

Women with HIV Are More Likely to Die from Trauma than the Virus

A detailed look at what happens to patients shows how death certificates often miss the real story and points to the need for a new approach to care.

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Women with HIV most often die from preventable, trauma-related conditions like substance use and mental illness—not the virus itself. Yet, these leading causes are largely missing from official death records, according to new research by the University of California San Francisco.

The study is the first to compare death certificates to the causes of death identified by doctors, nurses, social workers and pharmacists who knew them well. HIV was listed as a cause of death in 68% of cases, but the health care providers found that HIV played a role in just 15%. The providers, on the other hand, identified the leading causes of death as mental illness and substance use, each of which was implicated in 58% of deaths. Yet death certificates listed these causes in only 5% and 13% of cases, respectively.

The researchers said the findings support establishing broader goals for HIV care than simply trying to control the virus.

“There’s been a longstanding belief that it’s HIV—the virus itself—that is driving illness and death, but that ignores the primary causes of death in people living with HIV now,” said [Edward Machtinger, MD](#), who co-directs the Women’s HIV Program at UCSF. He is the senior author of the paper, which appears June 12 in the [Journal of Acquired Immune Deficiency Syndromes](#).

“Helping women with HIV survive,” he added, “requires a focus on healing from the many conditions related to past trauma—addiction, depression, stigma, isolation—much more so than focusing on getting people on antiretrovirals and having their viral load go down.”

Since the mid-1990s, new combined drug regimens have transformed HIV infection from a death sentence into a chronic but manageable condition. But despite that progress, U.S. women with HIV still have an overall life expectancy about 12 years shorter than those without HIV. Men with HIV also have shortened life spans, with some data suggesting similar reasons.

The study analyzed the experiences of 40 women who had been cared for at UCSF’s Women’s HIV Program and died between 2004 and 2023. Only the women whose providers were still at the

clinic to participate in the research were included.

The study found many instances in which the providers' understanding of what happened to their patients diverged significantly from what was depicted in the death records.

For example, the death records listed suicide in 3% of the cases, compared to 13% identified by clinicians.

Cigarette use, intimate partner violence, treatment non-adherence or the inability to follow medical advice, and HIV stigma, or a fear of discrimination that keeps people from seeking care, were all common causes of death identified by the clinical team, but they did not appear on any death certificates.

"Because of what we learned, we have designed all of our care and services to help our patients feel safe and heal from past trauma," said study co-author Katy Davis, PhD, a social worker and trauma therapist who co-directs the clinic. "This model of trauma-informed health care should be standard for everyone with HIV so they can have long healthy lives."

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