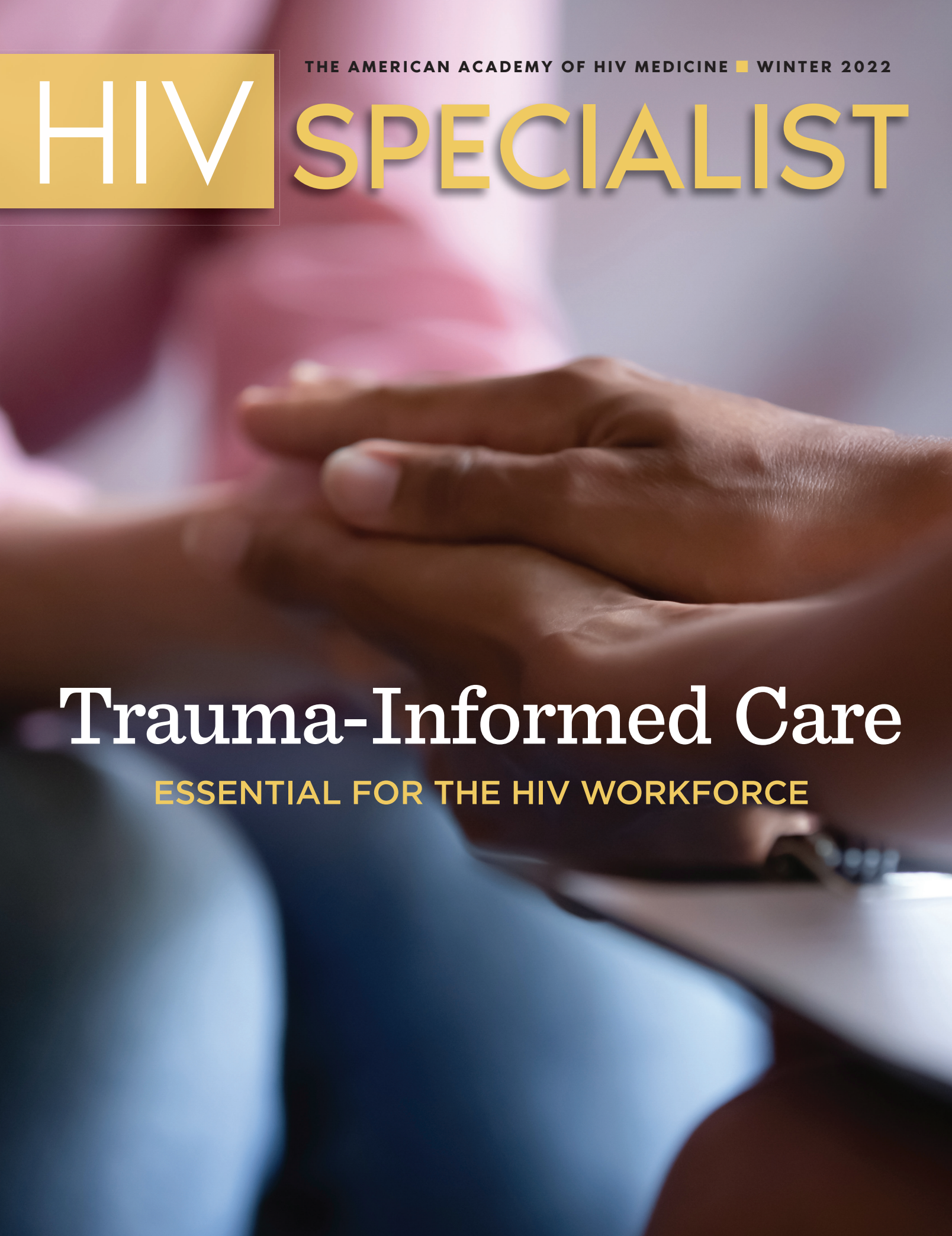


The background of the cover is a blurred photograph of two hands clasped together in a supportive grip. One hand is darker-skinned and the other is lighter-skinned. The overall tone is warm and empathetic.

THE AMERICAN ACADEMY OF HIV MEDICINE ■ WINTER 2022

HIV

SPECIALIST

Trauma-Informed Care

ESSENTIAL FOR THE HIV WORKFORCE

Experience the new direction in **DIAGNOSTICS**

Syphilis Health Check is the first and only FDA 510(k) Cleared and CLIA Waived rapid test in the United States. With accuracies above 97%, ten minutes to results, using simple fingerstick whole blood, with an onboard control to indicate if the test has been performed properly, Syphilis Health Check is able to play a major role in the battle to reduce Syphilis.

HIV and Syphilis Co-Infection

- Approximately 1.2 million people in the U.S. have HIV. About 13 percent of them don't know it and need testing
- HIV continues to have a disproportionate impact on certain populations, particularly racial and ethnic minorities and gay, bisexual, and other men who have sex with men
- In 2019, an estimated 34,800 new HIV infections occurred in the U.S.
- The incidence of syphilis is rising all over the world, partly due to the increased transmission in HIV patients and other high risk groups such as men who have sex with men
- Having an HIV infection raises the risk of syphilis infection up to 7 times.
- In 2020, 133,945 cases of all stages of syphilis were reported, including 41,655 cases of primary and secondary (P&S) syphilis, the most infectious stages of the disease
- All patients presenting with syphilis should be offered HIV testing and vice versa. In geographic areas in which HIV prevalence is high, patients who have primary syphilis should be retested for HIV after 3 months if the first HIV test result was negative



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Executive Director, AAHIVM

Caring for the Whole Person

TRAUMA-INFORMED CARE (TIC) has been around as a concept in the clinic at least since the 1970s, as soldiers who had witnessed extraordinary, gruesome death and suffering on the battlefields of Vietnam (a phenomenon identified bluntly in World War I as “shellshock”) came home for reintegration into American society. What clinicians and researchers found with veterans was that their extreme past experiences in wartime resulted in a “re-victimized” state in the present, even absent of the founding stimuli.

Though the Greek origin of the word “trauma” refers specifically to physical wounds, researchers found—especially from those soldiers returning home—that emotional and experiential trauma also has a profound effect on health outcomes. As health systems responded to the special needs of those soldiers experiencing post-traumatic stress disorder (PTSD) by implementing processes and structures to account for and mitigate trauma, it quickly became apparent that “trauma” is a larger umbrella that encompasses all kinds of ex-

cessive experiential harm on a human subject. This is inclusive of childhood trauma, physical abuse, sexual abuse, demographic-based trauma, medical trauma, societal trauma (slavery, Jim Crow, and on and on), refugees, migrations, upheaval, and any other harmful event’s impact on the unconscious processes of the human mind, personal or collective.

The literature on trauma suggests that a diagnosis of a life-threatening condition like HIV, even independent from the potentially traumatic risk-factors and social determinants of HIV, is absolutely on the spectrum of traumatic events that require special considerations and approaches from clinicians and other health service providers. This special issue on TIC presents to our readers precisely what those considerations and approaches may be to patients likely experiencing some form of PTSD. We are especially thankful to Drs. Quayle and White, who have contributed the feature article on the basics of TIC, what trauma is, its impact on health, and a comprehensive roadmap on implementing TIC in your clinic.

Also of special interest as a follow-up to the feature article is one written by Carsen Rhys Beckwith and Laura Gerson that reimagines the old stalwart HIV care continuum (HCC) and looks at how, when we use just the HCC to target our implementations and pass patients

through it, we may be missing trauma-informed interventions and other benefits to whole-person/holistic health. In these pages is also a case study looking at TIC interventions in Haitian asylum-seeking women and children, another article focusing on care engagement and retention (specifically approaches to avoid re-traumatizing patients seeking care), this month’s CE accredited article on creating a gender-affirming practice for transgender and gender diverse populations, a research article on the impact of utilization management (UM) and prior authorizations on HIV clinics and care access, and other high quality content.

As our members and other HIV clinicians know so well, TIC is not just another specialty consideration for engaging PWH, but rather a cross-cut of so many vulnerable and traumatized individuals who are most at risk, not only for HIV, but for re-traumatization and poor health outcomes due to that trauma. The Academy staff is endlessly thankful to those providers who work tirelessly to tend to their patients’ whole needs. We hope this issue will underscore those issues and provide good tools and thinking for you to implement in your respective clinics.

A stylized, handwritten signature in black ink, appearing to read "B. J. Packett".

Researcher Workbench

Controlled Tier and Genomic Data

The *All of Us* Research Program is building one of the most robust databases to transform the future of health research with extensive health data generously contributed by our diverse cohort. Data is accessible with tiered access, including Public, Registered, and Controlled tiers.

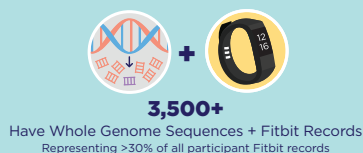
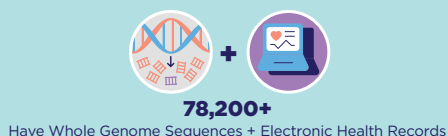
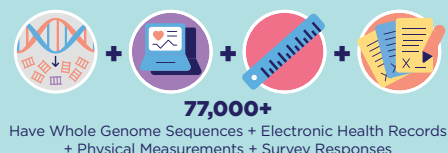


Data From

329,000+ Participants



Genomic Data is Paired with Rich Phenotypic Data



Within the Controlled Tier

Genomic Data and Tools

Includes all of the data available in the Registered Tier as well as genomic data, additional clinical fields in EHRs, and more granular demographic data both from surveys and EHRs.



98,600+
Whole Genome Sequences



165,000+
Genotyping Arrays



593,500,000+
Unique Variants
Represented and searchable through the public data browser



Genomics Analysis Tools
Hail and PLINK in addition to R, Python, and Jupyter Notebooks

More Individual-Level Information

- COVID-19 testing and diagnosis data
- Real dates of health events
- Residential location (first 3 digits of ZIP code)
- ICD codes



More Granular-Level Information

Non-generalized, demographic data provided by participants

- Race and ethnicity
- Sex at birth
- Gender identity
- Sexual orientation
- Education
- Employment status

Data Available in the Researcher Workbench



267,600+
Physical Measurements



214,200+
Electronic Health Records (EHR)



11,600+
Fitbit Records



329,000+
Survey Responses

For more information about our data, go to:

ResearchAllofUs.org

Data as of March, 2022

All of Us and the All of Us logo are registered service marks of the U.S. Department of Health and Human Services.

The *All of Us* Research Program's expansive dataset is housed on a broadly-available, secure platform. The Controlled Tier is available to registered researchers who have taken additional steps and training.



AMERICAN ACADEMY OF
HIV MEDICINE

IN THE NEWS

“Older People Living With HIV Cannot Be Ignored and Must NOT Be Left Behind”

Overlooked in global plans to end AIDS by 2030, a growing, International Coalition of Older People with HIV (iCOPE HIV) and allies have issued a wake-up call about serious gaps in the world’s HIV response

DURING A SESSION of the International Congress on Drug Therapy in HIV infection (HIV Glasgow 2022) on October 26, 2022, Mario Cascio of the European AIDS Treatment Group (EATG) stood up and read a prepared statement (known as the Glasgow Manifesto).

“Our bodies, hearts, minds, and pocketbooks reveal scars earned building the modern HIV response. As we age, many of us are living with multiple chronic health conditions, coping with frailty, disability and/or cognitive changes, becoming more socially isolated, and experiencing ageism in addition to HIV stigma and other forms of discrimination. Our independence, quality of life, and longevity are compromised and yet the HIV response has not evolved with us. It is past time for us to assert our rights to health, dignity, and support!” (from the preamble to the Glasgow Manifesto)

Later, Cascio said, “As a person who has been living with HIV for almost 40 years now, I was pleased and honored to be the one launching the Glasgow Manifesto at HIV Glasgow 2022. It was like speaking to the world about us, giving voice to the great number of older people living with HIV worldwide, struggling in their daily lives and often neglected. It was indeed a great moment with great response coming from the audience.”

The calls for action in the Manifesto, centering on three main themes—care, quality of life and empowerment—have emerged from experiences of marginalization, even within the

HIV community. The founding members of iCOPE HIV (authors of the Manifesto) have been struggling for years to have concerns of older adults with HIV taken seriously. This year’s International AIDS Conference in Montreal (AIDS 2022) (29 July–August 2, 2022) marked the first time a space for discussion of HIV and ageing issues (the Silver Zone) was approved—after earlier organizing efforts were denied.

