

# Treatment ISSUES

## Untangling the Intersection of HIV & Trauma: Why It Matters and What We Can Do

by Naina Khanna and Suraj Madoori

Despite the widespread availability of anti-retroviral therapy (ART) in the U.S., more than half of people living with HIV (PLHIV) in the U.S. are not engaged in regular medical care. Strikingly, only about one-fifth of the U.S. HIV-positive population has a suppressed viral load. Barriers to retention in care and anti-retroviral adherence range from financial and logistical, to actual and perceived discrimination in health care settings. However, these public health challenges reflect deeper-level determinants that drastically undercut HIV prevention efforts and the health care of PLHIV. Most notably, individual and community-level experiences with trauma negatively impact the health outcomes of PLHIV.

This article investigates ways in which unaddressed trauma in the lives of PLHIV negatively impacts access to and engagement in care, further complicating health outcomes as a consequence. In doing so, this article analyzes the existing evidence base for intervention, and posits recommendations for further research and action. In particular, we urge expansion of trauma-informed care practices (TIC) as a high-impact structural intervention to facilitate healing from trauma, improve individual health outcomes, and achieve progress towards public health goals, including those of the National HIV/AIDS Strategy.

### Trauma & HIV: What's the Connection?

The term "trauma" denotes negative events and circumstances that produce psychological distress and may have adverse effects on the well-being of an individual. Trauma has always been an experience shared by many PLHIV prior to diagnosis. And as the U.S. HIV epidemic has increasingly become a public health crisis disproportionately impacting communities who also face the detrimental effects of systemic racism, homophobia, transphobia, classism, and patriarchy, U.S. PLHIV have become increasingly impacted and burdened by lifetime individual and community-level trauma.

It is well documented that traumatic experiences, including histories of childhood sexual and physical abuse, are far more prevalent among PLHIV than in the general U.S. population. And trauma is all-too-frequently perpetuated by the health care and service delivery system itself, especially for communities of color, sexual minorities and others who suffer from the intentional and

unintentional effects of discrimination, prejudice and bias in the very settings entrusted to assure their well-being.

Recent data demonstrates that trauma experienced in adulthood and post-HIV-diagnosis is also significantly higher among PLHIV than among the general population. In part, this may stem from pervasive racism, homophobia, transphobia, classism, patriarchy, and policies that criminalize sex work and drug use, which in and of themselves perpetrate trauma and trauma-related stress, independently of interpersonal violence.<sup>1</sup> One study undertaken by the Center for AIDS Prevention Studies at UCSF, in collaboration with the Global Forum on MSM and HIV, demonstrated that past-year experiences of racism and homophobia were associated with depression and anxiety among U.S. racial/ethnic minority men who have sex with men (MSM).<sup>2</sup>

Numerous studies have demonstrated the adverse impact of trauma upon the health outcomes of PLHIV. The Coping with HIV/AIDS in the Southeast (CHASE) Study found that among 490 HIV-positive women and men from five rural Southern states, patients with more categories of lifetime trauma had almost twice the all-cause death rate as those below the median levels of trauma.<sup>3,4</sup> Furthermore, the CHASE Study showed that trauma was also associated with faster development of an opportunistic infection or AIDS-related death.<sup>3,4</sup>

In another study of 765 women living with HIV, women with chronic depressive symptoms were about twice as likely to progress to AIDS as those who had never experienced depression.<sup>5,6</sup> Chronic depression, which is associated with trauma, has been demonstrated to be associated with clinical and immunological progression of HIV/AIDS.<sup>3,6</sup> One study of 85 HIV-positive gay men illustrated that those whose close friend or partner died of AIDS had more rapid decline in CD4 count during a three to four year follow-up period.<sup>3,7</sup>

Another study by Leserman et al., revealed that HIV-positive individuals with less income, elevated childhood trauma, more recent stressful events, and increased depressive symptoms were more likely to rate high on intensity of fatigue and impairment in daily functioning. Leserman's study further demonstrated that recent stressors were a more powerful predictor of fatigue than childhood trauma.<sup>8</sup>

This finding was powerfully reflected in a recent study of HIV-positive women in clinical care published by Dr. Edward Machtinger of the University of California – San Francisco (UCSF). Machtinger’s study revealed evidence that recent trauma, defined as being abused, threatened, the victim of violence, or coerced to have sex in the last 30 days, was the single statistically significant predictor of anti-retroviral (ART) failure.<sup>9</sup> Participants reporting recent trauma in the UCSF study had greater than four times the odds of ART failure as those not reporting recent trauma (9). Findings of this study had further implications for HIV prevention efforts, in that participants with recent trauma were also four times less likely to report regular condom usage with sexual partners of HIV-negative or unknown status.<sup>9</sup>

In a study of 152 HIV-positive Black MSM, experiences of racial discrimination were significantly associated with lower adherence to anti-retroviral therapy<sup>10</sup>. Another study reported that among 57 black PLHIV, racial discrimination predicted significantly lower adherence, even more than sexual orientation and HIV-related discrimination.<sup>11</sup> These studies suggest that trauma related to racism alone can severely impact health outcomes for HIV-positive people of color, who are already burdened by increasing health disparities.

