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Causes of Death of Women With HIV: Discordance Between Interdisciplinary Primary Care Teams and Death Certificates

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Background: The unadjusted life expectancy of U.S. women with HIV is 12 years less than U.S. women without HIV. Understanding how women with HIV die is necessary to reduce this disparity but is compromised by well-documented flaws with death certificate data.

Setting: University of California, San Francisco Women's HIV Program.

Methods: Using a period cross-sectional design, we compared multiple causes of death in women with HIV determined by structured meetings of an interdisciplinary clinic team with multiple causes of death listed on death certificates. We included deaths occurring between 2004 and 2023.

Results: The study included 40 women (38 cisgender, two transgender) with HIV. The clinic team identified substance use and mental illness as the most common causes of death, each occurring in 58% of cases (n = 23). Death certificates included substance use in 13% (n = 5) of cases and mental illness in only 5% (n = 2) of cases. By contrast, death certificates identified HIV/AIDS as the most common cause of death, occurring in 68% (n = 27) of cases, although the clinic team determined it was a cause of death in only 15% (n = 6).

Conclusion: To track the epidemic and guide resource allocation, death certificate data should be supplemented with information from providers with in-depth knowledge of each patient. To improve life expectancies of women with HIV, it is necessary to move beyond a biomedical focus on viral suppression to robust efforts to address mental and behavioral health. We include several policy recommendations to reach this goal, including extending the HIV Care Continuum to include "survival".

Key Words: women, HIV, cause of death, psychological trauma, substance use, mental illness

(*J Acquir Immune Defic Syndr* 2026;101:701–708)

INTRODUCTION

Despite widespread access to effective antiretroviral therapy, women with HIV in the United States continue to experience higher rates of premature death than women without HIV. The unadjusted life expectancy of US women with HIV is estimated to be 12 years less than that of women without HIV (76 years compared with 88 years).[1]

Death in both men and women with HIV is now largely driven by common comorbidities not related to HIV/AIDS, such as cardiovascular disease, liver disease, substance use, and non-AIDS malignancies.[2–6] In North America and Europe, the proportion of deaths among men and women with HIV due to AIDS declined from 49% in 1996–1999 to 16% in 2016–2020.[7]

Higher rates of death unrelated to HIV likely explain the profound disparities in life expectancy between women with and without HIV. For example, an analysis of all coded conditions listed on death certificates (ie, underlying and contributing causes of death) among people with HIV in San Francisco between 1996 and 2013 found that women with HIV were 25 times more likely to die from a drug overdose, 7 times more likely to die from chronic lung disease, 5 times more likely to die from liver disease, and twice as likely to die from heart disease than women in the general population of California.[8]

Understanding how women with HIV die is critical to inform the surveillance of HIV, allocation of resources, evaluation of interventions, design of models of care, and reduction in the disparity in life expectancies between US women with and without HIV. However, this understanding is limited by well-known flaws with death certificates, which are often completed by hospital physicians, medical examiners, or coroners who are unfamiliar with patients' medical and psychosocial histories.[9] Stigmatized physical and behavioral health conditions, such as substance use, are known to be underreported on death certificates.[2,10]

As a result, death certificates are often incomplete or inaccurate, as evidenced by studies comparing death

Received for publication June 14, 2025; accepted January 30, 2026.

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The authors have no funding or conflicts of interest to disclose.

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certificates with expert medical record review,[2,11,12] autopsy reports,[13,14] reports from next of kin,[11] and hospital claims.[15] These alternative methods of determining causes of death may be more sensitive and specific than death certificates but do not include input from interdisciplinary clinical teams (eg, nurses, physicians, social workers, therapists, pharmacists) who typically care for women with HIV over many years within HIV-focused primary care clinics. These long-term relationships provide in-depth knowledge of patients' clinical and behavioral experiences and the social and structural determinants of health, making these teams a critical source of information on the intersecting medical and psychosocial factors that contribute to death. Soliciting this information directly from such teams can provide a more accurate and nuanced understanding of how women with HIV die. Direct comparisons between death certificate data and determinations made by interdisciplinary clinic teams are lacking in the literature. This study examined causes of death in a women's HIV primary care clinic over a 20-year period after the broad availability of antiretroviral medications.