Kate Murzin of Realize (Canada), one of the co-organizers of the Silver Zone, said, “the global community’s slow response to the changing demographics of HIV has been frustrating and difficult to understand. In 2020, there were an estimated 7.5 million people over the age of 50 living with HIV around the world. Close to 40 percent of people with HIV who live in high income countries will be at least 60 years old within the decade. And by 2040, over 9 million people living with HIV in sub-Saharan Africa will be over 50. These aren’t

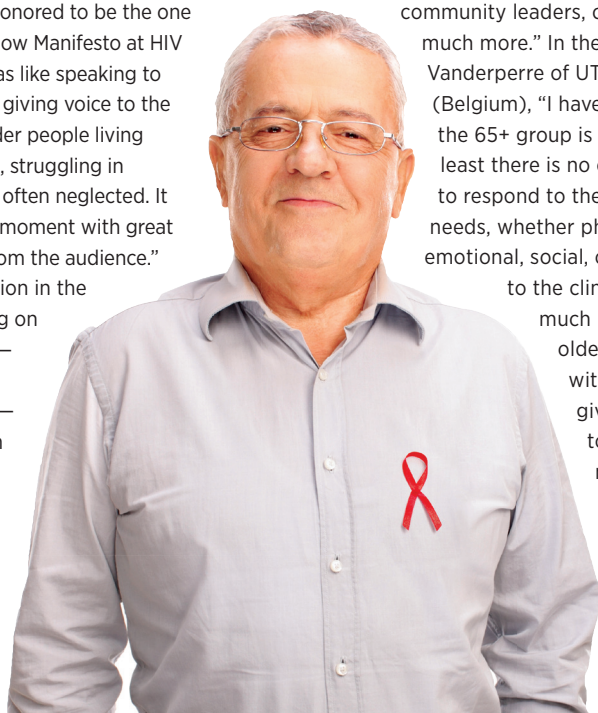
just numbers. They are people, organizers, community leaders, caregivers, and much more.” In the words of Axel Vanderperre of UTOPIA_BXL (Belgium), “I have the impression the 65+ group is forgotten, or at least there is no clinical pathway to respond to their many needs, whether physical, mental, emotional, social, or sexual. Visits to the clinic could be so much more effective if older people living with HIV were given the tools to share what’s most important to them in advance of

the appointment. The community also needs access to education and programs that enable us to take charge of our health—initiatives to prevent comorbidities and frailty, foster healthy behaviours, and reduce pain and mental health problems.”

Jules Levin of the National AIDS Treatment Advocacy Project (USA) added, “we are calling for an integration of comprehensive geriatric screening, care and support services for the elderly and older people living with HIV into the HIV clinic infrastructure. We are calling for all governmental health officials to design and implement new models of care in the clinic for prevention and care of comorbidities. Without this, premature mortality will increase.”

The authors of the Manifesto are clear that what is needed is not just improved care and quality of life. Cascio’s colleague at EATG, Anton Basenko, stated, “we expect that ageing and older adults are represented in all HIV research and that people living with HIV are included in ageing research, so we are clear on what the findings mean for our well-being. We demand access to the most up-to-date information on ageing with HIV. But knowledge, information and research are nothing if we are not meaningfully involved. We demand that ageing and older people be included in decision-making about the HIV response, including priority- and target-setting, funding allocation, and messaging about the impact of HIV on ageing and older adults. Stop talkenism—it’s time to act!”

The coalition’s calls to action have struck a chord with many people involved in the global fight against AIDS. According to Murzin, “since Mario delivered the Manifesto publicly on October 26, 118 HIV organizations around the world have signed-on—a groundswell of support we hope to translate into action and systemic change.”



THE ACADEMY OF HIV MEDICINE today announced the appointment of Adrienne Wyatt, MA, as their new Director of Communications and Marketing. With more than 15 years of experience in communications and marketing, Adrienne brings with her a solid foundation of strategic communications, content strategy and omnichannel marketing expertise.

"The Academy is excited to welcome Adrienne to the great team on staff," said Bruce J. Packett, II, executive director. "With her background, skills, and leadership, we are completely confident in her ability to serve the needs of the HIV provider community and to confidently grow and evolve the organization's communications functions."

As director of communications and marketing, Adrienne will be responsible for the Academy's overall communications and marketing strategy, including brand management, public relations, digital marketing, web content strategy and stakeholder outreach. She will also serve as the editor-in-chief of the Academy's

membership magazine, HIV Specialist.

Adrienne's experience spans nonprofit, government, and private industry, with much of that time spent working in health care communications and marketing. Most recently, Adrienne worked as the senior manager for media and public relations at the American Academy of Otolaryngology-Head and Neck Surgery (AAO-HNSF). There, she was responsible for managing their external communications and for creating and implementing targeted media relations and social media plans. She also served as an editor for their monthly membership magazine and supported marketing efforts for their peer-reviewed journals, Otolaryngology-Head and Neck Surgery and OtoOpen.

Prior to her time at AAO-HNSF, Adrienne worked at MedExpress, a nationwide urgent care company owned by Optum. While at MedExpress, she developed, implemented and evaluated content marketing strategies



and played an integral role in MedExpress's website relaunch to improve search engine optimization and domain authority. Before working at MedExpress, Adrienne established a new communications department

for University College at West Virginia University. She created and executed its first strategic communications and marketing plan and gained world-wide media exposure for WVU via a University College graduate story.

Adrienne has also worked for the American Academy of PAs and has worked for numerous initiatives on behalf of the Substance Abuse and Mental Health Services Administration. With knowledge of culturally-sensitive communications and an understanding of the needs of health care providers and patients, Adrienne will support the Academy's mission to ensure health care professionals have the resources needed to provide prevention, treatment and care for those with or at risk for HIV and related conditions to achieve optimal health.

HHS Office for Civil Rights Issues Bulletin on Requirements under HIPAA for Online Tracking Technologies to Protect the Privacy and Security of Health Information

THE OFFICE FOR CIVIL RIGHTS (OCR) at the U.S. Department of Health and Human Services issued a bulletin to highlight the obligations of Health Insurance Portability and Accountability Act of 1996 (HIPAA) on covered entities and business associates ("regulated entities") under the HIPAA Privacy, Security, and Breach Notification Rules ("HIPAA Rules") when using online tracking technologies. These online tracking technologies, like Google Analytics or Meta Pixel, collect and analyze information about how internet users are interacting with a regulated entity's website or mobile application.

Some regulated entities regularly share electronic protected health information (ePHI) with online tracking technology vendors and some may be doing so in a manner that violates the HIPAA Rules. The HIPAA Rules apply when the information that regulated entities collect through tracking technologies or disclose to tracking technology vendors includes ePHI. Regulated entities are not permitted to use tracking technologies in a manner that would result in impermissible disclosures of ePHI to tracking technology vendors or any other violations of the HIPAA Rules.

Today's bulletin addresses potential impermissible disclosures of ePHI by HIPAA regulated entities to online technology tracking vendors. The Bulletin explains what tracking technologies are, how they are used,

and what steps regulated entities must take to protect ePHI when using tracking technologies to comply with the HIPAA Rules.

Specifically, the Bulletin provides insight and examples of:

- Tracking on webpages
- Tracking within mobile apps
- HIPAA compliance obligations for regulated entities when using tracking technologies

"Providers, health plans, and HIPAA-regulated entities, including technology platforms, must follow the law. This means considering the risks to patients' health information when using tracking technologies," said OCR Director Melanie Fontes Rainer. "Our Bulletin answers questions for those using tracking technologies, importantly how to protect the privacy and security of the health information they hold."

Read the Bulletin here: <https://www.hhs.gov/hipaa/for-professionals/privacy/guidance/hipaa-online-tracking/index.html>.

HHS is committed to ensuring that all people can access health care and human services, free from discrimination. If you believe that your or another person's health information privacy or civil rights have been violated, you can file a complaint with OCR at <https://www.hhs.gov/ocr/complaints/index.htm>.

IN THE NEWS

WHO Recommends New Name for Monkeypox Disease

FOLLOWING A SERIES OF CONSULTATIONS WITH GLOBAL EXPERTS, WHO will begin using a new preferred term “mpox” as a synonym for monkeypox. Both names will be used simultaneously for one year while “monkeypox” is phased out.

When the outbreak of monkeypox expanded earlier this year, racist and stigmatizing language online, in other settings and in some communities was observed and reported to WHO. In several meetings, public and private, a number of individuals and countries raised concerns and asked WHO to propose a way forward to change the name.

Assigning names to new and, very exceptionally, to existing diseases is the responsibility of WHO under the International Classification of Diseases (ICD) and the WHO Family of International Health Related Classifications through a consultative process which includes WHO Member States.

WHO, in accordance with the ICD update process, held consultations to gather views from a range of experts, as well as countries and the general public, who were invited to submit suggestions for new names. Based on these consultations, and further discussions with WHO's Director-General Dr. Tedros Adhanom Ghebreyesus, WHO recommends the following:

- Adoption of the new synonym mpox in English for the disease.
- Mpox will become a preferred term, replacing monkeypox, after a transition period of one year. This serves to mitigate the concerns raised by experts about confusion caused by a name change in the midst of a global outbreak. It also gives time to complete the ICD update process and to update WHO publications.
- The synonym mpox will be included in the ICD-10 online in the coming days. It will be a part of the official 2023 release of ICD-11, which is the current global standard for health data, clinical documentation and statistical aggregation.
- The term “monkeypox” will remain a searchable term in ICD, to match historic information.

Considerations for the recommendations included rationale, scientific appropriateness, extent of current usage, pronounceability, usability in different languages, absence of geographical or zoological references, and the ease of retrieval of historical scientific information.

Usually, the ICD updating process can take up to several years. In this case, the process was accelerated, though following the standard steps.

Various advisory bodies were heard during the consultation process, including experts from the medical and scientific and classification and statistics advisory committees which constituted of representatives from government authorities of 45 different countries.

The issue of the use of the new name in different languages was extensively discussed. The preferred term mpox can be used in other languages. If additional naming issues arise, these will be addressed via the same mechanism. Translations are usually discussed in formal collaboration with relevant government authorities and the related scientific societies.

WHO will adopt the term mpox in its communications, and encourages others to follow these recommendations, to minimize any ongoing negative impact of the current name and from adoption of the new name.

UKHSA Finds Vaccination Offers Strong Protection Against Monkeypox

NEW UKHSA EVIDENCE indicates that a single MVA-BN vaccine dose provides around 78 percent protection against monkeypox 14 days after being vaccinated.

This is the strongest U.K. evidence yet for the effectiveness of the vaccine.

As part of the analysis, monkeypox cases in England and vaccination uptake data between July 4 to November 3, 2022, were reviewed to estimate vaccine effectiveness within the eligible gay, bisexual, and men who have sex with men (GBMSM) cohort, with vaccine coverage among cases compared to the wider eligible population.

Out of 363 monkeypox cases in this period, eight had been vaccinated at least 14 days before and 32 had been vaccinated between zero to 13 days before. The rest (323) were not vaccinated during this outbreak. This gives an estimate of vaccine effectiveness for a single dose of 78 percent 14 or more days after vaccination.

The U.K. Health Security Agency (UKHSA) will continue to investigate the duration of protection from a single dose and the combined protection of two doses.

Jamie Lopez-Bernal, Consultant Epidemiologist at UKHSA, said:

“While monkeypox cases are low it remains vital to stay alert to the risks. Thank you to everybody who has come forward for their vaccine already—it is helping to keep numbers low, but we can't get complacent.

We now know that a single vaccine dose provides strong protection against monkeypox, which shows just how important vaccination is to protect yourself and others. A second dose is expected to offer even greater and longer lasting protection.

Please come forward for your vaccine as soon as possible—don't put it off. Remember that it takes two weeks for the vaccine to have maximum effect so the sooner you get vaccinated, the better.”

NHS National Director of Vaccinations and Screening Steve Russell said:

“Thanks to hard-working staff, more than 55,000 doses of the monkeypox vaccine have been delivered so far, and we now know just how effective the vaccine is, offering 78 percent protection against the virus from just one dose.

While the risk of monkeypox remains low, we urge anyone eligible to come forward to get their vaccination and with the NHS monkeypox site finder, it's now easier than ever to book in for a first dose, giving yourself a high level of protection.”

Evidence Found for “Substantial” Monkeypox Transmission Before Symptoms Appear

Transmission detected up to four days before symptoms
Findings may have important implications for infection control globally

A U.K. STUDY PUBLISHED BY the BMJ today found evidence for “substantial” monkeypox transmission before symptoms appear or are detected (known as pre-symptomatic transmission).

Transmission was detected up to a maximum of four days before the onset of symptoms, and the researchers estimate that more than half (53%) of transmission occurred in this pre-symptomatic phase, meaning that many infections cannot be prevented by asking individuals to isolate after they notice their symptoms.

In a linked editorial, researchers say that if these findings are supported by other studies, pre-symptomatic transmission “would have important implications for infection control globally.”

Since the international outbreak of monkeypox in May 2022, more than 70,000 cases have been recorded globally, with just over 3,500 cases in the U.K.

Although case numbers are now declining, it’s still important to understand the “transmission dynamics” of the virus—for example, how it spreads from one person to another and how quickly symptoms appear—to help inform policy decisions and future interventions.

While previous research on pox viruses did not rule out transmission prior to symptoms, this work represents the first evidence to support this.

To explore this further, researchers at the U.K. Health Security Agency set out to analyse the transmission dynamics of the monkeypox outbreak in the U.K.

Their findings are based on routine surveillance and contact tracing data for 2,746 individuals who tested positive for monkeypox virus in the U.K. between May 6 and August 1, 2022. Their average age was 38 years and 95 percent reported being gay, bisexual, or men who have sex with men.

The two main measures of interest to the researchers were serial interval (time from

symptom onset in the primary case patient to symptom onset in the secondary contact) and incubation period (time from exposure to onset of symptoms).

To estimate this, they linked information on exposure and symptom onset dates from these individuals to their contacts through contact tracing case questionnaires, which they then analysed using two statistical models.

The models were adjusted for several biases common to virus outbreaks, such as changes in infection rates over time, that would otherwise affect the results.



The mean incubation period was estimated to be 7.6 days in one model and 7.8 days in the other model, while the estimated mean serial interval was 8 days in one model and 9.5 days in the other.

