Pain in HIV/AIDS

Pain is a very negative but common experience for patients with HIV/AIDS. It is often associated with significant psychological symptoms. In every case, it is a treatable problem that is all too often undertreated by physicians. Pain perception in patients is influenced by a number of cognitive-behavioral factors as well as sociocultural issues. HIV pain is often multifactorial in origin and the initial step in attempting to manage any pain complaint is a comprehensive assessment.

How common is pain for HIV+ people?

Even in the era of highly active antiretroviral therapy (HAART) to manage HIV infection, physical pain is widespread among HIV+ people. There are few studies of pain and other physical and psychological symptoms in the current treatment era. A study of 156 individuals—with a median age of 47.5 years, time since HIV diagnosis of 11 years, and CD4 count of 502 cells/mm—found that 76 patients (48.7%) reported pain, of whom 39 (51.3%) had moderate to severe pain, and 43 (57.3%) had pain that caused moderate to severe interference with their lives. Those with psychiatric illness were 39.8% more likely to have pain. Injection drug users also experienced pain in greater numbers.

Yet, pain tends to go unreported and untreated. A comprehensive assessment is the first step to find the origins of physical pain and properly manage it.

What kinds of pain do many HIV+ people experience?

HIV+ people can experience a variety of types of pain, from a variety of causes. The virus itself and the immune response to it can lead to inflammatory responses that cause pain. Secondary complications of poorly managed HIV—such as cancers and opportunistic infections—are also associated with pain. Older HIV medications themselves tended to be neurotoxic, associated with nerve damage that can lead to pain. Even HIV+ patients who are managing their infection with antiretroviral therapy and have higher CD4 counts can experience pain.

The most common pain syndromes reported include painful sensory peripheral neuropathy, headache, oral and pharyngeal pain, abdominal pain, chest pain, anorectal pain, joint and muscle pain, as well as painful dermatologic conditions and pain due to extensive Kaposi's sarcoma.

HIV+ women seem to experience pain more frequently than men, and report somewhat higher levels of pain intensity. This may partly reflect the fact that HIV+ women with pain are twice as likely as men to be undertreated for their pain.

HIV+ children can also experience pain because of such conditions as meningitis and sinusitis (headaches); otitis media; shingles; cellulitis and abscesses; severe candida dennytis; and dental caries; intestinal infections such as mycobacterium avium intracellular and cryptosporidium; hepatosplenicomegaly; oral and esophageal candidiasis; and spasticity associated with encephalopathy that causes painful muscle spasms.

Why is pain underreported and undertreated in HIV+ patients?

Even though the pain associated with HIV is widely understood to be comparable to the pain of cancer, pain in HIV is treated far less effectively than in cancer.

Patients often hesitate to report the pain they are feeling, believing it is a “normal” part of having HIV that they must endure. Some worry they will become addicted to pain medication, or that it will have serious side effects. Others may not want to add another medication to their daily regimen, or may be worried about receiving an injection, or may simply prefer a holistic, non-pharmaceutical approach to pain management.

Many health care providers do not know enough about the basic anatomy of pain and the pharmacology of effective analgesic care. This means they can’t adequately assess pain or understand the specific HIV-related pain syndromes. Physicians’ legitimate fear of regulatory scrutiny of their prescription writing patterns may also keep them from offering truly effective pain management.

At the health care system level, barriers to pain management include lack of access to health care and specialized pain services, the unavailability of opioid analgesics in many community pharmacies, the cost or insurance coverage of pain medications, and state and federal regulations that invite scrutiny of physicians who prescribe opioids (e.g., morphine, meperidine, oxycodone) for severe pain. Adjuvant analgesic agents, such as antidepressants, are also dramatically underused, despite the fact that such medications are recommended by the World Health Organization (WHO) for pain management.

How should a clinician evaluate for pain?

In either an initial or ongoing pain assessment, it’s important to bear in mind that only the patient knows for sure if pain is present or gone, and when there is or isn’t enough pain medication. Providers can usually tell when there is too much pain medication, but they often aren’t attuned to whether there is enough pain medication, evidenced by study after study showing that physicians consistently under-treat pain.

A physician should conduct a comprehensive pain assessment whenever a patient indicates that pain exists and when a circumstance arises...
that is typically associated with pain. The clinician should inquire about pain in a clinical interview, and may also use a variety of pain assessment tools, including the brief pain inventory (BPI) and the Memorial Pain Assessment Card (MPAC).

The MPAC is a helpful clinical tool that allows patients to report their pain experience. Using the MPAC, a patient can easily and quickly refer to a visual scale to describe his pain intensity, pain relief and mood. Patients can complete the MPAC in less than 30 seconds. The BPI is another pain assessment tool that a patient can respond to quickly and easily, using a 1-10 rating scale.

A physician should ask the patient what the pain feels like (e.g., burning, shooting, dull or sharp), how intense it is, when and for how long it has been present, and what actions or activities (e.g., taking any over-the-counter medications) either decrease or increase the pain.

Besides asking about the pain itself, a physician should make a detailed medical, neurological, and psychosocial assessment (including a history of substance use or abuse). Where possible, family members or partners should be interviewed. A careful history and physical examination can uncover a syndrome (e.g., herpes, bacterial infection, or neuropathy) that may be causing pain and can be treated in a standard fashion.

What psychosocial factors must be considered?

Certain psychosocial factors should be taken into account for any pain evaluation to be complete and accurate. Patients sometimes overstate or understate their pain, either intentionally or unintentionally. For example, a patient whose outward behavior seems cheerful might describe pain as an 8, on a scale of 0 to 10, while a patient clearly in physical discomfort (sweating, fever, etc.) might describe his pain level as a 2.

Some of this has to do with the effectiveness of a patient's coping skills (e.g., distraction and relaxation techniques). A patient for whom it is important to be stoic, or who is afraid that increasing pain means advancing illness, might not admit to being in severe pain. Another patient may figure that he is more likely to receive pain medication by rating his pain level fairly high. Physicians should be aware of these feelings and behaviors and sensitive to the anxieties they signify.

How is HIV-related pain managed or treated?

Although the best approach to treating pain in HIV is multimodal (pharmacologic, psychotherapeutic, cognitive-behavioral, anesthetic, neurosurgical and rehabilitative approaches), analgesic pharmacotherapy is the first step and foundation in pain management.

When using medication to treat pain, clinicians should make the choice of analgesic based on severity and mechanism of pain. Opioids are the first choice of management of moderate to severe pain. NSAIDs, adjuvants, and nonpharmacologic modalities are important supplements to effective analgesia. When a patient is in chronic or persistent pain, physicians may prefer to use around-the-clock administration and long-acting opioids. Short-acting analgesics are useful for intermittent pain and as supplement for breakthrough pain. There may be serious consequences when pain is undertreated or poorly managed in HIV+ people. Someone whose pain is not being managed can lose trust in the doctor and may have fear or anxiety that the pain will get worse and remain untreated. Pain also is known to increase suicidal ideation in patients struggling with this fear and anxiety. Careful and continuous pain assessment is critical in HIV+ patients struggling with those feelings, and complete pain management is crucial.

The World Health Organizations provides recommendations for treating and managing pain in their analgesic ladder, below:

![FREEDOM FROM PAIN](image)

**References**


**About this Fact Sheet**

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