Many PLHIV also exhibit symptoms of Post-Traumatic Stress Disorder (PTSD).<sup>5</sup> Yet PTSD among PLHIV goes largely unaddressed and untreated, even for those in regular clinical care. This may complicate engagement in care and treatment adherence, and certainly has negative implications for overall quality of life. A recent meta-analysis estimated a 30% rate of PTSD among HIV-positive women in the U. S., which is more than five times higher the rate of PTSD reported in a nationally representative sample of women.<sup>12</sup>

A 2002 study which examined psychiatric treatment for PTSD among HIV-positive women in an outpatient setting found that 42% of women in the study met the criteria for full PTSD, and an additional 22% met criteria for partial PTSD<sup>13</sup>. However, of the women likely with full PTSD, nearly 60% were not receiving any psychiatric treatment, and of those likely with partial PTSD, 78% were not receiving any psychiatric treatment.<sup>13</sup>

These myriad correlations between childhood trauma, the compounded effects of lifetime trauma, and the overwhelming prevalence of ongoing trauma in the lives and communities of PLHIV should mandate a focused response to mitigate trauma at the individual and community-level. Yet, despite the overwhelming evidence that trauma has a significant detrimental effect on the well-being of people living with HIV, care and service providers are largely serving traumatized HIV-positive populations without addressing the impact of traumatic stress in the lives of their clients.

Rather, at times, health care itself can be a source of trauma or retraumatization for historically discriminated

and trauma-impacted communities. For example, the National Transgender Discrimination Survey revealed that 19% of their sample reports having been refused medical care due to their transgender or gender non-conforming status.<sup>14</sup> Approximately 28% of the sample reported postponing or delaying care due to past experiences with discrimination in a health care setting.<sup>14</sup>

A study examining perceptions of race-based and socioeconomic status- (SES) based discrimination among 110 HIV-positive individuals found that 71% percent reported having experienced discrimination in HIV care settings attributed to race, and 66% reported discrimination based on their SES.<sup>15</sup> Even more troubling, greater race-based and SES-based discrimination were associated with higher rates of depression and post-traumatic stress, more severe AIDS-related symptoms, and lower levels of satisfaction with healthcare.<sup>15</sup>

Pervasive encounters of trauma challenge the health care system to consider methods and practices that address the source of trauma in the lives of PLHIV. The use and implementation of trauma-informed care practices across sites where PLHIV access care can be an effective and powerful strategy to begin to address the widespread impact of individual and community-level trauma.

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### **Understanding Trauma-Informed Care**

Trauma-informed care is an emerging concept in the treatment field, best described as an overarching framework that

“emphasizes the impact of trauma and that guides the general organization and behavior of an entire system.”<sup>16</sup> Maxine Harris describes a trauma-informed service system as: “a human services or health care system whose primary mission is altered by virtue of knowledge about trauma and the impact it has on the lives of consumers receiving services.”<sup>17</sup>

Based on an extensive literature review of trauma-informed care, primarily in mental health, substance use and homelessness fields, Hopper et al. developed this consensus-based definition of trauma-informed care: “Trauma-Informed Care is a strengths-based framework that is grounded in an understanding of and responsiveness to the impact of trauma, that emphasizes physical, psychological and emotional safety for both providers and survivors, and that creates opportunities for survivors to rebuild a sense of control and empowerment.”<sup>16</sup>

Thus, “trauma-informed care” describes a care system that philosophically recognizes the pervasiveness of trauma and demonstrates a commitment to identify and address it early, to the extent possible, throughout the system. Further, a trauma-informed care approach seeks to understand the connection between presenting symptoms and the individual’s past history.

Hence, trauma-informed care involves accurate identification of trauma and related symptoms as part of a

path toward healing, as well as a commitment to minimizing retraumatization, in particular by employing a “do no harm” approach that is sensitive to ways in which institutions may inadvertently re-enact traumatic dynamics. This requires building cultural competence among staff and institutional capacity to respond to trauma as key components of a successful system.

Trauma-informed care is not limited to the delivery of Trauma-specific services—interventions designed to directly address the impact of trauma, with the goals of decreasing symptoms and facilitating healing—although it may support, facilitate or refer to delivery of those services.<sup>16</sup> Rather, trauma-informed care requires creating an environment which can sustain delivery of such services and further supports positive outcomes for clients receiving those services. Importantly, trauma-informed care operates on an empowerment model, emphasizing strengths and resiliency of clients, and seek to minimize the power imbalance between the individual seeking services and the provider.