For both models, the median serial interval was between 0.3 and 1.7 days shorter than the median incubation period, indicating that considerable transmission is occurring before the appearance or detection of symptoms.

Analysis of individual level patient data, collected from a subset of patients with more detailed information, seemed to confirm this explanation, with 10 out of 13 case-contact patient pairs reporting pre-symptomatic transmission. Four days was the maximum time that transmission was detected before symptoms appeared.

Based on these results, the researchers say an isolation period of 16 to 23 days would be required to detect 95 percent of people with a potential infection.

These are observational findings, and the researchers point to several limitations, such as relying on contact tracing to identify the correct case-contact pairs and the self-reported data on date of symptom onset. What’s more, the results may not necessarily be directly applicable to other populations with different transmission patterns.

Nevertheless, this was a large study using robust methods and adjusting for key biases that are present in the data, providing greater confidence in the conclusions.

These findings have important implications for isolation and contact tracing policies, say the researchers, adding that backward contact tracing strategies (tracing from whom disease spreads) should account for a pre-symptomatic infectious period when trying to find the contacts of confirmed cases.

In a linked editorial, researchers based in the U.S., U.K. and Nigeria argue that pre-exposure vaccination and vaccine equity are urgently needed worldwide.

Vaccination is likely to be more cost effective than managing the consequences of preventable infections, including hospital admissions, loss of income during isolation, and long term complications, they explain.

However, they point out that many of the public health measures that have been critical during monkeypox outbreaks in high income countries remain unavailable in much of Africa.

“As the monkeypox outbreak declines in Europe and North America, we have a responsibility to deploy effective tools for viral control on a global level—not just in wealthy nations,” they write. “These tools include research into understanding transmission dynamics in African settings and the inclusion of endemic countries in vaccine trials.”



Trauma-Informed

Patients often hold a well-earned mistrust of the healthcare system and sexual/reproductive healthcare especially based on a legacy of coercion, violence, and trauma in this setting, particularly among communities of color and the LGBTQ+ community.

ESSENTIAL FOR THE HIV WORKFORCE

By Cara Berg Raunick, DNP, WHNP

PROVIDERS OF HIV-RELATED CARE have been incorporating elements of a trauma-informed approach into their work from the earliest days, perhaps without knowing it. Trauma-informed care (TIC) is built on several key assumptions. These include realizing how widespread trauma is, how great an impact it can have, and understanding potential paths toward healing. In the early days of HIV, with so much unknown, so much fear and loss, and so much stigma, these understandings were fundamental. Today, with pre-exposure prophylaxis (PrEP) and Undetectable=Untransmittable (U=U) entirely reshaping the landscape of HIV care, receiving a diagnosis and living with HIV may not be traumatic for all; however, the universal application of a trauma-informed approach to care is no less important.

To apply a trauma-informed approach to care, one must first understand trauma and its effects. The Substance Abuse and Mental Health Services Administration (SAMHSA) defines trauma as "...an event, series of events, or set of circumstances that is experienced by an individual as physically or emotionally harmful or life threatening and that has lasting effects on the individual's functioning and mental, physical, social, emotional, or spiritual well-being."¹ It is something that overwhelms a person's ability to cope.² With this perspective, trauma is unique to the individual; what is traumatic to one person may not be to another. The Diagnostic and Statistical Manual of Mental Disorders (DSM) is the handbook used by mental health professionals in the United States to diagnose mental illness, including trauma-related disorders such as post-traumatic stress disorder.

Interestingly, compared with the DSM-IV, the updated DSM-V narrowed the types of events that qualify as traumatic. It does not take into account individual experience and instead requires actual or threatened death, serious injury, or sexual violence to be considered trauma.^{3,4} In this view, psychosocial stressors are not considered trauma, nor is life-threatening illness if the threat is not immediate. However, in providing patient-centered TIC, how the person experiences the event is key and for our purposes the SAMSHA definition is more appropriate. One patient may find being diagnosed with HIV to be a trauma, where another may cope well with an understanding of medical advances and/or a strong support system in place and move forward without experiencing trauma. As providers, it is important to leave space for the individual's experience and avoid projecting onto our patients what we might expect to be traumatic or not.

In 1998, the Adverse Childhood Experiences (ACEs) study conducted by the Centers for Disease Control and Prevention (CDC) and Kaiser Permanente surveyed 17,000 people about their experiences with abuse, neglect, and household dysfunction, including living with someone with a mental illness, substance abuse within the home, parental separation or divorce, domestic violence, and having an incarcerated



Care

household member.⁵ Respondents received one point for each type of adversity they had experienced (without regard for frequency or severity), yielding a score of zero to 10. A weakness of the initial work is that the study population was majority White, middle-income, and college educated. In 2012, the original ACE categories were further expanded by the Philadelphia ACE study with a more diverse population to include witnessing violence, experiencing discrimination, adverse neighborhood experiences, being bullied, and living in foster care.⁶

The information gleaned from the ACE studies demands a change in the practice of medicine and our approach to public health that centers TIC. The studies showed a dose-response relationship where the more ACEs a person had the higher their likelihood of experiencing a host of negative health and life outcomes, including mental health concerns and chronic diseases. They are also associated with earlier sexual debut, multiple sexual partners, unprotected sex, adolescent pregnancy involvement, involvement in sex trafficking, earlier use of alcohol, and higher risk of substance use disorders.^{7,8,9}

Experiencing adversity and trauma is incredibly common. The Philadelphia ACE study showed that 70 percent of adults had at least one ACE and 40 percent had four or more. The original data showed 64 percent with at least one ACE and 12.5 percent with four or more. We also know that one in three women and one in four men are the victims of some type of physical violence by an intimate partner in their lifetimes, and that one in six American women, one in 33 American men, and 21 percent of transgender, genderqueer, and non-conforming college students have been sexually assaulted.¹⁰

There are infinite further examples of types of trauma people can experience, from car accidents to natural disasters to war. Now, the world has experienced a universal trauma in living through a global pandemic. Historical trauma such as genocide, slavery, police brutality, and forced relocation must also be considered. Patients often hold a well-earned mistrust of the healthcare system and sexual/reproductive healthcare especially based on a legacy of coercion, violence, and trauma in this setting, particularly among communities of color and the LGBTQ+ community.

Trauma can cause both short- and long-term effects on a person's functioning and well-being. Trauma affects neurodevelopment. The sympathetic nervous system, with hormones like adrenaline and cortisol, responds to trauma by invoking the fight, flight, and freeze response to seek safety. However, with chronic exposure, this protective response can become toxic. Brain structures can change with the amygdala (the brain's fear center) being overactive and the prefrontal cortex (critical for executive functioning, learning, and impulse control) being underactive.

Trauma can also cause changes in worldview and belief systems. This often includes difficulty with creating connections and building trust. This is especially salient in a patient care space. Decreased trust in systems, including the healthcare system, and difficulty building trusting relationships with providers, disease intervention specialists, or other clinic staff and helping figures can significantly impede care.

People who have experienced trauma employ many coping mechanisms. While people's capacity for resilience and for post-traumatic growth is incredible and their ways of coping are positive, some

copied mechanisms can appear counter-productive and be harmful. When those we care for, those we work with, and others in our lives self-medicate, take risks sexually, dissociate, self-harm, or show aggression, a trauma-informed lens reminds us that people employ all kinds of strategies to cope and survive in the face of trauma. This perspective shift does not mean ignoring the potential for harm but should allow greater empathy and suspension of judgement.

TIC demands this type of paradigm shift. One where we move from asking, "What is wrong with this person?" to asking, "What happened to this person?" We move from a posture of judgement to a posture of curiosity. SAMHSA defines a trauma-informed approach as one that "...**realizes** the widespread impact of trauma and understands potential paths to recovery. **Recognizes** the signs and symptoms of trauma in clients, families, staff, and others involved in the system; and **responds** by fully integrating knowledge about trauma into policies, procedures, and practices and seeks to actively **resist re-traumatization**."¹

These "4 Rs" are the four key assumptions of TIC. This type of care shares many qualities with patient-centered or patient-led care and includes the following six key principles 1) Safety; 2) Trustworthiness and Transparency; 3) Peer Support; 4) Collaboration and Mutuality; 5) Empowerment and Choice; and 6) Cultural, Historical, and Gender Issues.¹ The way this is operationalized will be somewhat different in each environment. As the CDC reminds us, "...a trauma-informed approach is not accomplished through any single particular technique or checklist. It requires constant attention, caring awareness, sensitivity, and possibly a cultural change at an organizational level."¹¹

Many are familiar with the concept of being "triggered" or activated. This happens when someone is reminded of or experiences a flashback to a previous trauma. Activators can be conscious or subconscious and can reach people through all five senses. They could be entirely unaware of the smell, word, or song that activated them and may be unprepared for and unable to predict the activator. Someone who is activated may feel extreme mental, physical, and/or emotional

There are many possible activators in a healthcare environment, including power imbalances between patient and provider, needing to repeat one's story or history, being undressed for exams, having the door closed in a small room, or feeling rushed or pressured into a decision.



distress similar to what they experienced at the time of initial trauma. This can lead to flashbacks, panic, anxiety, dissociation, decreased ability to process information, and unpredictable behaviors.

There are many possible activators in a healthcare environment, including power imbalances between patient and provider, needing to repeat one's story or history, being undressed for exams, having the door closed in a small room, or feeling rushed or pressured into a decision. In cases where an HIV infection was related to trauma, whether sexual assault, survival sex, harmful words from loved ones, infidelity, loss of a partner, or infinite other examples, that trauma may be revisited every day in healthcare and the taking of antiretrovirals.

Although healthcare providers and staff may not know what a patient's particular activator is, it is our responsibility to work to resist re-traumatization. We can do this through the six principles. For example, we can promote emotional and physical safety by being prepared for a range of responses including anger, dissociation, and difficulty with decisions and help the patient manage them to the best of our ability. We can promote trustworthiness and transparency by sharing why we are asking for intimate and private details around partners and sexuality, remembering that while this is normal for us as providers, it may be the farthest thing from normal for our patients. We can promote peer support by having resource lists of support groups readily available. Peer support can also be an important component for providers themselves to remember to foster and lean on networks of peers in the field for support and consultation.

We can utilize a shared decision-making and patient-led model of care, understanding that while providers bring extensive medical knowledge and experience to the table, it is

the patient themselves who is the expert on their own life and who will ultimately know what plan of care is best for them. Providers must also remember that an informed consent process also includes a right to informed declination; we cannot simply expect consent because someone presents for care. We can give patients as much power, choice, and control as possible. Would they prefer sexually transmitted infection testing through urine, self-swab, or exam? What positioning and draping would they prefer? What components of care are necessary at a given time and what could be deferred? And infinite other examples.

Finally, we must always remember the context in which our patients present for care. One colleague recently described several patients with complex feelings around receiving a diagnosis of HIV. She described an instance where a patient expressed fear and sadness but also relief at finally feeling like they were "really part of the community." We also spoke of patients who were not part of the LGBTQ+ community who struggled significantly with the idea of being affiliated with a group with which they did not identify or even hated or feared. We have seen the importance of this cultural and historical lens in TIC today as elements of the communal trauma experienced in the early days of HIV/AIDS have resurfaced due to the emergence of monkeypox. A trauma-informed approach must be aware of and honor this history.

TIC should be a universal standard of care. It is not something reserved for "special populations," or instances where we know of someone's history of trauma. No one owes us a disclosure of their trauma histories. It is our responsibility to understand the ubiquity of trauma and apply this approach the same way we use standard precautions for bloodborne pathogens. We do not wait for lab results to don gloves, and we should not wait for or

expect a disclosure to provide the highest quality care meant to minimize the possibility of re-traumatization. These concepts extend beyond our patients to our colleagues and coworkers, friends and family, and even to ourselves. By using a trauma-informed approach to care, we can reduce the burden of trauma on our patients and those around us and ultimately promote healing. **HIV**



