Developing Research Priorities for Chronic Pain in People Living with HIV

The Global HIV Pain Task Force seeks input from the HIV/AIDS community.

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People living with HIV experience chronic pain more commonly than others. Chronic pain is associated with reduced quality of life, poorer physical function, mental health problems, trouble working or staying in school, and in some cases greater difficulty adhering to antiretroviral therapy and keeping up with other basic health care needs.

People living with HIV, and leading doctors and researchers, have increasingly recognized the importance of chronic pain. The Infectious Diseases Society of America, the HIV Medical Association and the British HIV Association have all included assessment and treatment of pain in their guidelines and standards.

Additionally, world leaders have proposed a global focus on health-related quality of life in HIV. Building on the UNAIDS 90-90-90 campaign (90% of people with HIV diagnosed, on treatment, and virologically suppressed), a “fourth 90” has been proposed to address factors that heavily impact quality of life, such as pain.

Despite the large need in this area, there is currently an incomplete understanding of why chronic pain develops in people living with HIV. Explanations generally follow the biopsychosocial model, which explains that the chronic pain experience is a combination of biological, psychological and social factors.

Biologically, HIV can contribute to painful conditions like neuropathy or musculoskeletal pain. In addition, proteins produced by the virus and the body’s inflammatory response may cause the nervous system to become sensitized to pain. Psychological factors, including stress and coexisting mental health disorders, can also exacerbate pain, as can social issues, including isolation and lack of access to needed services.

Evidence-based guidance for how to optimally manage pain in people with HIV is also limited. Most medications used to manage pain, including prescription opioids, antidepressants, anti-

inflammatory drugs, have not been well studied in HIV, and some experts believe they have limited effectiveness. Psychological or physical therapy based approaches have demonstrated initial promise, however, the full potential of these therapies remain uncertain.

Clearly there is much work to be done, and now is a crucial time for chronic pain research. Given the turbulence of the past year, including the devastation of the COVID-19 pandemic, it can be easy to forget that not too long ago our focus was on another public health crisis, the entwined epidemics of opioid use disorder and chronic pain.

The death toll due to opioid overdose, increasing year after year with no end in sight, spurred major government action. In 2018, the Helping to End Addiction Long-term (HEAL) Initiative devoted substantial resources to developing science-based solutions to the opioid crisis, including better treatments for opioid use disorder and effective, non-addictive pain therapies.

It is crucial that the needs and perspectives of people living with HIV and chronic pain are given the attention they deserve as this research advances.

To achieve this we formed the Global HIV Pain Task Force in 2019. We are a group of researchers and people with lived experience from the United States, United Kingdom, Canada and South Africa. We study, treat and live with chronic pain and HIV, and are passionately committed to finding the safe and effective treatments we desperately need.

In the summer of 2019 we came together to brainstorm and strategize, focusing on establishing research priorities in this area. We came up with many ideas and developed a list of the research goals we thought were most important. But it’s not really about what we think.

We need the input of a diverse group of individuals with lived experience of HIV and chronic pain to tell us what’s important to them. Are the research goals we established good ones? Are there other important areas that we missed?

We also want to know about you. There is surprisingly little information out there about what it’s like to live with HIV and chronic pain. How are you managing, what helps and what doesn’t? If we don’t know the answers to these basic questions how do we even get started?

We humbly request your help in completing our survey. Your answers matter and your unique voice is crucial.

Click here to take the survey.

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