METHODS

Using a period cross-sectional design, we compared the multiple causes of death of women with HIV determined by interdisciplinary clinic team members who had in-depth knowledge of each patient ("clinic determined"), with the multiple causes of death listed on each death certificate. The study was conducted in a single HIV primary care clinic, the Women's HIV Program (WHP) at the University of California, San Francisco (UCSF). WHP is a US Health Resources and Services Administration Ryan White HIV/AIDS Program primary care clinic serving predominantly low-income women with HIV from racial and ethnic minority groups.

Using the clinic's electronic health record (EHR), we identified patients who (1) were in care at WHP at the time of their death; (2) identified as women (cisgender and transgender); and (3) died in the 20-year period between 2004 and 2023 (n = 47). We excluded individuals whose primary care provider had left the clinic and was not available to participate (n = 7). Excluded and included patients did not differ with regard to age at death, location of death, race, or gender identity, although more excluded patients died in the earlier half of the study period. Characteristics of the 40 people included in the analysis were obtained from death certificates, the EHR, and from an ongoing observational study (with permission from the UCSF Institutional Review Board).[16] The UCSF Institutional Review Board determined this study to be exempt.

Determination of Causes of Death by the Interdisciplinary Team

For each death, we convened an interdisciplinary "Causes of Death" meeting involving team members who had provided medical or psychosocial care for the patient. At minimum, each meeting included the patient's primary care provider (nurse practitioner or physician) and principal psychosocial provider (social worker or case manager). Additional participants included other team members with in-depth knowledge of each patient (eg, therapist, psychiatric nurse practitioner, clinic-based pharmacist, and other social workers and case managers), as well as study staff recording the meeting. The discussion for each patient lasted between 30 and 45 minutes. The median number of clinic team members attending each meeting was 5 (range 4–9).

Meetings followed a prescribed structure, starting with the primary care provider's summary of the patient's medical history. The team was then asked, "What were the most significant factors that led to the patient's death?" Participants answered from their perspective and experience with the patient. For the five deaths that resulted in autopsies, the primary care provider had previously reviewed the autopsy report. Team members were able to review the EHR and/or clinical notes before and during the meeting. Final determination of causes of death was achieved by group consensus.

All medical, psychological, behavioral, and social determinants of health could be considered causes of death except "experiences of psychological trauma." This cause of death was excluded because it represents a broad array of experiences, arose in nearly every meeting, is a near-universal experience for low-income women with HIV,[17] and because the many more specific trauma-related physical and behavioral health conditions were included.

Causes of Death meetings began in 2014. Initial meetings reviewed deaths that occurred up to 10 years earlier. Meetings were then conducted as patients died, typically within 2 months of each death. Causes of Death meetings are now a regular part of clinic activities.

Determination of Causes of Death From Death Certificates

We obtained copies of official California State death certificates for all 40 included patients. We identified multiple causes of death from death certificates by compiling the immediate and underlying causes of death listed on Line 107 "Cause of Death" and those listed on Line 112 "Other Significant Conditions Contributing to Death." For coroner-reviewed deaths, we included Line 119 "Manner of Death" (Natural, Accident, Homicide, Suicide).

Data Analysis

All causes of death (clinic-determined and death certificate) were coded by International Classification of Diseases (ICD)-10 category using a widely available, online database (ICD10data.com). A physician (EM) and member of the study team (YC) identified ICD-10 codes, with differences resolved by discussion and consensus. The same individuals repeated the process to confirm accuracy.

To ensure that discrepancies between causes of death identified by the interdisciplinary team and death certificates did not result from subtle differences in how similar diseases and conditions were coded, we created overarching categories of death (eg, lung disease, cardiovascular disease, mental illness) that encompassed individual subcategories. For

example, lung disease included chronic obstructive pulmonary disease, emphysema, and bronchiectasis. Because some causes of death occurred infrequently, we created 2 "other" categories. The other–life-threatening category, included conditions that are potential causes of death but occurred infrequently in our sample, such as myopathy and "other complications of vascular dialysis catheter." By contrast, the other–non-life-threatening category included common conditions associated with the dying process that are rarely considered causes of death (eg, fluid overload, pancytopenia) and conditions that are almost never considered causes of death (eg, cannabis use and mild cervical dysplasia). When a patient had multiple causes of death within the same overarching category (eg, chronic obstructive pulmonary disease, emphysema, and bronchiectasis within lung disease), the overarching category was counted only once.

