

## Finding the Invisible Patient to Address Substance Use, Violence, and Depression in Women Living with HIV

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### ABSTRACT

In the United States, women account for one-fourth of people living with HIV. Most women living with HIV are Black or Hispanic and acquired HIV from heterosexual contact. Many face significant barriers to appropriate medical care, with lower retention in care and viral suppression than men who acquire HIV from male-to-male sexual contact. Many factors contribute to these disparities, including high rates of alcohol abuse, substance use, intimate partner violence, depression, and socioeconomic marginalisation. HIV, substance use, and violence each contribute independently to the collective health burden on women. The co-occurrence of these factors, termed the SAVA (substance abuse, violence, and HIV/AIDS) *syndemic*, is particularly hard to address, as the conditions act synergistically to negatively influence health outcomes. In addition, mental health conditions frequently coexist and further contribute to adverse outcomes. Unfortunately, clinician knowledge of this syndemic is low, and patients living with HIV and other elements of SAVA, including depression, are not recognised and referred for appropriate services. In this paper we describe our pilot educational and quality improvement program and the subsequent educational program we developed to increase knowledge of SAVA with the goal of improving health outcomes for women living with HIV.

### ARTICLE HISTORY

Received 4 May 2024  
Revised 13 August 2024  
Accepted 16 August 2024

### KEYWORDS

HIV; SAVA; women; substance use; mental health; IPV; depression

### Background

In the United States, people assigned female gender at birth (hereafter referred to as *women*) account for approximately 23% of people living with HIV (PLWH) and 18% of new HIV diagnoses [1]. Most women living with HIV (WLWH) are Black (58%) or Hispanic (19%) and acquired HIV from heterosexual contact (81% and 76%, respectively) [1]. Many women with HIV face significant barriers to appropriate medical care. Only 53.8% are retained in care, and only 64.4% achieve viral suppression [2]. For comparison, 68.6% of men who acquire HIV from male-to-male sexual contact achieve viral suppression [2]. The reasons for lower viral suppression are multifactorial but include substance use, intimate partner violence (IPV), depression, and socioeconomic marginalisation.

Both substance use and IPV are independent risk factors for acquiring HIV [3,4]. Substance use is a major risk factor for HIV acquisition, with injection drug use accounting for 16% of transmission in women [1]. In addition, injection drug use, noninjection drug use, and alcohol abuse increase HIV exposure risk

through impaired judgement and disinhibition. A 2015 literature review found “robust evidence” that gender-based violence significantly increases risk of HIV among women who use drugs [5]. Physical IPV increases risk of HIV by 28% to 44% [4].

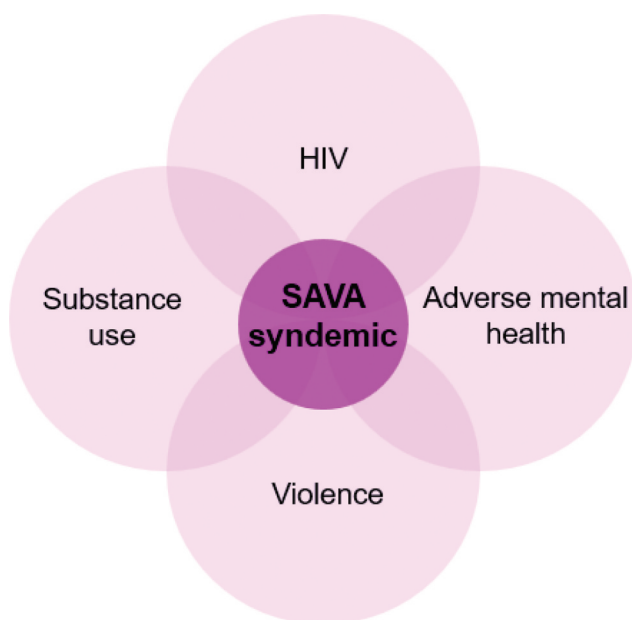
Depression, while not formally an element of the substance abuse, violence, and HIV/AIDS (SAVA) syndemic, is independently associated with increased risk of HIV in women with alcohol misuse. Depression is the most common psychiatric comorbidity among PLWH, affecting 30% to 40%, which is three times higher than in the general population [6]. Women with HIV are twice as likely as men with HIV to have depression [7]. For the purpose of this article, adverse mental health conditions, including depression, will be considered part of the SAVA syndemic (Figure 1).