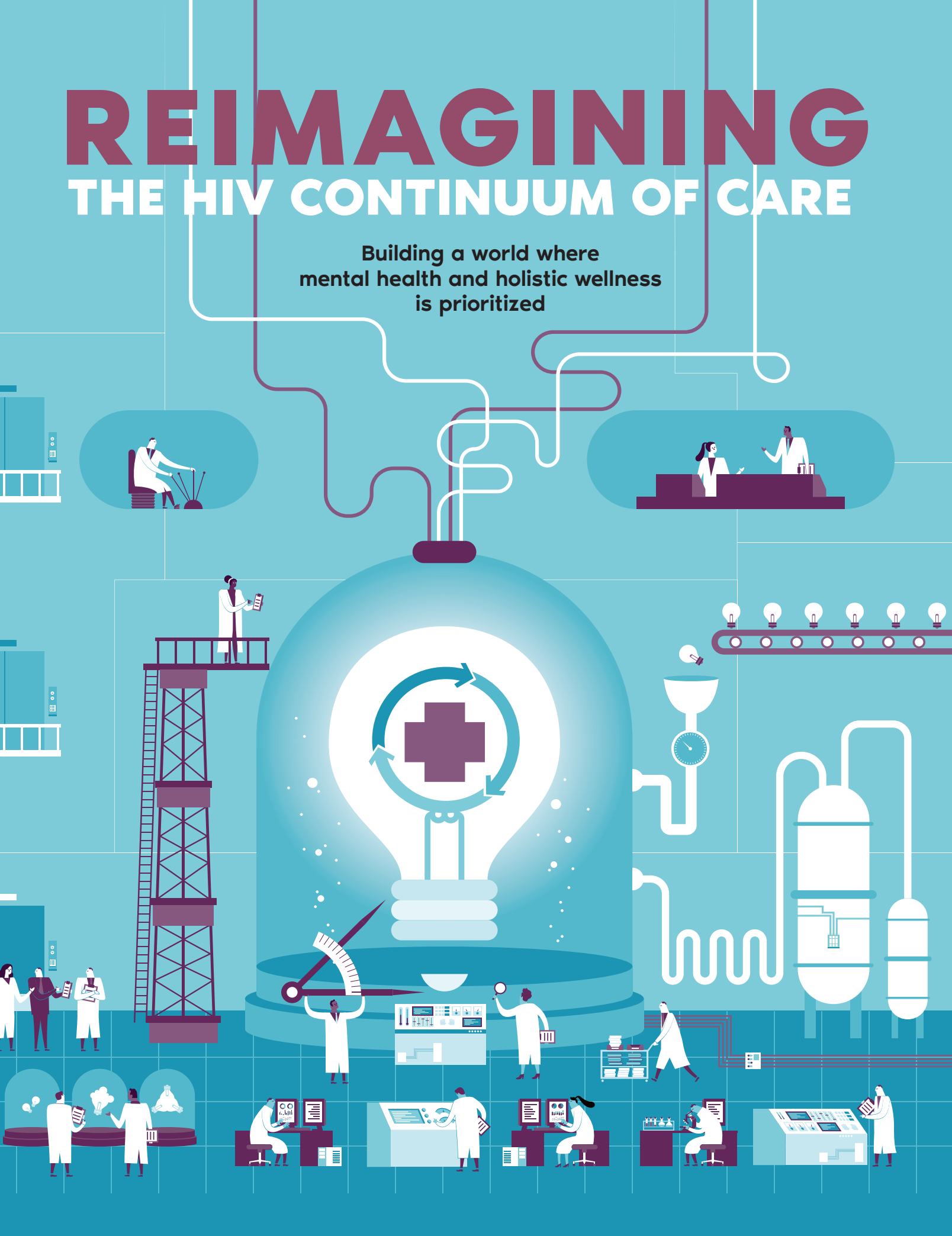
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REIMAGINING THE HIV CONTINUUM OF CARE

Building a world where
mental health and holistic wellness
is prioritized



THE LANDSCAPE OF HIV HAS SHIFTED significantly in recent decades. While major breakthroughs in biomedical HIV prevention and treatment move us toward the goal of ending the epidemic, there is an increasing need to address barriers that prevent access to adequate and sustained healthcare. Among these barriers is a lack of intentional care and services for the mental health of people navigating the continuum of HIV care. There is substantial evidence that impairment in mental health leads to negative health outcomes at each step in a patient's journey, starting with HIV diagnosis all the way to viral suppression.

With a heavy focus on the pathway to viral suppression, the HIV continuum of care often misses mental health considerations. In the initial provision of care, healthcare providers are quick to shuffle an individual through the care process with limited consideration of the needs of those who are dually navigating mental illness. A recent study of over 2,800 people with HIV showed that 36 percent of participants were living with major depression and nearly 16 percent were living with a generalized anxiety disorder.¹ Representing more than five times the national average for these rates, mental health should be a core pillar of our care provision.

Our approach offers opportunities for the inclusion of mental health considerations throughout the standard HIV continuum of care, with additional considerations for the deconstruction of this linear model altogether. We explore how to operationalize a person-centered and trauma-informed approach that tackles individual mental health needs, unravels relevant stigmas, and empowers individuals to build their own pathways to holistic health. This offering pulls from the fields of social work, clinical practice, harm reduction, and psychology.

Diagnosed with HIV

When initially diagnosed with HIV, people may experience a wide variety of emotions, including fear, distress, sadness, and shock.² Practitioners may be eager to launch right into intake for clinical services; however, it is essential to take time to recognize and validate these emotions and center the needs of the individual. It can be overwhelming for patients to learn that they have HIV, especially for clients who are simultaneously navigating mental health concerns interpersonally and within inaccessible healthcare systems.

Providers must also recognize that patients are demonstrating trust and vulnerability by getting tested; we have to take great care with this trust, as trauma, stigma, and mental illness can cause patients to feel such strong anxiety that they may cancel appointments to avoid it. An HIV diagnosis can be a heavy or traumatizing event, so providing mental health resources such as referrals, peer counseling, and connection to an HIV doula right from the outset is necessary to help support a person's journey.³

Linked to Care

Upon linking a newly diagnosed person to clinical HIV care, it is crucial to consider what other resources may be beneficial to an individual. While some people may feel comfortable speaking to a psychiatrist, it is important to consider alternative and nontraditional avenues to support that may be offered in your community. Providing linkage to services such as housing support, nutritional assistance programs, transportation vouchers, and other nonclinical services may ease some of the anxiety that the initial diagnosis may have caused.

People with mental illnesses—who often face other structural and societal barriers—may also significantly benefit from being linked to these services as well as a case manager who can assist them with setting up and keeping appointments.⁴ When linking patients to new providers, also keep in mind that representation across race, gender, sexuality, and ability within healthcare settings is affirming and often anxiety reducing for clients.⁵

Received Medical Care

Receiving care for HIV may look different for each individual living with HIV since each person's experiences vary. It is important to recognize that there may be many barriers to physical and mental wellness that fall out of the control of the individual, such as housing, transportation, food security, or stigma. A provider should plan to utilize a broad range of approaches based on what would be most useful to the individual, including psychopharmacological tools, motivational interviewing, and mindfulness techniques.

Within all these approaches, using a lens of cultural competence and trauma-informed care is essential to help create a safe environment for patients. Additionally, it is helpful to consistently level set and identify boundaries with patients, recognizing the impact that mental illness may have on their ability to adhere to medications and attend appointments. As with all prescribing, providers should be aware of any possible side effects between HIV treatment and medicines for psychiatric treatment.

Retained in Care

People who are living with HIV and depression (or other mental illnesses) are less likely to stay in HIV care throughout their lifetime.⁶ This is for a multitude of reasons, including the lack of cultural competency of healthcare providers for neurodivergent individuals, the sheer expense of both mental and physical health services, and the compounding effects of mental illness on other factors such as substance use and homelessness.

When we think about retaining someone in care, we must consider services that go beyond repeated testing and bloodwork, and include food provision services, peer support groups (both online and in person), linkage to housing, syringe exchanges and safe injection sites, and beyond. Retention in care—where most individuals drop off the care continuum—leads to improved health outcomes, and we must find more comprehensive means to bring people to the care they want and need.

Achieved Viral Suppression

Viral suppression is often touted as the exclusive option for health and wellness for people living with HIV. As mental health impairments create barriers on the pathway to viral suppression, the presentation of this pathway as the only one towards health creates an additional stigma and hierarchy that may stop individuals from pursuing care.^{7,8} Navigating mental health disorders—which may also impair the maintenance of viral suppression and medication adherence—may mean that an individual has alternate goals or priorities in their wellness journeys. In this sense, we must consider how peer navigators, therapists, social workers, and more can be integrated not only in the diagnosis stage of this continuum, but throughout. These support networks can assist and empower people with HIV to outline a version of health and wellness that feels holistic and achievable to them.

Moving Beyond the Continuum

Depression and a myriad of other mental health disorders correlate with poor outcomes along the HIV care continuum in comparison to those living without mental illness.⁹ What if our response to this disparity was not to adopt interventions that tailor the continuum to this population, but instead deconstruct the

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care continuum altogether? A holistic health and wellness model considers the multifaceted needs of an individual. Addressing the physical, emotional, social, spiritual, occupational, financial, intellectual, and environmental needs of a person with HIV empowers an individual to pursue wellness that puts their priorities first.

This type of holistic model is often discussed within the field of social work. It takes a person-in-environment approach, considering not only the direct physical needs of the individual but the factors and systems around them that may impact their wellness. When we consider all the structural components that create barriers for individuals to care for themselves—from socioeconomic inequalities to racial disparities to queerphobia within healthcare and so much more—we can begin to envision a model of care that is inclusive of more than just medication.

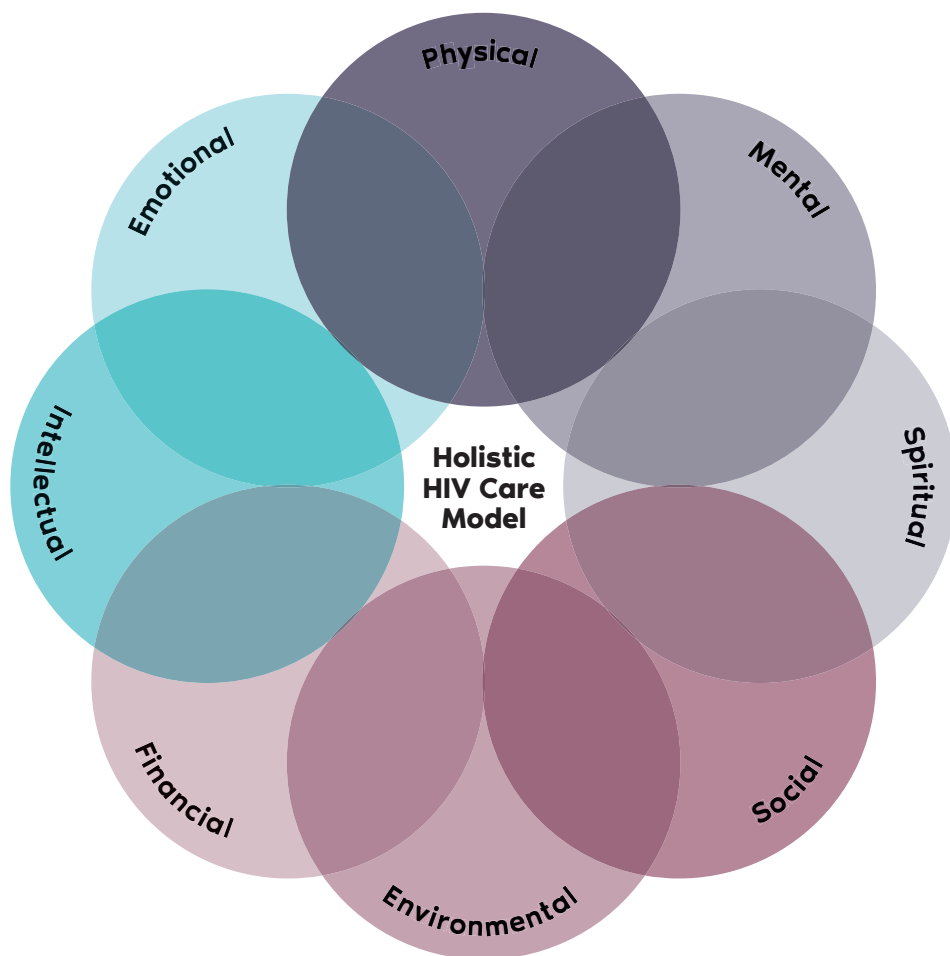
Crafting a Holistic Healthcare Model

So what does it look like to begin implementing a holistic healthcare model for people with HIV? This is where things start to get tricky. Under our current modes of financing and supporting people with HIV across the United States, funding tends to be allocated to individual programs and services. This might look like funding for syringe services programs, HIV testing programs, food pantries, housing, and more. Despite our knowledge that multiple programs are often needed to address social determinants of health, they are typically run through separate organizations, programs, and teams.

Overcoming that requires a number of actions. To start, we need to advocate for the funding and development of “one-stop shops” across the country. Whether in large cities like New York or the outskirts of rural South Dakota, people need access to a physical and virtual location where a multitude of intersecting needs can be met. Imagine a single building where people with HIV and their networks were able to:

- receive testing
- pursue immediate mental health support in a room down the hall
- connect to a case manager to discuss housing opportunities
- sit down and get assistance in filling out Medicaid, Medicare, and other insurance forms
- find access to a food pantry and free syringes

Creation of this type of ecosystem allows for an individual to pursue the resources that they feel are the highest priority in any given moment.



This also requires that our services speak to one another. We cannot exist in silos as we provide care. Too often we have come across departments and programs that provide support to people with HIV that have never spoken to one another. A housing department has not shared the urgent need for medications; healthcare providers have not shared the lack of access to food and water that their patients have; and testing sites have not known of the mental health resources available to those who test positive in our clinics. Infrastructure is needed to ensure that we are building networks with one another that allow for warmer communication and hand-offs of our clients, patients, and loved ones.

We would be remiss not to mention that the creation of a holistic healthcare model also requires deeper structural change. We must be able to shift narratives and break down the stigmas surrounding HIV. We must provide universal coverage for mental healthcare. We must rid our healthcare systems of deeply ingrained racism and transphobia. And we must be willing to search for innovative ways to provide care and support that validate

community-driven approaches to health (and not simply traditional, scripted understandings of what it means to be healthy).

What Comes Next

So many fields of work intersect with the services and lives of people with HIV. People with HIV are parents, employees, lovers, siblings, and friends. As we seek to improve—either within a holistic model or within a more traditional continuum—we must be placing individuals at the very core of every service we provide. Utilizing a “one size fits all” approach or continuum only serves to create a divide between providers and the real needs of their clients, preventing progress altogether.

