

Opioid Refugees: Patients Adrift in Search of Pain Relief

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Hi, I am Steve Passik, and welcome to *Emerging Solutions in Pain*. I am here to talk to you a little bit about my keynote lecture from PAINWeek this year. It had the intriguing title which Deb Weiner gave to me, the organizer of PAINWeek, and it was inspired by a line from last year's talk in fact. Last year, I was talking about nonscientific influences in the opioid debate, a talk that was entitled *Jesus, Bacon, and Hyperalgesia*, and I happened to mention that at the time I was still working at Vanderbilt seeing patients in Nashville, and I mentioned that when the Kentucky pain laws changed, that we were having a stream of refugees, the term I used was opioid refugees, who were coming from Bowling Green and other places around Kentucky after they had found it difficult to continue to be in pain management in Kentucky when the laws changed. I mentioned opioid refugees. Deb added the new diaspora perhaps because of the religious theme from last year, but in any case, it was a very challenging talk to put together as you might imagine it. It implies a lot very sensitive areas like patient abandonment and so on. Actually, I was fortunate enough to be able to get a video from the patient who inspired me to make the comments to begin with, a patient who lives in the Tennessee area near Nashville who filmed a video, wrote her comments down because she was too nervous to do it off the top of her head, but she really explained what happened. It was interesting to hear her point of view. She was a lady in her 70s who had breast cancer. When she found out that she had osteoporotic pain, not metastatic cancer pain, the breast cancer oncologists at Vanderbilt were not seeing her frequently enough to comply with the Tennessee laws. So, she went back. She is formally from the Bowling Green area. She went back to her old primary care doctor who really bailed the whole team out in a pinch and prescribed her medicines for her. He knew her for over 40 years. And then suddenly, when the laws changed, the way it was explained to the patient as she said in her video, the state is passing laws that regular doctors could not prescribe anxiety and pain medication, and so, she ended up coming back to me. I saw her at the Cancer Center, and I got her in the pain center. And for awhile, they also continued her medicines. We are not talking about a lot of medicine here. We are talking about 10 mg BID of sustained-release oxycodone and 0.5 mg BID of clonazepam. Interestingly, she ended up in expert care, not only to get this small amount of oxycodone in the setting of cancer survivorship but also the pain folks ultimately referred her to a psychiatrist who okayed the 0.5 mg twice a day of clonazepam. And then, since I had last seen her, I come to find out that she had experienced a recurrence of her breast cancer and actually debated whether or not to have the surgery because of her concerns of what her pain management would be like afterwards. I mean we are talking 2013 in United States of America. I was just blown away and asked her if she would do a video. She is a very anxious but just down-to-earth, salt-of-the-earth person, and she did it and it was very moving and the lecture started with that but it also then led to a discussion. I mean, you take one look at this

woman, my comment to the audience afterwards was I spent the last 25 years telling physicians you cannot tell a drug addict or a drug dealer by looking at them, but you see this lady on the video and I said, my bookie could say that this woman was not a drug dealer, and really the comment was very moving because the comments were, if our health care system cannot take care of somebody like this in this day and age, then there is something really wrong. So ultimately, in doing the research, I was able to find testimonials or complaints or statements of what patients were going through all over the country in fact. *The Huffington Post* had a thing where they invited people to talk about what their experiences had been like trying to get doctors to treat them, trying to get their medicines filled in pharmacies, and so on. It is not like you can find a definitive study of patients who have been locked out or whatever in any one source, but we were able to pull together a lot of that information to sort of set the stage.

Ultimately, I took on a discussion of recent legislative attempts to try to come to terms with the prescription opioid abuse problem in this country from arbitrary dose limits that some states have to trigger a pain expert consultation, started out in Washington with a 120 mg limit. Ohio then instituted one at 80 mg. Indiana was considering 50 mg of morphine equivalence to trigger an expert consultation. Basically, in each case in which I talked about the ways in which various aspects of opioid risk management were being legislated, even if it is an overly simple idea, overly simple solution to a complex set of problems, that nevertheless, some of the ideas themselves are not so bad. But then, they go out into an environment of hysteria; and on top of the hysteria, there is just unbelievably like logarithmically multiplying hassle factors for the doctors. And that, ultimately even relatively reasonable suggestions like having to check the prescription monitoring program in your state if you are prescribing opioids becomes almost the last straw, and then doctors tend to recoil and say I just cannot do this. I do not have the time. I do not have the resources. I just cannot do it. And of course, the patients are getting left out in the cold.

Finally, I talked a little bit about the ways forward. I talked about some innovative programs, everything from give-back programs that are run by police departments that get hundreds of thousands of pills out of people's homes, and some 30 such programs that exist. I talked about the existence of the recovery high schools and educational efforts that are directed towards young people to not experiment with these medications. And then I also cited Project Lazarus as probably the single best example I believe that we have of a public health approach to this problem and one that recognizes that, in fact, we have two epidemics not one. We have the epidemic of prescription drug abuse, yes, but we also have the epidemic of chronic pain. And that, when you play one against the other, all you do is leave legitimate patients out in the cold sometimes and you chase drug abusers to other drugs, especially if you do not answer alternatives. And also, I talked about it in the presentation that the recent new popularity of heroin again in several places around the country. Project Lazarus used a community educational approach mobilizing practitioners in the small counties in western North Carolina mobilizing them, educating them, educating the pharmacists, teaching the pharmacists to use the prescription monitoring program correctly, teaching emergency room doctors. And then, of course the signature element of Project Lazarus has been their intranasal naltrexone program where they give out kits so

that if someone sees a family member or a friend overdosing from opioids, whether it is legitimate pain medicines or illegally obtained opioids, they teach people how to use this kit, and they have saved unbelievable numbers of lives. They have decreased the number of opioid overdose deaths by 70% in these counties, and at that same time, there was no decrease in opioid prescribing in those counties. To me, ultimately, we need more approaches that do that, that do not play one health crisis off another but address them both through education and enfranchising various people involved in pain into a community, and truly that typifies the approach that I think offers the only way forward. I ended with nine suggestions. Most of them involved embracing of public health stance but also I told the audience at the tail end that our patients are really in need. They do not have a voice. There is all kinds of loud voices clamoring about the various aspects of this problem but not people in pain. They are underrepresented. They do not really have a say in what has become just a title wave of negative stigma and public opinion going against the treatment of pain. I closed by telling the audience your patients need you to be bright. They need you to be up-to-date. They need you to be thoughtful and creative, but do not neglect the fact that they need you to be an advocate as well. I was very happy that I thought my role as a keynote speaker was to stir the pot a little bit, and I hope people walked out a little bit ready to not neglect the advocacy aspect of their role as well.