

US CDC opioid guidelines and potential impact on ME/CFS patients - Lily Chu, MD, MSHS

Before I became immersed in ME/CFS, I specialized in geriatric medicine and one of my research focuses was improving medical care in nursing homes, specifically how pain was assessed and managed (or often not) in elderly patients. In the US, education and attitudes regarding opioids has fluctuated back and forth, from the time in the 1990s-early 2000s when pain was regarded as the [“5th vital sign”](#), [Californian clinicians](#) were required to take classes on pain management to retain their licenses, and opioids were considered safer than Tylenol or NSAIDs in elderly patients, to the current time, when an [increase in the number of death related to prescription opioid use has skyrocketed](#) and clinicians are accused of too easily prescribing opioids and/or not informing patients enough about the limitations and complications (e.g. addiction, respiratory depression, constipation) connected to such treatment.

Consequently, the US Centers for Disease Control sponsored and published guidelines directed at primary care clinicians, who prescribe 50% of all opioids in the US, in April 2016. The guidelines were [not without controversy](#). Many professional medical organizations, including major ones like the American Medical Association and American Pain Society, as well as disease and patient advocacy groups protested the process and content of the guidelines. For example, they noted that they were not consulted by the CDC, that evidence for certain recommendations were not well supported, and that actions suggested were not practical for busy clinics.

The [full guidelines](#) along with [supporting FAQ sheets, checklists, and posters](#) directed at clinicians and the public should be reviewed by everyone interested in this issue. I am ambivalent about them. On the one hand, some of the concepts covered, such as starting with a low dose and increasing the dosage slowly, trying or combining treatments, assessing who might be at higher risk for addiction, educating patients and caregivers about risks and benefits, I can fully support. But on the other hand, I found several statements and conclusions made rather strongly without evidence. For example, the high rate of complications and deaths from prescription opioids is a true problem but that does not mean people who suffer those consequences were being prescribed opioids legitimately or using them as prescribed. There are cases of people stealing or using other people’s drugs. I have yet to find a strong paper linking legitimate prescription/ use of opioids to high rates of death and of the articles I read, nothing was cited. (Maybe I did not look hard enough? If you know of such an article, send it to me at Newslettereditor@iacfsme.org.)

We should not jump to conclusions so easily.

Furthermore, a [Special Communication published in JAMA](#) by the authors of the guideline revealed that much of the evidence used to support recommendations were level 3 or 4, as assessed by the authors themselves, that is, “Observational studies or randomized clinical trials with notable limitations” or “Clinical experience and observations, observational studies with important limitations, or randomized clinical trials with several major limitations.” Other methods used included a contextual review “summarizing study quality based on author reports rather than applying objective quality rating protocols.” I have not read all the documents from the

CDC about study inclusion/ exclusion, assessment, data extraction, synthesis, etc. but those comments about how the guidelines were constructed make me very wary of them as unsuspecting busy clinicians and other health-related entities (e.g. insurance, hospital administrators, etc.) may undertreat pain, view chronic pain patients as drug seekers, and put policies in place believing them to be strongly supported by science when they are not.

What does this mean for ME/CFS patients or patients with related disorders like FM? I am not sure but I have concerns patients will face difficult obstacles in getting their pain taken seriously and treated appropriately. Surprisingly, there are few published studies about pain assessment and treatment in ME/CFS despite at least 60% of patients expressing they have some pain and pain being a key features of almost every ME/CFS case definition. In 2003, the US CDC found that [pain medication was the #1 category of medications used by patients](#), with 88% using something at least occasionally. However, the most commonly used (18% of all drugs) were OTC Tylenol-related products or NSAIDs (e.g. Ibuprofen, Naprosyn, etc.) with opioids composing a mere 1.3%, even less than the 2.6% used by healthy controls. Similarly, during [the survey](#) Dr. Jason's team and I conducted for the FDA Drug Development Workshop in 2013, over-the-counter drug use was very common; however, of those who had tried them, short- and long-acting opioids, were deemed the most effective pain medications (along with ibuprofen), cited by about 60% of users despite acknowledgement of complications such as constipation, confusion, etc. There were limitations to our survey, including that we did not ask specifically about what types of pain people experienced. A recent quick, informal survey of patients I know showed that several were taking opioids and were already encountering/ anticipating problems with obtaining them despite the opioids greatly helping them with their function and quality of life.

What can be done for the future? For treatment, the focus needs to shift away from politics and what patients may or may not take and focus more on how do we help a particular person. I also think more attention has to be paid to pain assessment and not only treatment. Clinicians may very well be carefully questioning patients about pain and diagnosing the different types or causes of pain but we do not see this reflected in research. Only one paper I know of asks patients about pain in detail; other papers assume pain is one entity and do not try to elaborate or diagnose it. [Marshall et al.](#) came to the conclusion that the most common type of pain was musculoskeletal pain of moderate intensity. This was despite only 1 patient being formally diagnosed previously with FM. However, based on the methods they used, I am not clear if Marshall and colleagues also encouraged subjects to talk about other types of pain (e.g. headache, neuropathic pain, sore throats, etc.)

In geriatric medicine, one central tenet is to not make assumptions about pain, e.g. don't assume pain is an inevitable companion of aging, that pain must be osteoarthritis, etc. Instead, assess and diagnose the reason for the pain. It might be something more dangerous and/or treatable than arthritis; pain control also makes a huge difference in the lives of patients. Already, we have heard anecdotes of non-opioid, non-Tylenol, non-NSAIDs treatments helping some patients with specific types of pain. For example, some ME/CFS patients with neuropathic pain and specific viral titers benefit from antivirals, some with IBS also are helped by rifaximin,

while [some with co-morbid FM find relief from low dose naltrexone](#). I hope more researchers will consider these topics for investigation in the future. In the meantime, I hope patients will be treated as individuals and ideas about pain treatment not applied broadly without careful consideration.

Have a question, opinion, or comment about this topic? Write us at Newslettereditor@iacfsme.org and we may publish some responses in the future.