While we continue to advocate for wider systemic changes that facilitate a more holistic model of healthcare, it is essential for providers to begin incorporating a mindset of collaboration with clients, creating a culture of empathy, understanding, and compassion. This shift in attitudes, in coordination with other efforts, will help pave the way for larger scale changes in how we work with communities. **HIV**



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TOOLS *for* PRACTICE

Trauma-Informed Care That's Accessible for Healthcare Providers

By Heather C. Quaile, DNP, WHNP-BC, AFN-C, CSC, IF, FAANP
and Amina White, MD, FACOG

RESPECTING AND VALIDATING EACH PERSON'S UNIQUE EXPERIENCES are what motivate healthcare providers to look out for their patients' best interests throughout their health-illness journey. These and other abilities are essential for building the patient-provider relationship and providing trauma-informed care (TIC). Understanding and caring for those who have experienced trauma has grown to be a significant public health need. Unfortunately, there is lack of awareness around the implications of trauma and how it affects individuals. Working with people who have trauma is frequently very expensive and has negative and pervasive impacts on the patient, the healthcare system, and society.

What is Trauma?

Trauma refers to experiences or encounters that result in significant physical and psychological stress responses.¹ It occurs from situations or events that a person perceives as physically and/or emotionally damaging or threatening and can include: adverse childhood experiences (ACEs); medical maltreatment or invasive procedures; personal experience of or exposure to substance use disorder; physical, sexual, and emotional violence; poverty; racism; discrimination and oppression; separation from or loss of a loved one; community violence; exposure to war or terrorism; and sex and gender-based violence, including marginalization.^{1,2}

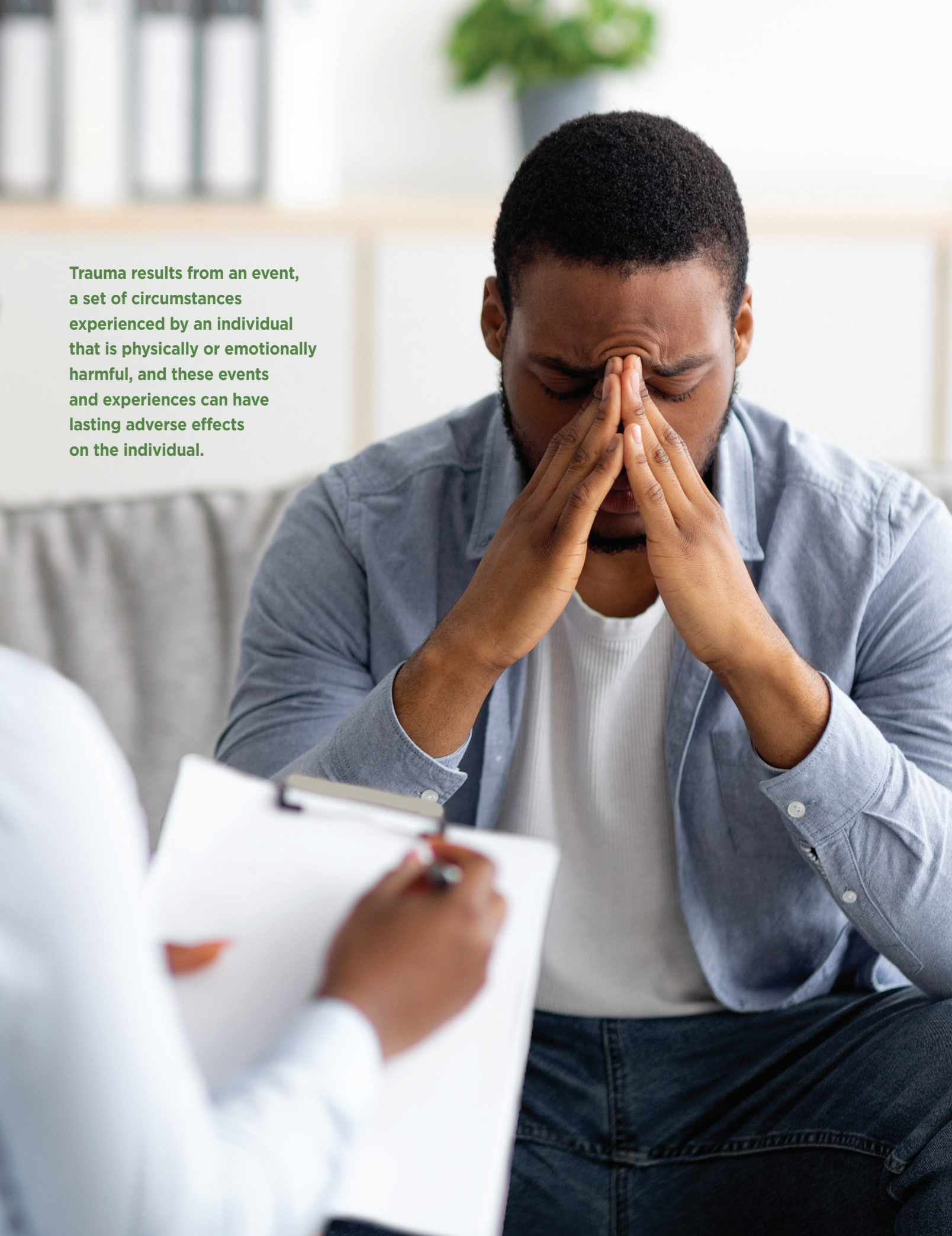
The framework for understanding trauma was developed by a working group of researchers, practitioners, trauma survivors, and family members convened by the Substance Abuse and Mental Health Services Administration

(SAMHSA) and defines trauma and the "Three Es": events, experiences, and effects. According to SAMHSA, trauma results from an event, a set of circumstances experienced by an individual that is physically or emotionally harmful, and these events and experiences can have lasting adverse effects on the individual.^{1,2}

The emphasis on the event places the cause of trauma on the environment rather than a flaw in the individual.^{1,2} The identification of a wide range of potential effects serves as a reminder that the response to healing must be holistic and that it is insufficient to concentrate only on symptoms or behaviors. The focus on experience emphasizes the fact that not every child or adult will experience the same events as traumatic.^{1,2} Understanding and acknowledging the broad range of potential effects reminds providers that their responses must be holistic and to not solely focus on symptoms or behaviors.



Trauma results from an event, a set of circumstances experienced by an individual that is physically or emotionally harmful, and these events and experiences can have lasting adverse effects on the individual.



Social-Ecological Model of Trauma and Resilience

Although the definition of trauma places a lot of emphasis on the individual, we also know that health is socially influenced and affects people at the societal, community, relationship, and individual level. Since we are relational beings, the relationships we have over the course of our lifetime within our families, the quality of life in our community, and the broader societal context in which we live all influence our personal health.

Traumatic experiences from the past have an impact on an individual's current behavior. Everyone must determine if, when, and where they will share their experiences, and they should never feel pressured to share a traumatic event or memory. Everyone interprets their experiences in a different way. While some may refer to a certain event as trauma, others may perceive it differently. Additionally, individuals may have diverse interpretations of the same experience. Everyone views life from a different angle, and different languages are used by different people to describe their experiences. Many people go through traumatic events throughout their lifetime. Even while a recent occurrence may be the current emphasis, the person's response to that event may be influenced by past experiences.

The likelihood of the long-term effects of trauma increases with the age at which the trauma occurs.^{1,2} For many people, the essential elements of the trauma experience are shame and humiliation. These feelings may be damaging and prevent recovery. One of the most crucial signals providers can convey to a trauma survivor is that whatever happened, it was in no way the survivor's fault. Giving trauma survivors the opportunity to share their story and be heard is among the most crucial things providers can offer.^{1,2} When a person's unique experience is acknowledged and valued, healing can begin.

How Individuals Experience Trauma

Many aspects of how trauma survivors choose to engage in healthcare are influenced by their experiences. They may neglect their health, harm themselves, avoid healthcare, not trust healthcare providers, and not

adhere to recommended therapies. Providing care that promotes healing and recovery for these patients requires a particular set of attitudes, knowledge, and skills encompassed in TIC.

The individual's experience of trauma may have a significant impact on how they are affected by it. Both short- and long-term impacts of trauma may not be evident immediately; however, how well the person is supported by their family, friends, and community following the trauma may also have an impact on the experience.³ Traumatic occurrences can result from a wide variety of situations. Events that the person does not recall, such as those that happened when they were young, might result in trauma. It may also result from actions that are well-intentioned and essential, such as medical procedures, or it might be brought on by something that did not specifically affect the person but rather a group with whom the individual feels a strong sense of identity.³

Being diagnosed with a chronic, life-threatening illness can be a traumatic stressor, and living with HIV, for example, can be a chronic stressor. Also, discrimination due to HIV status can be traumatizing. This discrimination can come from negative beliefs, feelings, and attitudes others have toward people with HIV, their families, and people who work with them.

Trauma can be caused by a single, catastrophic incident—known as single-episode trauma (also known as acute trauma)—or it can be caused by a series of stressful events over time, such as sexual assault and abuse that occurred repeatedly. It is equally significant to remember that exposure to or interaction with other people who have experienced trauma might result in trauma. This is often referred to as vicarious trauma.^{3,4,5}

Vicarious trauma is an occupational challenge for people working and volunteering in the fields of victim services, law enforcement, emergency medical services, fire services, and other allied professions, due to their continuous exposure to victims of trauma and violence. This work-related trauma exposure can occur from such experiences as listening to individual clients recount their victimization; looking at videos of exploited children; reviewing case files; hearing about or responding to the aftermath of violence and other traumatic events day after day; and responding to mass violence incidents that have resulted in numerous injuries and deaths.

Trauma can have an impact on a person's coping mechanisms, interpersonal interactions, and capacity to master developmental tasks. An individual's physiological reactions, health, psychological well-being, social interactions, and other factors may all be impacted by trauma.^{3,4,5}

ACE Trauma and Overall Health

Trauma has been linked to many negative health outcomes, and experiencing trauma causes neurochemical changes in the brain that have biological (as well as psychological and behavioral) effects on a person's health. Trauma causes changes in the hypothalamic-pituitary-adrenal (HPA) axis, a part of the brain that controls reactions to stress and regulates many body processes, including the immune system.⁶

The landmark ACE study, carried out by Kaiser Permanente and the Centers for Disease Control and Prevention (CDC), demonstrated the importance of distressing events for children and adolescents.

Giving trauma survivors the opportunity to share their story and be heard is among the most crucial things providers can offer. When a person's unique experience is acknowledged and valued, healing can begin.



The study has shown that ACEs are linked to health and social issues across the lifespan.⁶

For example, in adulthood, the history of ACE can result in complex clinical problems, with several coexisting mental and somatic disorders, such as post-traumatic stress disorder, depression, borderline personality disorder, compromised immune system, obesity, and diabetes. It has been suggested that during certain vulnerable developmental phases, the risk for subsequent ACE-related disorders is increased. All developmental domains may be affected by ACEs and trauma (i.e., attachment, physical, affect regulation, behavioral control, cognitive, self-image).^{6,7,8}

The ACE study found that the more adversity a person experiences, the greater the risk of many health conditions, including HIV and sexually transmitted infections (STI). As the number of ACE experiences increased, so did the chances of the individual experiencing cancer, chronic lung disease, skeletal fractures, and liver disease.^{6,7,8}

According to the CDC, the link between ACEs and later health and social outcomes helped explain a scientific gap. Research in the 1980s and 1990s showed that risk factors for many common diseases, such as smoking, alcohol abuse, and sexual behaviors, were not randomly distributed and that the risk factors for many chronic diseases tended to cluster. That is, people who had one risk factor tended to have one or more additional risk factors.

The ACE study provided data that linked ACEs to these risk factors. ACEs do not guarantee negative health outcomes for adults, but they increase the odds.^{6,7,8}

Neurobiology of Trauma

The most important function of the brain is to ensure survival, even under the most miserable conditions. The brain generates internal signals that register what one's body needs, such as food, rest, protection, sex, and shelter.⁹ All experiences change the brain, yet not all experiences have equal impact on the brain.⁹ Early experiences, especially traumatic ones, shape human development and the brain.