Considering the historical and collective trauma inflicted on communities of color, LGBT communities, and other communities vulnerable to acquiring HIV, minimizing the power imbalance and promoting a trauma-informed response require high levels of cultural competency, which should prioritize employment of peers and leadership by people from disproportionately impacted communities in service delivery.

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### **Promising Elements for HIV Care**

The majority of models addressing trauma-informed service delivery have been designed and evaluated for users of mental health and substance use services, or for use in correctional or domestic violence shelter settings. A 2008 paper by the National Center for Trauma-Informed Care at the Center for Health Services asserts that integrating a trauma-informed response into mental health systems is likely to be cost-effective for the service delivery system, and that many of the existing trauma-based integrated treatment approaches are effective and can be replicated within public service sector settings.<sup>18</sup>

Because of the population overlap between PLHIV and populations in which trauma-informed service delivery has been evaluated, and because of HIV’s strongly collaborative service delivery networks in the U.S., it is logical that elements of evaluated trauma-informed service delivery may be applicable to HIV outpatient care and service delivery settings.

Resources that may be worth exploring include the Sanctuary Model, a framework for intervening with trauma survivors and for facilitating organizational change originally developed for traumatized adults in inpatient settings and adapted for use in domestic violence settings. Organizations and agencies that seek to become more trauma-informed can look to resources including Creating

Trauma-Informed Systems of Care: Facilitating Recovery in Mental Health Services Settings and Developing Trauma-Informed Organizations: A Tool Kit, both designed for use by mental health provider agencies.

The integration of peers (defined, in this case, as trauma survivors and those in trauma recovery) throughout program design and implementation, has been widely acknowledged as key to the success of trauma-informed service delivery. The Substance Abuse and Mental Health Services Administration’s (SAMHSA) Women, Co-Occurring Disorders and Violence Study (WCODVS) set out to explore the development of comprehensive, integrated service approaches and the effectiveness of those approaches for women whom they deemed “high-end” users of publicly funded services.<sup>19</sup>

This nine-site study found that it was critical and necessary that programs actively integrated consumer/survivor/recovering (C/S/R) women as program staff, on project committees, and/or to provide trainings and support for other C/S/R women.<sup>19</sup> Other key lessons from the WCODVS were that becoming trauma-informed is a continuous process, not a one-time event, and that one or two people within a system (a strategically placed “trauma champion” or a “trauma liaison”) can help to drive change towards trauma-informed service delivery.<sup>19</sup>

More recently, the Center for Mental Health Services’ National Center for Trauma-Informed Care released a 96-page technical assistance guidebook, *Engaging Women in*

Trauma-Informed Peer Support, designed to help organizations strengthen peer-based services.

### **Future Directions for Research and Advocacy**

Trauma-informed practices represent an essential component for the overall health and well-being of impacted individuals and communities, and help create a better-equipped health care system that can more holistically meet the care needs of PLHIV. Trauma-informed practices as a high-impact strategy can help fulfill specific National HIV/AIDS Strategy (NHAS) goals to increase access to health care and improve health outcomes for PLHIV, particularly among groups that are dually and disproportionately impacted by the epidemic and trauma.

Among heavily traumatized populations (including women survivors of violence, LGBTQ communities, and most acutely, the transgender community), trauma-informed care practices may allow health providers to fully support healthy expressions of gender, sexual orientation, and self-efficacy.<sup>20</sup> This allows individuals to live as fully vested members of society, rather than reinforce the marginalization that many in the LGBTQ community experience throughout their lifespan.<sup>20</sup>

However, additional research is needed to investigate the potential role of trauma-informed care services for people living with HIV and to develop models for the spe-

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cific trauma recovery needs of LGBT populations. Such models could be adapted and evaluated in HIV care settings. In particular, Ryan White funded clinics may provide a favorable milieu for testing and evaluating such models.

Furthermore, the deeply-rooted trauma of systemic racism, homophobia, transphobia, classism, and patriarchy requires advocacy efforts to address this structural violence that continues to perpetrate trauma upon PLHIV and hamper prevention efforts among vulnerable communities. Part of the strategy might be to align with advocacy networks focused on underlying issues of trauma, such as the Positive Women's Network of the United States (PWN-USA) and the HIV Prevention Justice Alliance (HIV PJA). The work of advocacy organizations such as these, have historically pointed public health authorities towards addressing issues of structural violence and seek to empower the voice of communities impacted by and vulnerable to disproportionate trauma.

The price of unaddressed trauma is apparent: trauma leads to worse health outcomes and a lower quality of life for PLHIV. Unaddressed trauma complicates public health efforts to stem the HIV epidemic, creates inefficient delivery of services and places additional strain upon scarce public health resources. A system ill-equipped to heal trauma among highly-impacted communities may lose its ability to engage clients in care and thus to perform its very function. For PLHIV accessing services, multidisciplinary care settings including existing Ryan White care models may provide an ideal environment to integrate trauma-informed services for vulnerable populations.

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