Intimate partner and other forms of violence have also been found to be a consequence of HIV [8–10]. Nearly one-fourth of women (24%) experience abuse by their partners after disclosing their HIV status [10]. WLWH experience more frequent and more severe IPV than women without HIV [11]. Data show that

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**Figure 1.** SAVA (substance abuse, violence, and HIV/AIDS) syndemic. This figure depicts the elements of SAVA.

55.3% of WLWH experience IPV, which is more than twice the national rate [10,12].

Substance use is also common among PLWH. About 40% to 50% of PLWH in the United States have a history of alcohol abuse or dependence [13].

HIV, substance use, and violence each contribute independently to the collective health burden on women. The co-occurrence of these factors, termed the SAVA (substance abuse, violence, and HIV/AIDS) syndemic, is particularly hard to address as the conditions act synergistically to negatively affect health outcomes (Figure 1). In addition, mental health conditions frequently coexist and further contribute to adverse outcomes [14,15]. A syndemic is more than simply the interaction of diseases. A syndemic is the mutually reinforcing interaction of disease and social conditions [16].

Substance use and violence increase HIV-associated risk behaviours [4,17–20] and decrease adherence to antiretroviral therapy [21–23]. A recent cross-sectional analysis of the National Health and Nutrition Examination Survey data from 1999–2018 found that depression was associated with HIV infection – vulnerable populations among adults in the United States [24]. Depression is also associated with an increase in missed health care office visits and reduced viral suppression [25,26].

In general, WLWH face more risk factors that interfere with treatment than men living with HIV, such as higher stigma and rates of poverty, lack of support and empowerment, lack of women-specific

HIV care, and the additional challenges many women face as mothers and caregivers [27]. In one study, even after controlling for drug use, only 57% of WLWH adhered to treatment compared with 77% of men [28]. For women affected by SAVA, this deficit is compounded by alcohol and drug use [29,30], trauma, abuse and violence, and depression [29,31,32]. Of all the barriers to care that women with HIV encounter, SAVA may be the most difficult to overcome. One research group created a “SAVA score” by summing psychosocial measures; not surprisingly, as the number of psychosocial problems increased, the success of viral suppression therapy decreased [33].

Clinical management of HIV in women requires awareness among clinicians and a multidisciplinary approach to treatment [34]. However, awareness of SAVA is lacking.

### SAVA Pilot Program

We partnered with the Johns Hopkins HIV Women’s Health Program to develop our pilot quality improvement and education program (*Optimizing Disease Management [ODM]: Finding the Invisible Patient*). The primary goal was to improve medical and social outcomes for WLWH by (1) educating health care providers about the existence and effects of SAVA so they could identify people who suffer from the syndemic and (2) developing a referral program so that people who need further treatment are linked to appropriate care.

Thus, the program had three components: (1) education for clinicians at Johns Hopkins HIV clinics, (2) development of a screening protocol, and (3) creation of a referral network so that patients could be linked with an appropriate intervention when needed.

During development of the grant for this program, we surveyed 53 clinicians at Johns Hopkins clinics and elsewhere. More than one-half of the survey respondents (58%) were not familiar with SAVA [35]. Most clinicians were not very confident in their ability to identify patients at risk for the individual SAVA components (Table 1).

### Clinician Education

Education was delivered to clinicians at Johns Hopkins clinics treating patients with HIV, including clinicians at the John G. Bartlett Specialty Practice, over two 30-minute live presentations held one week apart. After the live presentations, a webcast of the live presentations was made available as an enduring program.