The brain creates a map of the world to point individuals where to go to satisfy their needs and it must warn individuals of dangers and opportunities along the way as well as adjusting actions based on the requirements of the moment. Psychological problems occur when one's internal signals do not work or when one's maps do not lead them where they need to go, when one is too paralyzed to move, or when one's actions do not correspond to needs.^{9,10}

The brain has a bottom-up organization. The bottom regions, such as the brainstem and midbrain, control the simplest functions. The top areas of the brain, such as the limbic system and cerebral cortex, control more complex functions. The development of the brain during infancy and childhood follows the bottom-up structure. The most regulatory, bottom regions of the brain develop first; followed, in sequence, by adjacent but higher, more complex regions. Sensory information about the outside world is processed through our eyes, nose, ears, and skin. These sensations converge in the thalamus. The thalamus receives all the input from our perceptions into an integrated and coherent experience. These sensations are then passed on in two directions, down to the amygdala (the unconscious brain) and up to the frontal lobes (our conscious awareness).^{9,10,11}

The "fire alarm" of the brain is in the amygdala. It sounds the alarm about a threat and activates the fear response. The amygdala is constantly scanning the environment for potential threats and danger. It will integrate sensory and cognitive information and determine whether the situation is a threat or not.^{9,10,11} Because the amygdala processes the information it receives from the thalamus faster than the frontal lobes do, it decides whether incoming information is a threat to our survival even before we are consciously aware of the danger. This has important implications for how individuals respond to crisis situations or to people who are responding to the present through the lenses of their past. When a person remembers a traumatic event, the fear response can be activated, just like it was when the event occurred.^{9,10,11}

Applying to Practice

It takes a multidimensional approach to comprehend trauma and treat individuals effectively. Healthcare providers frequently lack the tools or the knowledge necessary to recognize a patient who is going through the phases of trauma depending on their unique risk factors. There is a knowledge gap on understanding trauma and applying TIC to practice. This approach requires a delicate balancing act of objectivity, skill, and compassion to care for the individual in acute or chronic trauma.^{12,13}

TIC is a strengths-based service delivery approach. This approach to care acknowledges the need to understand a patient's life experiences to deliver effective care. It has the potential to improve patient engagement, treatment adherence, health outcomes, and provider and staff wellness. This integrated, comprehensive approach includes providing a safe environment for all individuals, identifying individuals who are survivors of trauma, and implementing practices to avoid re-traumatization. It also involves assessing individuals' needs, providing them with resources and referrals that will facilitate recovery, and monitoring both processes and outcomes in the clinical setting for ongoing quality. It is crucial to have an integrated, all-encompassing strategy that covers everything from assessing individuals for trauma to evaluating the results of quality improvement.^{12,13}

Guidance for Clinicians Seeking to Provide TIC

Integrating TIC practices into one's clinical encounters involves a series of considerations that any clinician can begin to put into practice. However, these considerations cannot be reduced to a simple checklist. Rather, they involve seeing patients, colleagues, staff, and oneself through a trauma-informed lens that heightens one's awareness of the "Four R's" of TIC by SAMHSA:¹⁴

- 1. Realize** the widespread impact of trauma and potential for recovery
- 2. Recognize** signs of trauma
- 3. Respond** by implementing appropriate policies, procedures, and practices
- 4. Resist** re-traumatization

Approaching the clinical encounter using a trauma-informed lens first requires acknowledging that trauma is prevalent; in fact, the prevalence of trauma is higher among individuals living with HIV than the general population.^{15,16} Anyone may have a trauma history, whether they have disclosed that history or not. While evidence suggests that patients generally want to be asked about past traumatic experiences, many may choose not to disclose past trauma, particularly in a clinical setting with a new healthcare professional with whom they have not yet established a trusting relationship.^{17,18}

TIC does not require compelling patients to disclose past trauma, "screening" patients to identify those with a trauma history, or becoming an expert in treating post-traumatic stress symptoms. Rather, the trauma-informed clinician integrates certain patient-centered practices into every clinical encounter with every patient universally.^{19,20,21}

Introduction to the TIC Toolkit

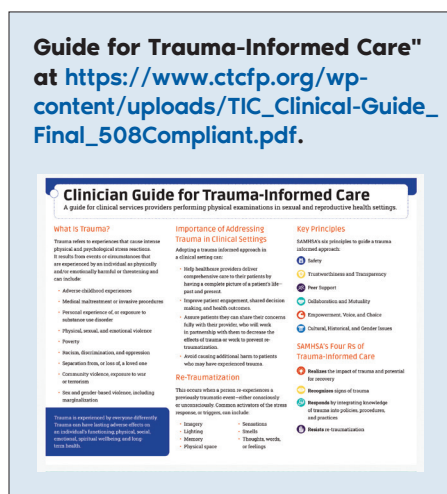
To aid clinicians in providing TIC, the National Clinical Training Center for Family Planning and the National Coalition for Sexual Health recently developed a downloadable toolkit. This helpful resource contains a TIC roadmap for the clinical encounter with action steps, sample phrases, and practical tips for how to implement a trauma-informed approach in a clinical encounter. While the guide was developed specifically for clinicians performing physical exams in sexual and reproductive healthcare settings, the roadmap can easily be applied to other clinical settings, including HIV medicine.

As background for clinicians who may be unfamiliar with TIC, the



TIC is a strengths-based service delivery approach. This approach to care acknowledges the need to understand a patient's life experiences to deliver effective care. It has the potential to improve patient engagement, treatment adherence, health outcomes, and provider and staff wellness.

guide provides an at-a-glance overview of the definition of trauma, examples of common traumatic experiences, and SAMHSA's "Four R's" and six key principles that ground the trauma-informed approach. Those key principles (safety, trustworthiness and transparency, peer support, collaboration and mutuality, empowerment/voice/choice, and cultural/historical/gender issues) are critical for supporting patients to feel physically and psychologically safe, respected, able to trust their clinicians, able to exercise their own agency and to partner with their clinicians in the management of their own health without fear of discrimination based on their cultural





background or gender.¹⁴ This first part of the guide also lists common aspects of the clinical encounter that could trigger memories or re-experiencing of a traumatic event, such as disturbing imagery on the walls, clinic lighting, smells, specific words, and other potential stressors.

There are several aspects of the guide that users may find especially useful in providing clinical care. First, it provides suggestions for how to respond appropriately if a patient chooses to disclose their past trauma by offering validation, expressing empathy, describing the assurance of and limitations on confidentiality, inquiring about safety and overall wellbeing, and avoiding inadvertently re-traumatizing the patient making the disclosure. The guide also recommends specific trauma-informed actions to consider before, during, and after a physical exam—an aspect of the clinical encounter that can be particularly re-traumatizing if not performed using a trauma-informed approach. Clinicians may wish to use the sample phrases and key discussion points which integrate universal trauma precautions for avoiding re-traumatization. Finally, the guide includes a self-assessment checklist to evaluate one's own progress implementing TIC approaches throughout the clinical encounter.

Conclusion

A culture that upholds and supports TIC principles cannot exist without organizational support. Emphasizing the importance of and providing chances for self-care, empathy, and other forms of support for all healthcare providers, patients, and personnel is crucial. Reinforcing the healthcare team's ability to use their expertise to develop strength, resiliency, and hope is necessary in creating a trauma-informed clinical practice that ensures that all patients as well as clinical and administrative personnel and staff feel physically and psychologically safe, respected, and supported. **HIV**



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A double board certified, women's health nurse practitioner and advanced forensic nurse specializing in human trafficking and female sexual health, she created and implemented a medical program for emergency stabilization for commercial sexual exploitation of youth in Georgia. Dr. Quaille is also trained and certified as an AASECT sex counselor and sexual assault nurse examiner providing sexual health education, trauma-informed care, and information to patients of all ages. She is widely published in the field of women's health, trauma-informed care, and regularly lectures to local and national audiences.



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Health & Healing

Trauma-Informed HIV Care for Haitian Asylum-Seeking Women and Children

By Nicole Pepper, PhD, LCSW, Karen Deutsch, MPH, FNP, and Kelsie Nuño, LCSW

OVER THE PAST THREE YEARS, there has been a significant increase in Haitian asylum-seeking women and children with HIV presenting to our program for medical care, resulting in the need to quickly adapt our services. Most are new to the United States (U.S.), newly diagnosed with HIV and, in many cases, multiple members of the family, including children, are living with HIV. To meet the unique needs of this population and promote care engagement and retention, we had to ensure delivery of culturally responsive, trauma-informed approaches.

Background

Our Ryan White funded program provides comprehensive integrated HIV primary care and support services to women, children, and youth with HIV—most of whom are living at or below the poverty line and receiving medical services through Medicaid or Ryan White funding. We are located in San Diego, Calif., a designated Ending the HIV Epidemic priority jurisdiction located on the U.S.-Mexico border. San Diego County is a large geographic region that includes urban, suburban, and rural areas and is home to a vibrant binational community and the world's busiest land border crossing.

Over the past decade, there has been a growing crisis at the U.S.-Mexico border. This was officially recognized in 2014 when the U.S. government declared a humanitarian crisis at the border. Asylum seekers are individuals who arrive in the U.S. or at a port of entry legally seeking refuge due to

persecution in their native country. In 2019, the federal government implemented and the Supreme Court upheld new laws specifically aimed at keeping asylum seekers at the border and denying them entry.

One of these policies, the “Remain in Mexico” program (Migrant Protection Protocols), removed 65,000 people seeking asylum in the U.S., sending them across the border to await their asylum proceedings in Mexico. In 2020, as COVID-19 spread across the globe, the U.S. government implemented Title 42 of the Public Health Service Act. Title 42 is a public health authority that authorizes the Director of the Centers for Disease Control and Prevention (CDC) to suspend entry of asylum seekers into the U.S. and to deny individuals the right to seek



asylum in order to protect public health. At the U.S.-Mexico border, these policies resulted in large migrant camps with scarce resources in Tijuana, Mexico, and other border cities.

While we also serve patients seeking asylum from Africa and Central and South America, the majority of recent asylum-seeking patients in our program are from Haiti. Many Haitian asylum seekers have faced a harrowing migration journey. For many migrants, their path began in Brazil where they were offered work in preparation for the World Cup and Olympics.

As these events passed, Haitians were left without work and, in many cases, faced racism and violence. As a result, many continued their journey through South and Central America, eventually arriving at the U.S.-Mexico border. In December 2021, 2,000 Haitians arrived in the San Diego area, primarily from South America. The asylum process can take several years, and few Haitians are ultimately granted asylum; over 20,000 Haitians were removed from the U.S. in 2021 alone.

Cultural Considerations and Unique Needs

History of Systemic Discrimination and Stigmatization

Historically, policies and practices have contributed to HIV stigma and discrimination experienced by people from Haiti. In 1982, the CDC included Haitians among four groups considered “high risk” for HIV (including people who inject drugs, gay men, and people with hemophilia); Haitians were the only group included based on nationality. Haitians have also been identified in the media for bringing HIV to North America, banned temporarily by the Food and Drug Administration from donating blood, and detained in a segregated camp within Guantánamo Bay.

People with HIV were banned from immigrating to the U.S. between 1993 and 2009, and in 2017 it was reported that then President Trump made erroneous and stigmatizing comments about people from Haiti and HIV. The effects of stigma have resulted in isolation, diminished support systems, discrimination, and loss of economic resources. Many of the families we serve have not disclosed their HIV status to anyone in their support system and may decline resources and referrals for fear of disclosure.

Unmet Basic Needs

Our patients seeking asylum often lack access to resources to meet basic needs, including food. Many have little to no income while they await work permits (asylum seekers cannot apply for a work permit until 150 days after applying for asylum). They face significant challenges securing safe and stable housing, and also face rates of housing instability in San Diego County that surpass state, regional, and national averages.

Many of the families we work with experience homelessness, temporary shelter, or end up in communal living arrangements where they share small homes, apartments, or rooms with several other people or families. This presents significant barriers to HIV adherence, particularly for pediatric patients who use liquid antiretroviral formulations, as many families are so fearful of HIV disclosure due to stigma that they hide their medications, remove labels from medications, or decline medication delivery.

Lack of Culturally Appropriate Resources

Many of the resources available in the community do not provide culturally responsive resources or language services. For example, patients are not able to find foods they are familiar with preparing or do not have access to refrigerators or kitchens. Many of the shelter options available do not accommodate families. Other subsidized housing options require citizenship. Patients must often navigate incredibly complex systems (e.g., healthcare, legal system, benefits) and other resources without adequate access to language services. Even where language services are available, such as within our healthcare system, patients sometimes decline use of interpreters due to fear of HIV disclosure.

COVID-19

The pandemic exacerbated barriers for asylum seekers by suspending the right to seek asylum and caused excessive delays in the legal and court systems. Further, many healthcare and other social services limited or eliminated in-person services during the pandemic, reduced available services, and moved to telehealth platforms.

Legal

Few free or low-cost legal resources are available in our community to asylum seekers and even fewer offer language support. The asylum process is incredibly lengthy and complex and many of our patients’ cases remain ongoing for several years. To date, none of our patients from Haiti have been granted asylum and their court dates continue to be extended.

Referrals and Engagement in Care

Many of the referrals we receive are from community-based organizations serving asylum seekers or Labor and Delivery departments of local hospitals. Many pregnant asylum seekers referred to our obstetric program present late in pregnancy with limited or no prenatal care, having been diagnosed with HIV upon their arrival in the U.S.

In our experience, the priority of both the newly-diagnosed parent and the healthcare team is solely to prevent perinatal HIV transmission during pregnancy and delivery, which can result in overlooking the need for pregnant

Understanding the trauma histories our patients and their families have experienced in their country of origin, on their migration journey, and at the border has shaped the way that we provide services.



patients to process their new HIV diagnosis or engage in their own care. For the majority of our Haitian patients, their male partners have tested HIV-negative. While most of our clients are hesitant to disclose any additional risk factors, many have shared experiences of sexual violence on their journey to the U.S.

Implementing Trauma-Informed, Culturally-Responsive Approaches

Understanding the trauma histories our patients and their families have experienced in their country of origin, on their migration journey, and at the border has shaped the way that we provide services. Our family nurse practitioner and pediatric and obstetric clinical social worker work collaboratively to assess and address the needs of the population by engaging in cultural sensitivity training, tailoring trauma-informed approaches, building on our existing integrated multidisciplinary model, networking with other HIV clinics situated in border regions, and building partnerships with local agencies. Below we describe some of the strategies we have adopted.

