pain Medicine* is eerily similar: A patient undergoing non-consensual opioid tapering tells his pain specialist, "I can't live like this," and ultimately dies by suicide (Webster, 2014). I mention this similarity because the unintended effects of non-consensual opioid tapering are represented in the broader literature, not just these narratives.

A less drastic example of unintended consequences comes from Jeff Moyer, who discusses his struggles to maintain an effective pain management regimen as a patient with post-kidney donation pain. Of a for-profit, franchised pain clinic that would not continue the methadone prescription a previous provider initiated, Moyer writes: “The doctor who interviewed me breezily said that I would likely not even notice the cessation of methadone since I was taking other pain meds. However, I went through terrible withdrawal as I slowly discontinued its use.” That his pain clinic could not foresee that withdrawal might accompany forced tapering is obviously troubling; so too is the clinic’s recommendation that Moyer simply “double the levels of his remaining meds” to make up for the additional post-tapering pain he felt.

To contextualize these narratives, it is instructive to consider the evidence on opioid tapering. A 2017 systematic review suggests that when done judiciously and with consent, opioid tapering may be beneficial and help steer chronic pain patients towards alternative pain management practices (Frank et al., 2017). But the researchers note that they did not find any “prospective studies of mandatory, involuntary opioid dose reduction among otherwise stable patients.” If tapering is evaluated as a means of promoting beneficence, non-maleficence, and respect for autonomy, then these results weaken the case for forced tapering in patients like Jay Lawrence and Moyer and strengthen the case for voluntary tapering in patients like Start and the anonymous healthcare professional.

Resentment of Bureaucratic Intrusion into Medical Choices

While medical choices are supposed to be between clinicians and their patients, many of the narratives display resentment of government guidelines, policies, and law enforcement actions that the authors see as disrupting the clinician-patient relationship. Lawrence and Rochelle Odell even include government agencies in the titles of their respective narratives: “How the CDC Guidelines Killed My Husband” and “My Pain Journey: When Physicians Treated with Confidence to Now Fear of Reprisal from the DEA.”

Patient advocacy groups have long suggested the Centers for Disease Control and Prevention (CDC) Guideline for Prescribing Opioids for Chronic Pain would have a chilling effect on appropriate opioid prescribing (Anson, 2015; Lawhern, 2017; Tedeschi, 2017). Indeed, the nine narratives commenting on reduced access—from Becker-Leckrone, Zwarenstein, Merriweather, Milliken, Moyer, Teti, K., Lawrence, and Odell—support this concern, as does an (unscientific) online survey of chronic pain patients (Pain News Network, 2018). But the CDC guideline is not binding; it is a series of recommendations created to help primary care providers manage pain while preventing addiction (Dowell, Haegerich, & Chou, 2016), not a shield that clinicians can hide behind to limit care. Using the specter of a possible Drug Enforcement Administration crackdown to justify medical decisions that may increase pain patients’ suffering—particularly when that suffering would stem from reducing opioid medication without offering suitable non-opioid alternatives—is the opposite of doing no harm. Lawrence’s case illustrates this abdication of responsibility:

I really felt as though this [reduction] had to be a misunderstanding that would be easily corrected. During the visit I found out quickly this was not a mistake. ... The

last thing that he said to us was that “his patient’s quality of life was not worth risking his practice.”

It would be unfair to categorize all clinicians adhering too rigidly to the CDC guideline as sharing the misplaced priorities of Lawrence’s doctor, however. A more likely explanation is that clinicians require better training for pain management and OUD prevention and treatment so that they can augment the CDC recommendations with their own clinical judgment.

