

FDA HEARING ON USE OF OPIOID ANALGESICS/ SEPTEMBER 2001

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“Pain is a more terrible lord of mankind than even death itself”
-Albert Schweitzer

Interstitial Cystitis (IC) is a non-malignant chronic disease characterized by inflammation of the bladder that causes severe pelvic pain, urinary urgency and frequency (up to every 20 minutes, both day and night). The cause is unknown and there are no uniformly effective treatments. Symptoms are similar to an acute urinary tract infection, but urine cultures are negative and symptoms do not respond to antibiotics. A diagnosis of IC is made on the basis of symptoms in the absence of other definable causes such as infection or bladder cancer. At the present time, there is no specific diagnostic test for IC. Approximately one million people in the United States suffer from IC, an incidence similar to Parkinson's Disease. Epidemiological studies reveal that:

- 1) it takes on average 5-7 years to get diagnosed, and sometimes even longer.
- 2) the quality of life of IC patients has been shown to be worse than that of patients undergoing dialysis for end-state renal disease.
- 3) economic impact is estimated to be \$1.7 billion per year when combining medical expenses and lost wages due to inability to work.

Suicides occur every year because patients are left in severe pain with nowhere to turn to for help. Because standard urologic tests are negative and physicians are often not familiar with the condition, patients are often told that their symptoms are “all in their heads,” or that the symptoms are caused by stress, thereby minimizing or invalidating the patient and compounding an already devastating condition.

Opioid analgesics are an absolute necessity for many patients with IC, particularly for those who do not respond to any of the available treatments. Pain as a "Fifth Vital Sign" has been promoted by both the American Pain Society and the Joint Commission on the

Accreditation of Healthcare Organizations (JCAHO). This is a major advancement for patients because it recognizes that the level and type of pain an individual is experiencing are critical to effective patient care. For IC patients, it can mean the difference between life and death.

Opioid analgesics, when used appropriately, rarely cause dependency. Addicts use pain medication to escape life, while people in chronic, severe pain use pain medication to get their lives back! People who use pain medication to treat very real pain are not going to get the same response in their brain as those who use it unnecessarily.

While preparing for this testimony, we received the following e-mail from an IC patient:

I am having a very hard time finding a urologist that "understands" IC. I am in constant, chronic, severe pain, and every doctor I see seems to be "afraid" to give me the pain medication I need for fear of dependency problems.

What they don't understand is that my life can be no worse than it is now. I am unable to leave the house, and am struggling with severe pain, hopelessness, and depression. Please help me.

And when we contacted this patient to offer her help and support, we also asked for her permission to present her poignant statement, anonymously, at this meeting today. This was her response:

You have my permission, if it is at all necessary, to even use my name. I am not ashamed of this disease... It is the medical profession that should be ashamed of themselves....

Opioid analgesics are an essential part of treating chronic, painful and poorly understood non-malignant conditions such as IC. Physicians confronted with a patient in severe pain due to IC often ask themselves whether the patient should receive treatment for pain. Perhaps the question should be, "Why should this person be left in pain?"

References

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