Team Cultural Humility and Trauma-Informed Care Learning

Our multidisciplinary team participates in routine multicultural and trauma-informed care trainings and has sought out trainings relevant to working with Haitian asylum seekers. Our medical providers were trained in providing trauma-informed physical and pelvic exams. We have also learned by listening to our patients' perspectives of the health system and receiving medical care. Patients have shared about the importance of developing trust and rapport in the patient-provider relationship and the role faith plays in achieving health outcomes.

Family-Based Care

Our team attempts to engage the entire family system when possible and appropriate. We offer HIV testing to partners and children and quickly link patients into our obstetric, pediatric, and women's HIV clinics where they receive integrated medical care and intensive case management. For families in which both the parent and child are diagnosed with HIV, our coordinated team strives

to streamline care with continuity across pediatric and adult programs with our family nurse practitioner. Social workers and medical providers conduct conjoint home visits during which family medication teaching and health education are provided.

Coordinated and Integrated Multidisciplinary Care

Our care model offers integrated medical and support services; based on patient preference, social workers often participate in the medical visit in collaboration with the patient and medical provider. We universally screen our patients for experiences of trauma; however, we allow discussion and disclosure of trauma to be patient paced and occur over time as patients develop trust and rapport with their care team. Psychiatric care, mental health counseling, and support groups are available for patients who wish to engage in trauma-focused treatment.

Basic Needs Support

Before patients can focus on HIV care, basic needs must be met. Through fundraising

efforts, we have been able to provide grocery vouchers and infant care items. We offer ride share services when transportation is a barrier. Through the development of community partnerships, we are able to offer on-site childcare during appointments and warm hand-off tailored referrals for people seeking asylum, which include benefits navigation (e.g., Medicaid, work permits, cash aid), legal services, and employment and education services.

Language Services

Many Haitian families are multilingual (e.g., Creole, Spanish, Portuguese, and/or English) and often elect to receive services in Spanish with our bilingual providers, rather than use Creole interpretation services, citing HIV disclosure privacy concerns. We assess language preference for each patient and offer care in their language of choice. We have also adapted by utilizing smartphone applications that assist in translation and WhatsApp communication for individuals without mobile service who rely on public Wi-Fi access.

Cultural Norms/Expectations of Childbirth and Feeding

While guidelines about chest/breastfeeding are adapting, we recognize that the cultural norms and expectations, as well as our patients' preferences, often shape complex decisions around infant feeding. Our program is working to partner with our patients in shared and informed decision making. We have partnered with the obstetric and pediatric hospitalists, midwives, doulas, and lactation support services to overcome barriers and create a supportive and well-informed community of providers and caretakers for childbearing patients in our program.

We have also partnered with the local donor milk bank to help finance donor milk, for patients who choose that option, and we provide formula for those who opt to formula feed. While we offer postpartum support groups, we have had difficulty engaging Haitian patients due to language barriers and fear of HIV disclosure. We are currently working to establish a relationship with a doula in the Haitian community who can offer services in Creole to support our pregnant, birthing, and postpartum patients as well as their infants.

Outcomes, Strengths, and Successes

Since 2019, 16 Haitian women with HIV have been referred to our program. We also care for five Haitian children with HIV and seven infants born to Haitian women with HIV for whom we provided prophylactic care. Among Haitian asylum-seeking women referred to our care, nearly three-quarters had detectable HIV viral loads at baseline and 82 percent have achieved viral suppression since engaging in care. Among asylum-seeking Haitian children with HIV (newborn to three years), all had detectable HIV viral loads at baseline, and all have achieved viral suppression since engaging in care.

We have found that despite multiple barriers, including trauma, low literacy, language barriers, and complex systems, our clients are overwhelmingly successful. They have strong family bonds, cultural ties and faith belief systems, are adherent to medications, quickly achieve viral suppression, and demonstrate determination and resilience in navigating incredibly complex systems.

Conclusion

In our program's 30-plus year history, we have never faced a larger influx of patients from one country in such a short period of time. Our team quickly pivoted to learn about the asylum legal process, the Haitian migration journey, and the history and culture of Haiti. We also strove to understand the cultural expectations, barriers to care, and the needs of our new patients. We sought out and engaged new community partners, delivered medications secretly behind stores, and networked with other HIV providers around the country.

Our success is apparent, not only in the rates of viral suppression and care retention, but also in our patients' satisfaction. One of our patients said it best when we asked her about her experience with our program: "[My experience receiving care in your program has been] very good because I don't have a car, but I always have transportation. I always have medications. Everything is good because they treat me well. They are very caring. They never treat me bad or look at me badly. Everything is good for me, for my family." We are humbled that patients have trusted us with their stories and are inspired by their

resilience. We strive to be a positive part of their journey. **HIV**



DR. NICOLE PEPPER (she/her) is a licensed clinical social worker with a PhD in interdisciplinary research on substance use with over 15 years of experience working with people living with HIV and co-occurring disorders. She has a strong clinical, administrative and research background in HIV, substance use and mental health with a focus on vulnerable populations. She has been with the UCSD Mother Child Adolescent HIV Program since 2010. As Social Services Supervisor, she provides mental health and medical case management services, as well as clinical supervision for a team of case managers and mental health providers. In addition to clinical services, she is part of the leadership team and provides administrative and grants management support.



KAREN DEUTSCH, MPH, FNP (she/her) is a Board-Certified Family Nurse Practitioner who has been with the Mother Child Adolescent HIV Program at UCSD since 2019. She works primarily in the Women's Health and Pediatric Virology Clinics. In addition, she takes call for all San Diego County hospitals when possible new HIV cases are identified in Labor and Delivery. Prior to relocating to San Diego, Karen worked in primary care for San Francisco County with underserved and immigrant communities. She also spent many years working on migrant health projects and nursing education in Africa, Asia and South America. She is passionate about caring for migrant communities who face unique barriers to care.



KELSIE NUÑO, LCSW, MSW (she/her) has a background in social work with an emphasis in children and families. She began working for the UCSD Mother Child Adolescent HIV Program in 2019 and currently provides comprehensive medical case management and mental health services to a diverse population that includes refugee and asylum seeking families. She serves women and children dealing with complex psychosocial barriers and is a strong advocate for accessible medical and social care. Kelsie provides trauma-informed care and specializes in postpartum mental health services. Kelsie is passionate about bridging the gaps in maternal mental health, especially among the growing asylee population. Kelsie has partnered with UCSD Volunteer Doula Program in efforts to start expanding services and better support patients.

Research Into the Impact of Prior Authorizations on Antiretroviral Therapy

BY WILLIAM R. SHORT, MD, MPH, AAHIVS

Editor's Note:

William Short describes recent research on prior authorizations (PAs) that he and his colleagues conducted. The research team includes:

- David E. Koren, PharmD, MPH, BCPS, AAHIVP
- Bruce Packett
- Scott Brawley, MSW
- Leslie McGorman, MPPA
- Jonathan Appelbaum, MD, FACP, AAHIVS

Background

The American Medical Association has highlighted concerns around PAs, including delays in care, abandonment of treatment, and serious adverse events. Although research on PAs has been helpful to assess the effect of healthcare practice overall, there is a gap in research on the effects of PAs on antiretroviral (ARV) management. My colleagues and I sought to uncover what these effects are, if any.

Research Methods

Using a questionnaire adapted from a previously validated survey, the American Academy of HIV Medicine (AAHIVM) distributed a cross-sectional survey to its members and credentialed providers (n=4510) between August 3, 2021, and September 9, 2021.

Participants included physicians, pharmacists, physician assistants, and nurse practitioners. Participants were asked 28 multiple choice or open-ended questions to describe utilization management techniques (UMT) and the impact that they may have on their practice as well as their overall impressions. Descriptive statistics were used to summarize multiple choice questions.

Survey Results

- There were 173 questionnaires completed (66% prescribers and 33% pharmacy professionals) with varied HIV experiences (39% greater than 20 years).
- For treatment naïve patients, 43 percent of the respondents stated that PAs were needed one to 25 percent of the time.
- For medication switches, 51 percent of the respondents stated that PAs were required 26 to 50 percent of the time.
- Per month, 56 percent of respondents described PAs affecting up to 10 patients.
- Over the last five years, 64 percent of respondents noted an increase in PAs.
- Due to UMTs, 48 percent of clinicians responded that their patients/clients have resorted to taking a partial antiretroviral regimen and 71 percent of respondents described UMTs as causing a negative impact on patients' emotional or mental health.
- Roughly 67 percent of participants needed dedicated staff for PAs, and among those who did not have dedicated staff stated that they would prefer to have such a person (45%).
- Overall, 72 percent of participants reported UMTs hindering their ability to prescribe optimal ARVs.
- Over 50 percent of respondents described: UMTs causing altered prescribing habits (55%), prescribing a less desirable ARV regimen (50%), and opting for generic alternatives of ARVs (56%).

The Takeaway

One of the four key strategies in ending the HIV epidemic is rapid treatment of people with HIV to achieve sustained viral suppression. This approach mandates minimizing barriers to ARV access as well as any disruption to therapy. PAs are a barrier to achieving this goal. ARV UMTs require further study to ensure optimal patient care as well as to find ways to reduce interruptions in therapy and the likelihood for adverse events. **HIV**

WILLIAM R. SHORT, MD, MPH, AAHIVS, is an associate professor of medicine at the Perelman School of Medicine at the University of Pennsylvania. He is also associate director and co-investigator of the AIDS Clinical Trial Unit at the University of Pennsylvania and the co-director of the Clinical Core for the Penn Center for AIDS Research. His research interests include assessing the impact of treatment strategies on surrogates of immune dysfunction and end-organ disease and studies evaluating new drugs for the treatment of HIV. He is chair of the board of directors of the American Academy of HIV Medicine.

HOLISTIC HEALING

for the LGBTQIA+ Community

A personal essay on the intersection of hope, activism, spirituality, and mental health

By Rev. Valerie Spencer, MSW

T ALL BEGAN FOR ME by way of one magical voice in the person of Archbishop Carl Bean of the Unity Fellowship of Christ Church in Los Angeles, Calif. Back then, he was just “Rev. Bean.” There at the “Unity” I was exposed to a whole new way of thinking about biblical interpretation and myself as a transgender woman. But we also learned about social justice and its role in supporting those with HIV ... how to love those with HIV, how to regard the family members of those with HIV, and how to question systems that overlooked and failed to properly respond to the needs of the people. For this was living scripture: to serve the weak, feed the poor, and clothe the naked.

Unity and Rev. Bean changed the entire trajectory of my life and many others. We learned that God has no hands but our hands, and God had no feet but our feet. Unity was always at the forefront of addressing the needs of queer people of color, particularly those navigating HIV. Back in those days, Unity even had couches in the back that were especially for people with HIV. This was to give them comfort as they sat during the church service, making celebration and worship accessible to them in such time of physical, spiritual, and emotional need.

Heeding the Call

But one day my life completely turned upside down. On this particular Sunday, we had a special guest in the audience, the iconic AIDS activist Connie Norman, better known as the AIDS Diva. During the service, Connie walked out to the back parking lot and I found myself there as well, needing a breather. A good ol’ Black Pentecostal worship service can be a little rough, y’all, and can call for a breather. There, while smoking a cigarette, Connie talked to me and told me she was dying. She wanted me to take over her work, and I agreed. Both she and Rev. Bean seemed to conspire on this. It was like they had a back door conversation and agreed that I was going to be an activist focusing on transgender individuals. So, I went for it!

I became an AIDS activist locally, which grew to national representation. It did not

take me long before I discovered that the uniqueness of queer people affected by HIV needed much more than information concerning transmission and prevention. Our people, just like Connie did that Sunday morning, needed healing. I began a long journey that led me to investigate healing tools and practices that would benefit our people, queer people, queer people living and navigating through HIV, fighting low self-esteem and low self-worth. It was a long and winding road that led to the development of an organization called the Holistic Empowerment Institute that is the center of my work in promoting healing for LGBTQIA+ communities.

A Place for the Whole Person

The Holistic Empowerment Institute combines whole-person, cultural affirmation, and intentional spiritual integration as primary tools to empower LGBTQIA+ communities. The Holistic Empowerment Institute is a healing organization dedicated to merging evidence-based practices with the sacred. As an organization, our goal is to cultivate and maintain a holistic position in the development of systematic, community, group, and individual interventions toward sustainability and well-being. This holistic position is the foundation of LGBTQIA+



spiritually integrative community mental health and healing. This is our movement! As an organization, we are able to develop tools and practices that are nonjudgmental and non-biased, that instead affirm the queer experience and directly infuse self-directed spirituality into the conversation knowing that spirituality can be a tool of healing for our people. We call this intentional spiritual integration.

The point of our work is not to engage people in a rehashing of the “shoulds” and “should nots,” but to support persons in getting to know their own internal landscape. We create environments whereby the uneasy conversations can be had. We are able to talk about spiritual abuses of the past that contribute to problematic behavior of today. We are able to provide a safe space whereby healing can take place by the use of self-directed and non-biased spiritual tools. We merge evidence-based practices with world and indigenous healing practices to form spaces where queer people can engage in radical self-affirmation and healing.