For homicides, suicides, and accidental drug overdoses, we did not separately count the specific mechanisms of death (eg, "assault by handgun discharge," "acute fentanyl and cocaine intoxication"). Drug overdoses were considered accidental unless they were suicides. The category of substance use (nonprescribed, illicit) was defined as a problematic pattern of illicit substance use (opioids, cocaine, methamphetamines, and/or LSD) that affects health and well-being, similar to the clinical term "substance use disorder." Treatment nonadherence included nonadherence to prescribed medications and/or treatment recommendations (eg, regular clinic appointments and/or hospitalization). We included HIV stigma as a cause of death. HIV stigma is defined as negative attitudes, beliefs, and/or discrimination directed toward people with or associated with HIV/AIDS[18] and is consistent with the ICD-10 codes Z60.4 (social exclusion and rejection) and/or Z60.5 (target of perceived adverse discrimination and persecution). HIV stigma was considered a cause of death when it interfered with necessary medications and/or treatments or was a clear contributor to another cause of death (eg, medication nonadherence, depression).

We compared the frequency of each cause of death category determined by the clinic's interdisciplinary team with those on the death certificates. We used Stata 18.0 to calculate descriptive statistics.[19]

TABLE 1. Demographic and Death Characteristics of Women With HIV, 2004–2023 (N = 40)

	Mean (SD), Median, Range	n (%)
Age	55.5 (11.0), 58, 23–76	
Gender identity		
Cisgender		38 (95.0)
Transgender		2 (5.0)
Race/ethnicity		
African American/Black		19 (47.5)
Caucasian/White		13 (32.5)
Asian/Pacific Islander		3 (7.5)
Hispanic		3 (7.5)
Multiple races/ethnicities		1 (2.5)
Other		1 (2.5)
Education		
High school, GED, or less		21 (52.5)
Some college, associate degree, or professional training		13 (32.5)
Completed college, or more		5 (12.5)
Unknown		1 (2.5)
CD4 count*		
<200 cells/mm^3		9 (22.5)
200+ cells/mm^3		19 (47.5)
No data within 1 year of death		12 (30.0)
Viral load*,†		
Detectable virus (≥200 copies/mL)		11 (27.5)
Undetectable (<200 copies/mL)		23 (57.5)
No data within 1 yr of death		6 (15.0)
Year of death		
2004–2009		4 (10.0)
2010–2014		7 (17.5)
2015–2019		9 (22.5)
2020–2023		20 (50.0)
Location of death		
Residence, including under hospice		14 (35.0)
Hospital inpatient		14 (35.0)
Facility (hospice, nursing home, etc)		10 (25.0)
Community/street		2 (5.0)

*CD4 and viral load values preceding death, up until 1 yr prior.
†We use the threshold of 200 copies per milliliter as undetectable because this allowed for consistency over the 20-year study period.

RESULTS

The study included 40 cisgender and transgender women with HIV (Table 1). Most were women from racial and ethnic minority groups (68%) with a high school education or less (53%). Approximately one-third died in a residence, one-third in a hospital, one-quarter in another type of facility (eg, hospice, skilled nursing facility), and two were victims of homicide in the community. Among the 70% of women who had laboratory tests within a year of their death, 68% had a viral load less than 200 copies per milliliter, and 68% had a CD4 count >200 cells per cubic millimeter.

Substance use (nonprescribed, illicit) and mental illness were the most common causes of death identified by the clinic team, with each occurring in 58% of cases (Table 2). By contrast, death certificates only included substance use in 13% of cases and mental illness in 5% of cases (Fig. 1). The clinic team identified suicide as a cause of death in 13% of cases, whereas death certificates only included it in 3%. The clinic team identified 4 causes of death that were not included on any death certificate: treatment nonadherence (30%), HIV stigma (15%), substance use (cigarettes) (13%), and intimate partner violence (IPV; 13%).