**Table 1.** Survey of clinicians ( $n = 53$ ).

How confident are you in your ability to identify patients at risk for ...	Not at all confident	Somewhat confident	Very confident
Substance use	11.3%	60.4%	28.3%
IPV	25.0%	59.6%	15.4%

**Note:** SAVA, substance abuse, violence, HIV/AIDS.

The learning objectives of the program included how to (1) recognise the impact that substance use, violence, and depression have on patient adherence and quality of life in the setting of HIV; (2) review screening for IPV, substance use, and depression in the clinical setting; and (3) discuss appropriate referrals for care (social service, psychiatric, and substance use specialists) when screening is positive. Clinicians were educated about the importance of screening, specific screening tools and their use, and how to overcome barriers to screening.

Overall, 125 learners participated in the live ( $n = 60$ ) and enduring ( $n = 65$ ) activities (46% medical doctor, 16% advanced practice provider [eg, nurse practitioner and physician assistant], 15% registered nurse). Knowledge and confidence across the three learning objectives increased by 61% and 62% for learners in the live and enduring activities, respectively [36].

### Screening Protocol

The protocol for this program called for WLWH who sought care at the Johns Hopkins HIV Women's Health Program in the John G. Bartlett Specialty Practice to be screened by HIV counsellors for IPV, substance use, and depression using the Abuse Assessment Screen; Screening, Brief Intervention and Referral to Treatment approach; and the Patient Health Questionnaires 2 and 9, respectively, at every clinic visit. Screening instruments were embedded in the electronic health record to facilitate use.

Over the course of 12 months, 116 WLWH receiving care at the Johns Hopkins HIV Women's Health Program and the John G. Bartlett Specialty Practice were screened. Of the 116 women, 70 (60.3%) screened positive for at least one element of SAVA [37]. Table 2 indicates screening results.

Possible associations were determined using chi-square testing. Women who screened positive on any

screening test had a significantly higher “no show” rate than women who screened negative on all tests (31.3% vs 20%;  $p < 0.05$ ). Women screening negative on all screening tests were significantly more likely than those who screened positive for IPV to have CD4 < 200 cells (13.3% vs 0%;  $p = 0.028$ ), demonstrating a weakened immune system [37].

### Referral Network

Women screening positive were further evaluated and, if appropriate, offered a brief intervention or referral to social services, psychiatric services, or other resources.

Follow-up after the intervention was significantly impacted by the COVID-19 pandemic and the interruption of in-person visits. However, chart review at six months after the intervention showed that 56% of patients who screened positive for SAVA and were not previously involved in any form of therapy were engaged in care: 50% entered psychological therapy, 28% entered treatment for substance use disorder, and 39% received a prescription for a mental health condition [37].

### Subsequent Activity

#### Clinician Education

The preliminary findings from *ODM: Finding the Invisible Patient*, and particularly the observation that 60.3% of women screened were positive for at least one SAVA element, led us to develop an extension of this educational program that would be targeted to community-based clinicians treating women with HIV in underserved areas, with a particular focus on women who are Black, indigenous, and other people of colour, using the Project ECHO model.

*ECHO HIV: Finding the Invisible Patient* (ECHO HIV) was based on the design of Project ECHO (Extension for Community Healthcare Outcomes), which began two decades ago to help primary care clinicians practicing in rural areas deliver state-of-the-art hepatitis C care by linking these clinicians to specialists via videoconferencing [38]. Over the past 20 years, the ECHO model has been used repeatedly in many disease states and in numerous countries.

The ECHO model typically involves a short series of meetings (or modules) via online videoconference that

**Table 2.** Screening results for women living with HIV ( $n = 116$ ).

SAVA element	Positive screen
IPV	33.6%
Depression	16.7%
Alcohol abuse	29.3%
Drug use	29.3%

**Note:** SAVA, substance abuse, violence, HIV/AIDS.

begin with a brief (20 minute) lecture and are followed by a question-and-answer session and group discussion, where the participants can bring challenging cases to seek the expert faculty guidance.

To facilitate interaction among participants and expert faculty, groups are generally kept small. For ECHO HIV, we limited each group to 20 participants. We planned on 10 groups, for a total of 200 participants, each meeting five times (approximately every other week) for a total of five hours. We specifically proposed an ECHO model for this activity because the time spent in instruction and conversation with peer participants and expert faculty allows for deeper engagement.

