


# Chronic Pain Patient “Advocates” and Their Focus on Opiophilia: Barking Up the Wrong Tree?

Michael E Schatman <sup>1-3</sup>  
Hannah Shapiro<sup>3,4</sup>

<sup>1</sup>Division of Medical Ethics, NYU School of Medicine, New York, NY, USA;

<sup>2</sup>Department of Anesthesiology, Perioperative Care, and Pain Medicine, NYU School of Medicine, New York, NY, USA; <sup>3</sup>School of Social Work, North Carolina State University, Raleigh, NC, USA; <sup>4</sup>McLean Hospital, Division of Alcohol, Drugs, and Addiction, Harvard Medical School, Boston, MA, USA

The “war on opioids” is well publicized, albeit sometimes misguided. Much has been written on how efforts to reduce the flow of prescription opioids have morphed into a war on chronic pain patients.<sup>1-3</sup> There have been numerous editorials and articles published expressing concerns regarding the unfortunate consequences of the resulting “opiophobia” and “oligoanalgesia”,<sup>3-5</sup> and many other key opinion leaders have and continue to express similar concerns.<sup>6-9</sup> Efforts to counteract these tragic consequences have met with a degree of success, although much more needs to be done if chronic pain patients for whom there are frequently no other viable, accessible alternatives to opioid analgesia are to regain access to judiciously prescribed opioids.

Unfortunately, advocacy for patients with pain, particularly on social media, has seemingly devolved into purely advocacy for access to opioids. We see this as problematic on a number of levels. First and foremost, opioids are not the only treatment for many types of chronic pain, and certainly not necessarily the safest and most effective. Pain management should be based on best practices guided by clinical judgement and the supporting science.<sup>10-12</sup> Opioids and other analgesics, as well as many procedures and surgeries, generally represent purely biomedical approaches to chronic pain. Over 2 decades ago, Rollin “Mac” Gallagher astutely noted that “The history of pain medicine is replete with failures of the biomedical model”.<sup>13</sup> (p. 559). Numerous others with broader understandings of pain management have subsequently echoed his sentiments.<sup>14-18</sup> The importance of providing chronic pain patients with education in order to help them reconceptualize their pain away from flawed biomedical approaches has also been addressed in the literature.<sup>19,20</sup> Accordingly, we posit that advocating solely for access to opioid analgesia is in fact advocating for ineffective, purely biomedical care, as opposed to coordinated interdisciplinary treatment that is likely to be far more beneficial for most patients.

Second, the image of patients with chronic pain (as well as that of many of us who treat them) is less than stellar at this juncture. Radically anti-opioid forces have done their best to discredit patients with chronic pain through the use of stigmatizing and marginalizing rhetoric and hyperbole. For example, when interviewed for an article published in the Richmond Times-Dispatch in 2015, Andrew Kolodny (an addiction psychiatrist, not a pain physician) reportedly stated, “When we talk about opioid painkillers we are essentially talking about heroin pills”.<sup>21</sup> More recently, Dr Keith Humphreys (an addiction psychologist, not a pain psychologist) testified to a US House of Representatives subcommittee, stating “as long as we continue putting countless Americans in 'heroin

Correspondence: Michael E Schatman  
Division of Medical Ethics, Department of  
Population Health, NYU School of Medicine,  
550 First Avenue, New York, NY, 10016,  
USA  
Tel +1 425-647-4880  
Email Michael.Schatman@NYULangone.org

prep school' each year by overprescribing opioids, the next generation of users will soon replace those who exit the heroin market".<sup>22</sup> In addition to both of these statements being inaccurate, anti-scientific rhetoric and hyperbole has had a negative psychological impact on patients with chronic pain, which some believe has contributed to their development of a sense of worthlessness and futility, and appears to be one of the causes of suicidality in these patients.<sup>23–25</sup> By striving solely for increased access to opioid analgesia, these advocates have essentially reinforced the message that their anti-opioid detractors have deviously developed, ie, that all chronic pain sufferers are actually a group of medication-seeking addicts.