By contrast, death certificates identified HIV/AIDS as the most common cause of death, including it in 68% of cases, whereas the clinic team determined it was a cause of death in only 15%. After HIV/AIDS, death certificates most commonly identified other–non–life-threatening conditions (38%) and cardiovascular disease (33%) as causes of death. Among major organ system causes, clinic and death

TABLE 2. Clinic-Determined Causes of Death Among Women With HIV (N = 40)*

Cause of Death	Number of Women	Percent of Women
Mental illness	23	57.5
Substance use (nonprescribed, illicit)	23	57.5
Treatment nonadherence	12	30.0
Renal disease	8	20.0
Cardiovascular disease	7	17.5
Non-AIDS cancers	7	17.5
HIV stigma	6	15.0
HIV/AIDS	6	15.0
Liver disease	6	15.0
Other: life threatening	6	15.0
Substance use (cigarettes)	5	12.5
Suicide	5	12.5
Intimate partner violence	5	12.5
Substance use (alcohol)	4	10.0
AIDS-related opportunistic infections	4	10.0
Lung disease	4	10.0
Infections	4	10.0
Accidental drug overdose	3	7.5
Hepatitis C	3	7.5
Endocrine/metabolic/nutritional	3	7.5
Homicide/murder	2	5.0
Stroke	2	5.0
AIDS-related cancers	1	2.5
Other: non–life threatening	1	2.5

*Some women had multiple causes of death, so the total number of women is not equal to 40.

certificate-determined causes of death were nearly congruent (differing by 5% or less), with the exception that death certificates identified cardiovascular disease almost twice as frequently (33% versus 18%).

DISCUSSION

To our knowledge, this is the first study that compares multiple causes of death listed on death certificates to those determined using structured input from interdisciplinary clinic team members who knew each patient well. We found substantial differences in causes of death when comparing these two methods in a cohort of women with HIV. Substance use (nonprescribed, illicit) and mental illness were the two most common clinic-determined causes, each contributing to 58% of the deaths. By comparison, just 13% of death certificates included substance use and only 5% included mental illness. As such, death certificates missed substance use 91% of the time and mental illness 78% of the time. Death certificates also underrepresented other mental/behavioral health and violence-related factors, including treatment nonadherence (10% versus 5%), suicide (13% versus 3%), HIV stigma (13% versus 0%), and IPV (13% versus 0%). Conversely, death certificates overrepresented HIV/AIDS as a cause of death compared with structured input from providers (68% versus 15%).

These discrepancies have serious real-world consequences. Governmental agencies use death certificates to compile vital statistics, which guide public health officials, policy makers, researchers, and clinicians in tracking the HIV epidemic, allocating resources, designing and evaluating interventions, and developing models of care. These data are also used by people with HIV and their allies to understand and respond to risks to the health and well-being of their communities and themselves. Inaccuracies or omissions in death certificates undermine the ability of public health professionals and medical providers to support women with HIV and reduce threats to their mortality. Underrepresentation of mental/behavioral health and violence as causes of death on death certificates detracts attention from these important areas. Conversely, overrepresentation of HIV as a cause of death likely contributes to a narrower emphasis on control of the virus as a focus of HIV research, public health, and care. Controlling the virus has been lifesaving for people with HIV and continues to be critical for prevention. However, at this juncture, maintaining this narrow focus does little to address the most common causes of death among women who already have HIV and are dying from causes unrelated to it.

The high rates of deaths related to mental/behavioral health and violence observed in this study can be explained, at least in part, by disproportionate rates of childhood and adult trauma experienced by women with HIV.[16,17] In a prior study conducted in the same clinic,[16] 58% of women with HIV reported experiencing four or more categories of adverse childhood experiences (ACEs), compared with 19% in the general population of women.[20] Women with HIV also experience twice the rate of IPV (55% versus 25%), 5 times the rate of lifetime sexual abuse (61% versus 12%), and more than 5 times the rate of posttraumatic stress disorder (30% versus 5%).[17] Trauma, especially during childhood or in the absence of strong protective factors (eg, safe stable nurturing relationships and environments), is strongly correlated with adult physical and behavioral illness and early death.[21–25] For example, populations experiencing four or more ACEs are more than 30 times more likely to attempt suicide,[21] 10 times more likely to use injection drugs, heroin, or cocaine,[21] 7 times more likely to be a victim of violence,[23] 5 times more likely to be depressed,[25] and over 3 times more likely to smoke,[25] compared with those with no ACEs. In this way, experiences of trauma among women with HIV are strongly associated with subsequent health outcomes. Providing care designed and resourced to help people heal from and prevent further trauma is critical to reducing deaths among women with HIV.