More worthy of alarm are ongoing state and federal efforts to limit opioid prescribing through existing laws and proposed bills and policies (National Conference of State Legislatures, 2018). For instance, Maine prescriptions for chronic pain are currently capped at 30 days and limited to the equivalent of 100 milligrams of morphine per day (Haskell, 2018). Oregon is weighing a more drastic proposal: Medicaid patients would be limited to 90 days of opioid medications and tapered off those medications entirely within a year (Facher, 2018; The Associated Press, 2018). On a federal level, the Centers for Medicare and Medicaid Services seriously considered “refus[ing] to pay for long-term, high-dose prescriptions” for Medicare patients (Hoffman, 2018). While well-intentioned, such policies leave little, if any, room for clinical judgment.

Ultimately, the combination of poorly understood guidelines, insufficiently nuanced prescribing policies, and defensive prescribing practices makes it challenging for clinicians to uphold their primary responsibility for their patients’ health and well-being. The upshot is patients wondering “what to do now,” as Odell describes:

Finding a physician to bring me back to the level [of opioids] I had been on will never happen. I had no desire to go to the streets for drugs either. I can’t afford it, nor would I risk my health by getting something other than what I thought I was getting... I would probably get caught and thrown in jail. What are pain patients like myself supposed to do now?

Missing Voices

Finally, it is worth noting that while the twelve authors have described varied life experiences and approaches to pain management, their circumstances are not representative of all American chronic pain patients. The authors almost all describe college and graduate education and white-collar jobs in academic or professional settings. They talk about the financial strain that chronic pain creates, a sentiment Lucas pithily captures: “Should I stop working *and* hire people to do yardwork *and* pay for twice daily massages? Next alternate reality TV series: ‘Lifestyles of the Rich with Chronic Pain.’” Yet, it appears from the narratives that the authors have insurance that at least partially mitigates medical costs, as well as the wherewithal to pursue treatments that require varying levels of preparation, time, and social support. Most of all, these authors are eloquent and persistent advocates for chronic pain patients, even when their own outcomes are far from ideal. They are, by and large, the “right” kind of people coping with chronic pain.

In contrast, the literature shows that chronic pain disproportionately burdens less educated and less wealthy people in both prevalence and severity (Grol-Prokopczyk, 2017). And while only Lucas's narrative explicitly discusses the influence of race or gender ("Why, in mid-2017, did my new pain management physicians who'd never known me offer me opioids? Would they have made the same offer if I weren't visible as a white man?... Do they realize that they're treating me differently—with less skepticism about the existence of my pain and what I might do with opioids—than people of color?"), there are sharp race- and gender-based disparities in the prevalence, severity, and treatment of pain. Hispanic and Black Americans are more likely to report any pain and severe pain, respectively, than White Americans (Grol-Prokopczyk, 2017), and Black Americans are more likely to have their pain undertreated than White Americans (Campbell & Edwards, 2012). Compared to men, women are more likely to report pain in general and pain that is severe, but they are less likely to have their pain taken seriously (Grol-Prokopczyk, 2017).

The silence on these demographic features is not surprising, given that these narratives were collected for an academic journal. (Indeed, I benefit from graduate education, financial stability, and Whiteness in navigating my chronic pain too.) But we should worry about the voices we are not hearing: the patient who cannot take time off her minimum-wage job for hands-on therapies and by default opts for cheaper, quicker medication-based management, for example. Or the patient who is mistakenly diagnosed with an OUD, partly because he is Black and partly because he is unfamiliar with the language his clinician associates with searching for pain relief, not highs. I could fill this entire commentary just trying to list some of the many socioeconomic hurdles that impede care for chronic pain: uncertainty about how to appeal denials of coverage, difficulty finding transportation for procedures, and so on.

The narratives in this issue demonstrate that navigating chronic pain is a demanding task, even under the best of circumstances. Health disparities increase the burden of chronic pain even more. We must work harder to give this suffering a voice and advocate for better treatment of the most disadvantaged and vulnerable patients.

Acknowledgments and Disclaimer

This research was supported by the Intramural Research Program of the National Institutes of Health (NIH) Clinical Center. The author would like to thank David Wasserman for providing helpful discussion and editorial suggestions. The views expressed herein are solely those of the author, and do not represent the position or policy of the NIH or the U.S. government.

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