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COMMENTARY

Life and Disability Insurance for People with or at Risk of HIV: Aligning Policy with Evidence

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Antiretroviral medications have substantially improved life expectancy for people with HIV. These medications are also highly effective in preventing HIV acquisition in people who do not have HIV, a strategy known as HIV preexposure prophylaxis (PrEP). Despite these advances, some life and disability insurers continue to deny or limit coverage for people with HIV, and some have even refused to cover people who are using PrEP to protect themselves. These policies unfairly deny people with HIV, PrEP users, and their families the peace of mind and financial protection that can come with life and disability insurance coverage. This article summarizes the current evidence on HIV treatment and prevention, arguing that underwriting decisions by life and disability insurers should not be made based on HIV status or use of PrEP.

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On June 5, 1981, the Centers for Disease Control reported a case series of five young men in Los Angeles with *Pneumocystis carinii* pneumonia, a disease previously seen only in severely immunosuppressed people. Within months of falling ill, two of the men were dead.[1] The scientific community eventually identified a novel pathogen: human immunodeficiency virus (HIV). The U.S. government's response to the burgeoning epidemic was glacial, in part because of its disproportionate impact on gay men and other marginalized populations.[2] Mortality attributable to HIV/AIDS would peak in 1995, with 51,670 HIV-related deaths in the U.S. that year.[3]

Without an available treatment, most people with HIV/AIDS died within 8 to 10 years.[4] As a result, life and disability insurers refused to underwrite people with HIV (PWH).[5] Today, however, HIV is nearly 100% treatable and preventable.[2] Driven by the tireless work of scientists, clinicians, and activists, the evolving treatment landscape has transformed HIV from a death sentence into a chronic disease that can be medically managed. Antiretroviral therapy (ART) is now widely available, such

that most PWH in the U.S. can expect to have a near-normal lifespan. Antiretroviral medications are also highly effective in preventing HIV acquisition in people who do not have HIV, a strategy known as HIV preexposure prophylaxis (PrEP).

Despite these advances, some life and disability insurers continue to deny or limit coverage for PWH based on outdated evidence suggesting that HIV substantially shortens life expectancy.[6] Some have even refused to cover HIV-negative people who are using PrEP, presumably because this population is considered "risky."[7,8] These policies unfairly deny PWH, PrEP users, and their families the peace of mind and financial protection that can come with life and disability insurance coverage. In this article, we summarize the evidence on HIV treatment and prevention in the modern ART era and, based on that evidence, argue that underwriting decisions by life and disability insurers should no longer be made based on HIV status or the choice to use PrEP.

In the early years of the HIV epidemic, treatment required numerous daily pills with toxic side effects and limited efficacy. The turning point for life expectancy for PWH came in 1996, with the emergence of highly effective ART.[9] Initially, studies showed that even with widespread ART availability the life expectancy of PWH in high-income countries remained shorter than that of the general population.[10–12] However, by comparing PWH with the general population, those studies could not account for important sociodemographic and clinical differences between people with and without HIV, including comorbid conditions and access to health care.[13,14]

To address those limitations, research conducted at Kaiser Permanente compared life expectancy between PWH and a matched comparison group of health plan members without HIV. Those studies confirmed that 1996 was a landmark year for PWH: mortality rates began to plummet and life expectancy soared. In 1996, an individual with HIV who had survived to age 20 would have been expected to live another 19 years, to age 39.[9] In 2014-2016, an individual with HIV who had survived to age 21 was expected to live another 56 years, to age 77.[13] By 2016, the life expectancy gap between PWH and similar people without HIV had narrowed to 5.7 years.[9,13] Recent data have confirmed those findings, with appropriately treated PWH reaching a life expectancy comparable to that of the general population.[10,15]

Research on survival for PWH has demonstrated the critical importance of early initiation of ART. In the studies from Kaiser Permanente, life expectancy for PWH in 2011-2016 was highest for those who initiated ART with CD4 counts $\geq$500 cells/μL, reaching 57 additional expected life years at age 21.[13] In 2015, a randomized controlled trial confirmed what had been seen in observational studies: PWH who were immediately treated with ART were at a lower risk of morbidity and mortality compared with those who delayed treatment initiation until their CD4 count had dropped to 350 cells/μL or they had developed AIDS.[16] That seminal study contributed to clinical guidelines recommending immediate ART initiation at the time of HIV diagnosis regardless of CD4 count, further improving life expectancy for PWH.

Today, the most common causes of death among PWH in the U.S. are no longer HIV-related. Instead, leading causes of death among PWH, such as cardiovascular disease and cancer, are similar to the leading causes of death in the general population.[17] Likewise, the main risk factors for cardiovascular disease and cancer among PWH are not HIV-related factors, such as CD4 count or HIV RNA levels, but are instead similar to the risk factors—such as smoking—that have been identified among people without HIV.[18] Although PWH tend to be diagnosed with comorbidities at earlier ages,[13] PWH are otherwise clinically similar to people without HIV. The diagnosis of such comorbidities may continue to inform underwriting, but evidence suggests that HIV status

itself should no longer be a driver of decisions about life or disability insurance coverage.

In addition to resulting in near-normal life expectancy for PWH, ART reduces the number of new HIV infections by preventing transmission to partners. In 2016, a prospective cohort study tracked serodifferent couples in which the partner with HIV was on ART and had an HIV RNA level below 200 copies/mL. Despite 36,000 condomless sex acts among heterosexuals and 22,000 condomless sex acts among men who have sex with men, there were zero linked cases of HIV transmission.[19] A follow-up study tracked an additional 76,000 condomless sex acts in gay male couples, again demonstrating that HIV cannot be transmitted from an individual with HIV who is durably virally suppressed.[20] These data support the message of "U-U" (undetectable=untransmittable) and further reinforce that PWH and their partners should not be considered a "high-risk" population by insurance underwriters.

Life and disability insurers have denied coverage not only to PWH but also to PrEP users, with evidence of PrEP use deemed to be a marker of risk. Notably, PrEP reduces the risk of sexually acquired HIV infection by 99% – far exceeding the effectiveness of condoms, which reduce risk by only 63% to 91%, depending on the study population.[21] Moreover, evidence shows that PrEP is a gateway to engagement in health care, with users establishing and sustaining relationships with primary care providers and accessing other preventive care services more often than their counterparts who are not using PrEP.[22,23] In the words of Dr. Robert Grant, a leading PrEP researcher, refusing to insure people because of PrEP use is "like refusing to insure someone because they use seatbelts."[8]

Taken together, HIV infection can now be successfully treated and prevented with antiretroviral medications. The best available data show that PWH starting ART early today will have a near-normal life expectancy. Based on those data, the Equal Insurance HIV Act went into effect in California in 2023 to protect PWH from discrimination by life and disability insurers.[24] However, outside of California, some life and disability insurers have maintained outdated policies that limit or deny coverage for people with or at risk of HIV—policies that may inadvertently discourage the use of highly effective treatment and prevention tools. Life and disability insurers can play an important role in ending the HIV epidemic by ensuring that their underwriting decisions are based on the current scientific evidence, which strongly supports the insurability of both PWH and those using PrEP.

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