Overrepresentation of HIV on death certificates may be due to prior effective advocacy to overcome the stigma of acknowledging HIV as a prevalent condition and cause of death.[26] It may also reflect a lack of awareness among physicians of the progress that has allowed most women with HIV to take antiretrovirals, have an undetectable virus, and be noncontagious to sexual partners.[27–29] Inflammation from uncontrolled HIV and/or toxicity from antiretroviral

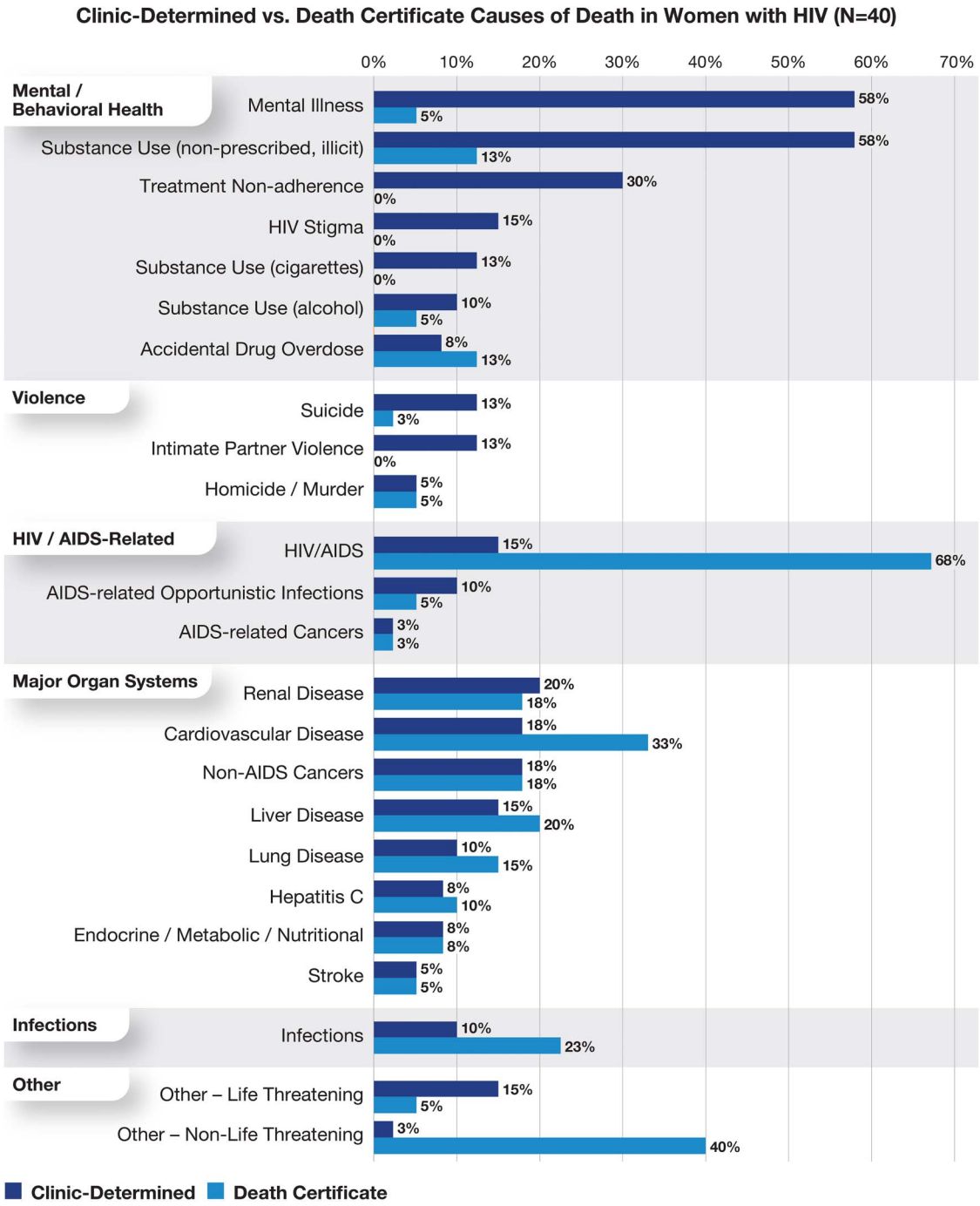

Figure 1. Clinic-determined versus death certificate causes of death in women with HIV (N = 40).