Third, social media has seen the ascendance of pro-opioid rhetoric, hyperbole, and disregard for science. For example, pro-opioid crusaders, including a small group of physicians, have insisted that any treatment other than opioids is of no medical value to chronic pain patients. We recently addressed the ridiculous falsehood that has been disseminated regarding spinal cord stimulation "killing thousands of patients every year" due to malfunction.<sup>26</sup> Perhaps due to the marginalizing language of a small group of the harshest critics of opioid analgesia, a small group of so-called "patient advocates" have convinced patients who are vulnerable and often uninformed that any treatments other than opioids are ineffective and likely dangerous, and we express concern that this has resulted in too many patients becoming convinced that it is in their best interests to reject the offers of any treatments that are not opio-centric. These treatments include interdisciplinary chronic pain management, interventional approaches, complementary/integrative approaches, and even necessary surgeries. The ascendance of Enhanced Recovery after Surgery (ERAS) protocols has resulted in some anti-opioid pain management "specialists" misrepresenting the science behind and the "universal" effectiveness of enhanced recovery approaches, and we have addressed the need to consider ERAS protocols as "opioid-sparing" as opposed to "opioid eradicating".<sup>27</sup> Irrespective, reports of patients who have awakened from anesthesia in unbearable pain and being refused medication other than acetaminophen or NSAIDs, even if this occurs in very few cases, has led to many patients deciding to forego elective surgeries – including those commonly utilized as an effective approach to gaining long-term pain relief (eg, total knee and hip arthroplasties).

Finally, it is apparent that legitimate pain patient advocacy groups, such as the American Chronic Pain Association and the US Pain Foundation, among several others, are doing excellent work to promote access to high-quality patient-centered pain care, rather than simply clamoring for increased

access to opioid analgesics. Those groups that are solely focused on access to opioids are guilty of reliance on "junk science" to "prove" that opioids are a panacea for chronic pain universally, mirroring the reliance on poor quality data by the most extreme of the anti-opioid faction to support their assertion that any exposure to opioids, even in acute settings, puts opioid-naïve patients at "great risk" for developing an opioid use disorder (OUD). For example, in a recent article on the risk of nonmedical opioid use behavior, the authors included "request for specific opioid" by a patient in their list of risk factors, even though this has never been empirically established.<sup>28</sup> The inclusion of this and other behaviors that most clinicians consider benign served to inflate the authors' conclusion that 19% of cancer pain patients demonstrate non-medical opioid use, which is quite inconsistent with the findings of a more methodologically sound study in which a range of 3.2% to 4.3% was determined among cancer survivors requiring opioid analgesia.<sup>29</sup> As the authors' inflation of the prevalence of opioid misuse had the potential to result in higher levels of oligoanalgesia, broadly, a letter to the editor elucidating issues with the quality of the science was written and published.<sup>30</sup> Groups that are solely focused on increasing access to opioid analgesia do not produce data, as they are not researchers. However, they cherry-pick data in order to "prove" that opioids are completely safe. For example, a recent systematic review and meta-analysis<sup>31</sup> found that the prevalence of problematic opioid use among chronic noncancer pain patients ranged from 3.2%<sup>32</sup> to as high as 80.5%,<sup>33</sup> with the authors of the review concluding an estimated prevalence of 36.3%. Although this figure may seem high, we are puzzled by the common assertion of "patient advocates" on social media that the figure is less than 1%. Misrepresentation of data and intentionally flawed methodology are never appropriate, irrespective of the side of an argument which one supports.

## Conclusions, Recommendations

Forced tapers from opioids in adherent and stable chronic pain patients for whom there are no realistic, accessible alternatives represent a humanitarian crisis,<sup>34</sup> and our hope is that society is in the process of reversing this trend. Chronic pain patients whose quality of life have been adversely affected by anti-opioid rhetoric and hyperbole as well as poor quality and misrepresented data have resulted in a need for sound and moderated patient advocacy. That the quality of medical advice regarding pain management on social media is woefully poor has been empirically established.<sup>35</sup> Social media serves as a sounding board in which patients suffering from chronic pain and its sequelae can vent their frustrations and support

each other and can be beneficial in this regard. Additionally, a number of medically trained key opinion leaders with lengthy histories of pain patient advocacy contribute to the social media chronic pain discourse, providing much-needed accurate information and even making referrals to high-quality pain care providers to patients who lack the ability to access these excellent clinicians on their own. However, we have recently observed an increase in self-proclaimed pain patient “advocates” dedicating their efforts to help their peers solely to advocating for increased access to opioid analgesia, “demanding” that patients are prescribed the same high dosages that were prescribed a decade ago, which have not been empirically established as safe or effective. In doing so, their efforts are misguided, as they exacerbate the stigmatization and marginalization that chronic pain patients already find so deleterious, as well as dissuade them from consideration of the numerous non-opioid treatments for chronic pain that have the potential to improve patients’ quality of life.

## Disclosure

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