Expert faculty for this program included the director of the Johns Hopkins HIV Women's Health Program/Gynecology and Obstetrics, a nurse manager from the Johns Hopkins HIV Women's Health Program, and a social worker. The faculty developed the educational modules and hosted the live meetings.

In total, 208 learners participated in our ECHO HIV program [39]. Of these 208 learners, 22% were physicians, 23% were nurses, and 17% were nurse practitioners or physician assistants. About one-half (52%) were primary care providers, 13% specialised in infectious disease, and 4% each worked in substance use and psychiatry.

The learning objectives of the program included how to (1) evaluate the prevalence of SAVA in underserved women and describe how SAVA negatively impacts antiretroviral adherence, (2) develop a screening plan for the contributing factors of SAVA and outline a referral plan for patients screening positive, and (3) analyse specific risks of SAVA for pregnant women, American Indian/Alaska native women, and immigrant women.

Pre-activity and post-activity assessments showed that improvements in knowledge and confidence were achieved by learners for all learning objectives (Table 3) [39]. Competence improved for learning objectives 2 and 3; change in competence was not assessed for the third learning objective.

Knowledge was assessed by asking specific questions that addressed the identified learning objectives. For example, we asked, "Approximately what percentage of

women living with HIV have experienced intimate partner violence?" To measure knowledge of the prevalence of SAVA, we asked, "Injection drug use accounts for the highest proportion of HIV transmission among women from which racial/ethnic group?" To assess knowledge of screening tools, we also asked, "Which of the following screening tools for intimate partner violence has been validated in pregnant women?"

Confidence was assessed by asking participants to rate their level of confidence in several areas. For example, to assess confidence in use of screening tools, we asked, "How confident are you in assessing your patients with HIV for SAVA and depression?"

Almost one-half of the participants (41%) indicated that they planned to implement changes to their practice, and 49% indicated that their current practice was reinforced as a result of participating in the education. Feedback from learners was positive, including the following statements:

- "These 5 weeks have been great learning sessions . . . Thank you".
- "I can use this course to start up an HIV care community pharmacy and put in all I have learned to achieve better clinical outcomes for people living with HIV here in Lagos, Nigeria".
- "Your program was great and very informative. I am looking forward to additional sessions". [39]

## Discussion

The high prevalence of SAVA seen in the cohort of women screened as part of *ODM: Finding the Invisible Patient* (60.3%) [36] and in other published cohorts, coupled with low awareness of SAVA among clinicians who encounter PLWH [35], underscores the pressing need for greater attention to this syndemic. Use of validated screening tools increases detection of SAVA, which is the first step towards remediation of co-occurring conditions that further risk the health and well-being of a large population of people who are already vulnerable to stigma, morbidity, and mortality because they are living with HIV.

**Table 3.** Outcomes for clinician education. NA, not assessed; SAVA, substance abuse, violence, HIV/AIDS.

Learning objective	Knowledge			Confidence			Competence		
	Pre	Post	Gain	Pre	Post	Gain	Pre	Post	Gain
1. Prevalence and effect of SAVA	32%	44%	37%	41%	82%	100%	NA	NA	NA
2. Screening tools/referral plan	34%	55%	61%	43%	87%	102%	48%	76%	57%
3. Specific risks for special populations	29%	53%	81%	41%	88%	115%	27%	65%	141%
Overall	33%	51%	53%	42%	86%	105%	43%	74%	73%

## Conclusion

Both programs were successful in increasing clinician knowledge, confidence, and competence around SAVA, including identifying and using screening tools to identify women who may be affected by SAVA. However, until the HIV epidemic is over, women will continue to be impacted by SAVA, and continued education will be required to help clinicians identify women and others who require additional support and services.

## Abbreviations

ECHO	Extension for Community Healthcare Outcomes
IPV	intimate partner violence
ODM	Optimizing Disease Management
PLWH	people living with HIV
SAVA	substance abuse, violence, HIV/AIDS
WLWH	women living with HIV.

## Disclosure Statement

No potential conflict of interest was reported by the authors.

## Funding

Gilead Sciences, Inc., provided independent medical grants to fund the programs

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