medications can contribute to cardiovascular disease, renal disease, and other causes of early death among people with HIV.[30] However, antiretroviral medications have become less toxic over the past decade,[31,32] and the rate of complete viral suppression is now estimated to be 89% among women receiving federally funded HIV Ryan White primary care.[33] As such, the persistence of high rates of premature death and lower life expectancy among women with HIV are more likely due to experiences of childhood and adult trauma than inflammation from HIV or toxicity from antiretroviral medications.

The overrepresentation on death certificates of cardiovascular disease and other–non-life-threating conditions (eg, hyponatremia, pancytopenia) has been reported previously and is likely due to hospital-based physicians completing death certificates in the setting of end-stage illness and such conditions being common mechanisms of the death process while not necessarily being the underlying or contributing cause.[13,14]

TABLE 3. Policy Recommendations

Overarching Goal: Move Beyond a Narrow Focus on Viral Suppression to Address the Principal Drivers of Premature Death Among Women with HIV			
Level	**Objective**	**Actions**	**Responsible Actors**
Providers, clinics, and community health systems	Implement and expand interdisciplinary team-based primary care for people with HIV	Integrate behavioral health services into primary care, including mental health care, substance use services, and violence prevention	Clinic champions (clinicians and staff);,clinic directors, executive leadership, advocates, foundations
		Transform care delivery to be trauma informed for both patients and staff[35]	
		Incorporate clinic-based programs that reduce isolation and stigma and create community among patients (eg, expressive therapy through theater, patient leadership councils)	
		Institute complex care management for patients at high risk of death[39]	
		Convene interdisciplinary team conferences for patients at high risk of death to ensure that everything is considered and tried before someone dies	
		Convene interdisciplinary team conferences after any patient dies to clarify clinic-determined causes of death to guide clinic resources	
	Strengthen and fund community services that address drivers of premature death	Expand access to trauma-informed inpatient and outpatient substance use services, including intensive outpatient programs, residential rehabilitation facilities, and medication assisted treatment	Local Ryan White care Councils; local, state, and federal government; advocates; foundations
		Expand visiting nurse programs to provide medical and mental health assessments and treatment in patients' homes	
		Preserve and expand options for supportive housing including traditional board and care	
Research and policy	Determine accurate causes of death for people with HIV	Replicate current study with other populations of people with HIV (eg, men, primarily transgender women)	Researchers; NIH
		Consider methods to integrate clinic-determined causes of death into vital statistics to supplement death certificate data	National Center for health statistics, CDC; local and state health departments
	Add "survival" as the last step of the HIV care Continuum[38]	Determine the most appropriate methodology for measuring and tracking "survival" on the HIV care Continuum	CDC; HRSA HAB; advocates
		Track and update "survival" step annually	
	Determine and monitor all-cause survival among people with HIV	Benchmark survival statistics against general-population expectations rather than (or in addition to) race- or risk-matched comparators to clarify excess all-cause mortality for people with HIV	Epidemiologists; CDC
		Track and report survival statistics annually for people with HIV, benchmarked against general-population expectations rather than (or in addition to) race- or risk-matched comparators	Local and state health departments; CDC
	Reauthorize the Ryan White HIV/AIDS Program	Ensure the continuation of evidence-based interdisciplinary primary care including integrated mental health and substance use services by formally reauthorizing Ryan White HIV/AIDS Program with statutory inflation-adjusted funding baseline	Congress; advocates

CDC, Centers for Disease Control and Prevention; HRSA HAB, Health Resources and Services Administration HIV/AIDS Bureau; NIH, National Institutes of Health.

This study's methodology—comparing death certificates to structured input from an interdisciplinary team of providers who knew each patient well—adds to the literature in several important ways. Our study revealed substantially higher rates of mental illness being missed as a cause of death on death certificates than a prior study comparing death certificates with expert review of medical records in a cohort of US men and women with HIV.[2] Chart review may not be as sensitive for stigmatized psychosocial conditions due to limitations in provider charting compared with the shared knowledge of an interdisciplinary team. Our study also identified several relatively prevalent causes of death of women with HIV not mentioned on a single death certificate: HIV stigma, treatment nonadherence, and IPV. The absence of such information in vital statistics renders these conditions invisible as causes of excess mortality for women with HIV. Finally, anecdotally, the study's innovative methodology of convening an interdisciplinary team of providers to determine

causes of death of their longtime patients was universally described by participants as positive, cathartic, and community building. Such experiences are potential antidotes to provider burnout endemic to the field of primary care.

LIMITATIONS

This study has several limitations. First, there is no gold standard for determining the multiple causes of how people die. Although our results suggest that the methodology used in this study may offer more accurate causes of death than others previously reported,[2,11–14] the lack of a gold standard prevents definitive determination of the relative accuracy of different methods of determining causes of death. Nonetheless, our results align with these prior studies using different methodologies. In addition, including input from interdisciplinary teams addresses concerns expressed in prior studies that clinicians completing death certificates have insufficient knowledge about patients' medical and psychosocial histories. Second, the cross-sectional design over a long study period introduces the potential for recall bias. Case reviews of deaths that occurred many years before interdisciplinary conferences relied on older EHR information and more distant recollection as compared with case reviews of more recent deaths. Third, the study focused exclusively on women with HIV. Its findings are thus not generalizable to men with HIV. Given the low percentage of transgender women in the sample, the results are similarly not generalizable to this population. Fourth, clinic team participants may have been influenced by having seen the autopsy reports for the 5 patients whose deaths were evaluated by the coroner. This may have resulted in increased awareness about substance use from the toxicology analysis and other observations or conclusions in autopsy reports. Nonetheless, in these cases, the patients' substance use and other conditions described in the autopsy reports were well known and reported by multiple participants. Finally, the study was conducted in a single HIV primary care clinic. The causes of death identified there may not be representative of the types and frequencies of deaths among the general population of US women with HIV. Nonetheless, the clinic is part of a national network of federal Ryan White HIV/AIDS Program-funded clinics that provide interdisciplinary primary care for low-income individuals with HIV. Approximately 50% of US individuals with HIV receive care in such clinics.[33] Different frequencies of causes of death compared with the national population, if present, would likely not impact the study's principal finding of omissions on death certificates of mental/behavioral health problems and violence. Nonetheless, this limitation justifies and informs similar studies in other clinics and regions of the country.

In conclusion, the results of this study argue for several practice and policy changes to address the disparity in life expectancy between women with and without HIV and move beyond a narrow focus on viral suppression to one that includes a robust effort to address mental/behavioral health and violence (Table 3). Given that these conditions are driven, in large part, by experiences of childhood and adult trauma, we are afforded pathways for how to do so. Guidance exists for how to deliver care that is trauma informed[34,35] and that acts as a protective factor[36] to buffer the impact of trauma on later health and well-being. Evidence also supports robust integration of effective alcohol and substance use treatment into primary care to prolong life expectancy for people with HIV.[37] Policies that affect funding for research and health care delivery for women with HIV should prioritize integration and evaluation of such models of care. Finally, given the persistent and significant disparities in life expectancy experienced by individuals with HIV, the HIV Care Continuum[38] should be extended beyond viral suppression to include "survival." As a first step, an expert consensus panel should be convened to determine the most appropriate methodology for measuring and tracking "survival" on the HIV Care Continuum.

Most prior studies identifying inaccuracies in death certificates have called for improved education of providers. Although training is important, the long-standing, seemingly intractable flaws of death certificates and results of this study suggest that information from death certificates should be supplemented with input from interdisciplinary teams of providers with in-depth clinical and behavioral knowledge of each patient to inform more accurate vital statistics.

ACKNOWLEDGMENTS

The authors acknowledge Judith Auerbach, PhD, Trina Johnson, PhD, Jessica Haberer, MD, and Manya Magnus, MPH, PhD, for their generous and thoughtful input.

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