During our empowerment groups and virtual spiritual support sessions, people are able to express the trauma associated with navigating HIV, both as a person with the virus and those navigating prevention with healthy sex/living practices. The Holistic Empowerment



Institute is currently developing a training on intentional spiritual integration for behavioral health and allied health professionals. We want to teach how they can affirm the LGBTQIA+ experience rather than posturing our community in terms of deficits or “risk groups.”

I often find it funny when I talk to behavioral health professionals who completely overlook the spiritual dimensions of providing services or treatment. I discovered through conversations that our people crave spiritual attention but are most often afraid of reliving the spiritual traumas of their pasts. But why is healing so important and just what is healing in the first place? We define healing as a restorative experience that supports resolution of historical trauma. We find that in many cases, this is the primary conversation that we are having: the need to resolve the issues from the past by way of a restorative process that incorporates the internal along with evidence-based practices.

Healing Others and Myself

The work has changed me as a woman, as a healer, and as the founder of this organization. I brought with me my challenges with navigating caregiving as an only child while caring for my elderly bedbound mother. I brought with me depression and suicidal ideation and came to discover that navigating the world in this form of womanhood brought these emotional barriers as a part of my experience. I had to practice what I preached, find help, be consistent with that support, and surround myself with people who saw both my possibility and problems in context.

Losing friends to HIV, living with the expectation that I would be next and, well, just being lonely took a toll on me. Traveling the country as a community planning and public policy consultant, navigating social justice activism, and being a woman who is both Black and trans often dictated that I seek support. But I had to go even further and name myself a healer intentionally. For me, this created a whole new context of my contribution. I’m now an interfaith minister and behavioral health therapist who supports my community and my own deep and profound healing needs. I encourage others to seek and secure support for their mental and spiritual health.

In doing this work, I hope others hear the call to the path that both Rev. Bean and Connie set me on years ago. Now that both of them are ancestors, I hope that my work keeps their names alive and the work they gave their all to. The whole point is that we are flawless. Our lives and healing matter. I hope to continue providing space for healing for all those affected by HIV. We must thrive and we will, one dismantled belief system at a time.

Learn more about the Holistic Empowerment Institute at beholistic.org. **HIV**

REV. VALERIE SPENCER, MSW, is a healer, behavioral health therapist, cultural visionary, national community leader, and interfaith minister. She has been at the forefront of addressing behavioral health issues as it relates to LGBTQIA+ communities of color. She is the founder of the Holistic Empowerment Institute.

Creating Affirming Practice for Transgender and Gender-Diverse People with HIV

Release Date: December 19, 2022
Expiration Date: March 19, 2023

This accredited continuing education activity is jointly provided by



and



FACULTY: Jay Holloway, PharmD, Health Corner Pharmacist at Walgreens

TARGET AUDIENCE: This activity is intended for frontline providers of care to persons at risk for or who are living with HIV, including specialist and primary care Physicians, NPs, PAs, Nurses, and Pharmacists. Other HIV care team members are also encouraged to participate.

DESCRIPTION/LEARNING OBJECTIVES: The goal of this article is to help members of the frontline HIV care team to be better able to:

- Identify terminology used to define transgender and gender diverse (TGD) populations, health disparities, and barriers to care that TGD patients face when accessing care.
- Reflect on how current language and assumptions that take place in patient interaction with the care team may lead to an unsafe environment or inaccurate assessment of TGD patients.
- Work with your care team to implement changes to healthcare policies, practice and procedure which results in accurate and respectful interactions with TGD patients.



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Creating Affirming Practice for Transgender and Gender-Diverse People with HIV

BY JAY HOLLOWAY, PharmD

TRANSGENDER AND GENDER-DIVERSE (TGD) **INDIVIDUALS** are a key population disproportionately affected by the HIV pandemic. When seeking HIV testing and treatment, TGD patients are less able to access care due to fear of stigma and discrimination, while stigma also results in poor health outcomes and increased risk of HIV incidence.¹ In the clinical setting, the omission or pathologization of trans identity in our electronic health records (EHR), can result in gaps in care.² This deficiency in care can be addressed by the care team through implementing individual and systemic changes in the practice setting that create an inclusive, affirming environment for TGD people to access testing, treatment, and support.

Definitions and Disparities

Cisgender people are those whose gender identity matches their sex assigned at birth. Transgender encompasses a wide variety of gender identities in which a person's gender is different than their sex assigned at birth. In addition to transmasculine (including trans men) and transfeminine (including trans women), some individuals are also nonbinary, in which their identity does not fit into exclusively man or woman. While nonbinary can function as an identity in itself, a person may also describe themselves as genderqueer, agender (lack of gender), bigender, or other labels. All of these identities fall under the umbrella of



transgender and gender-diverse (TGD).

It is important to note that gender identity and expression is shaped by one's culture, and there are gender identities outside of White Western binaries of man and woman; whether a person identifies as transgender is up to the individual. An example is the gender identity "winkte," a gender in Lakota culture which describes "a male-bodied person who speaks like a woman," and may serve in unique community roles.³

Stigma and discrimination are contributing factors to the increased HIV prevalence in TGD populations. In 2019, the Joint United Nations Programme on HIV/AIDS found that the risk of acquiring HIV was 13 times higher in TGD people compared to cisgender adults.⁴ A 2021 global meta-analysis concluded that odds ratio of HIV in transgender individuals worldwide is 66 times higher for transfeminine and approximately seven (6.8) times higher for transmasculine people.⁵ Stigma and discrimination also create barriers to care and poor health outcomes. These stressors, both through direct consequences of discrimination and the background stress of navigating as a stigmatized person, puts

additional strain on physical and mental health, also known as the "minority stress model."⁶ As a result, TGD people experience higher rates of depression, substance use disorders, and other chronic health conditions, including HIV.⁷

TGD patients are often less able to adequately access treatment for health concerns. According to the August 2021 Center for American Progress report, transgender patients experience higher rates of unemployment and poverty than their cisgender peers.⁷ Higher rates of unemployment results in less healthcare coverage, and even if a TGD individual has health insurance, their gender-affirming care may not be covered, or outright excluded due to state legislation. A patient's healthcare plan also may not have their chosen gender on their record, or a patient may keep their original sex assigned at birth on the plan to ensure coverage of preventative health, such as pap smears and prostate screenings.

The 2021 Center for American Progress survey found that 28 percent of transgender people delayed or avoided seeking care due to discrimination.⁷ As well, 51 percent of

transgender people avoided or delayed care due to cost. Thirty-three percent of transgender respondents said they had to teach their provider about transgender identity in order to receive appropriate care.⁷

These barriers and outcomes are compounded along intersecting marginalized identities; Black, Indigenous, and trans women of color face even higher rates of discrimination.⁷ If healthcare professionals are to address this troubling discrepancy, the care team must take the initiative to be educated on TGD patients so the patient does not have to provide this education. The healthcare team must also be mindful of these health disparities and utilize a trauma-informed practice approach. Trauma-informed care is practice which acknowledges the harm that an individual may have faced on both an individual and community level, and seeks to prioritize developing a trusting relationship between the patient and the healthcare team.⁸ This practice also includes acknowledging historical sources of medical distrust, and works to empower the patient as an active participant in their health.

A TGD patient may also be hesitant to start or continue antiretroviral therapy (ART) due to misconceptions about the interactions of gender-affirming care and ART medications.⁹ There are few studies specifically studying the effects of ART on transgender patients. The NIH HIV Guidelines for Antiviral Use in Special populations notes that "...for many transgender people, gender-affirming therapy (e.g. feminizing hormones) is a greater priority than HIV treatment and care," while also stating that engagement in HIV care by TGD patients increases when gender-affirming care needs are met, as well as ART adherence.⁹ Thus in addition to ensuring a safe and supportive environment, access to gender-affirming care should be emphasized by the members of the care team.

Self-Reflection Question: How does your place of practice ask about sexual history during intake? What assumptions are potentially being made regarding gender identity and genitalia/sexual acts involved? How could you work with your team to improve the wording?



Affirming, Inclusive Language and Taking a Sexual History

A key point of impact to create better care for TGD patients is how a sexual history is obtained. Gendered language which makes assumptions based on gender identity may result in an incorrect assumption of patient needs. For example, if an HIV clinician asks a patient “Do you have sex with men, women, or both?” it makes assumptions regarding the genitals and acts involved, and may not provide a complete picture.

Incorrect treatment choice, such as FTC/TDF (Truvada) vs. FTC/TAF (Descovy) for pre-exposure prophylaxis (PrEP), may also occur if a patient does not feel safe disclosing the sex they were assigned at birth. For example, FTC/TAF is not indicated for individuals at risk from receptive vaginal sex.¹⁰ If a transgender man who does not feel comfortable sharing this with his provider, he may be accidentally prescribed FTC/TAF instead of FTC/TDF, which is indicated regardless of sex assigned at birth. The wording of the previous question also doesn’t account for nonbinary individuals. When taking a sexual history, it is recommended instead to use language that decouples acts and genitals from gender identity, such as:¹¹

- “What types of sex do you have? What actions and body parts are involved?” If a patient has anal intercourse, ask if it was receptive or insertive.
- “What are your experiences with condom use?”
- “Do you enjoy having sex? Do you feel safe having sex? Does your partner(s) affirm your identity?”
- “Can I ask you a few questions about your sexual partner(s)?”
- “Do you have sex as part of work? Do you have sex in exchange for money or other goods?”

When asking questions about sexual history, it is important to establish a safe environment and explain why a question is being asked so patients don’t withhold information that would result in an incomplete sexual history, which might negatively impact current or future care, or which might lead them to forgo engaging in care in the future.

Gendered language to refer to genitals is also a barrier to care. TGD people may use

unique terminology to refer to their body in ways that do not induce dysphoria. For example, some transgender men may refer to their vagina as “front,” or their clitoris with terms like “t-dick.” It is important to note how a patient identifies their bodies and use these affirming terms in patient conversations.¹²

Self-Reflection Question: Reflect on your practice location (hospital, clinic, pharmacy, etc.). What elements of your practice may make it difficult for TGD people to access care? What elements are implemented to accommodate TGD people? Are TGD people visible in practice signage and advertisement? Staff and leadership?

POST-TEST QUESTIONS

1. Which of the following statements regarding health disparities for TGD patients is INCORRECT?
 - A. In one study, 33 percent of TGD patients reported they had to teach their provider about transgender people in order to receive care.
 - B. Transgender health disparities are generally level across intersected identities such as race and gender.
 - C. TGD people may avoid seeking care from a healthcare provider due to fear of discrimination.
 - D. TGD people experience higher rates of unemployment and poverty than cisgender people.
2. Which of the following are ways that the healthcare team can create a transgender-affirming practice environment?
 - A. Have TGD staff leading policy development and providing input at all levels of patient care.
 - B. Display signage and promotional materials featuring TGD patients and healthcare team members.
 - C. Implement changes to electronic health records which allow for chosen name, gender, and pronouns.
 - D. All of the above.
3. A 31-year-old transmasculine nonbinary individual presents to your HIV clinic. Which of the following are appropriate to ask when taking a sexual health screening to ensure accurate, quality care?
 - A. Ask if the patient has sex with men, women, or both.
 - B. Ask the patient how often he seeks care for women’s health, to ensure if an HPV screening is needed.
 - C. Asking what genitals and acts the patient is involved in, as well as the patient’s preferred terms for their parts.
 - D. Ask the patient if he has noticed an increase in sexual attraction to women since starting testosterone.

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Systemic Changes

A critical point in which care for TGD patients can be improved is at the first impression when a patient walks into the clinic. One best practice is to provide visible signage towards the public that your practice is affirming; this can come in the form of pronouns on staff badges, community pride symbols, and publicity material featuring TGD people.

Policies and procedures should also encompass training for all staff members on caring for TGD patients, include non-discrimination policies, and provide feedback and accountability for patients if an incident occurs. TGD people should also be involved

CONTINUING EDUCATION

in all sectors of the practice and leadership; lived experience is a form of expertise and having identified individuals as part of the development process will reduce the chance of inadvertent blind spots within the practice. Finally, encountering TGD members of the healthcare team may add to patients' feeling of safety as they see themselves represented in those who care for them.

Finally, outreach and collaboration should be made with TGD individuals and communities in the area. It may be difficult for an individual to prioritize proactive sexual health or adhere to an ART regimen if they are also facing insecurities in housing, food, and safety. An affirming practice cannot be fully effective if it is not accessible. The healthcare team may be able to provide their knowledge and resources by contributing free or reduced cost services to local communities, or contributing to TGD mutual aid funds. This also creates connections and shows investment in the well-being of TGD patients as complete individuals.

Under the status quo, TGD people are a critically-affected population who may receive inadequate care. Community identity and experience, like our clinical knowledge, evolve over time; a continuing dialogue and collaboration with TGD community members is also, therefore, necessary to continue to address disparities and ensure best practices and engagement. As daunting as the healthcare disparities experienced by TGD people may appear, improvement can be made with individual and systemic changes, and it is important that as HIV care team members we educate ourselves, reach out and work to close the gaps in care experienced by TGD people. **HIV**



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HELPFUL RESOURCES:

CDC – HIV Prevention and Care for Transgender People
<https://www.cdc.gov/hiv/clinicians/transforming-health/index.html>

WPATH Standards of Care Volume 8–
<https://www.tandfonline.com/doi/pdf/10.1080/26895269.2022.2100644>

HIV.gov – <https://clinicalinfo.hiv.gov/en/guidelines/hiv-clinical-guidelines-adult-and-adolescent-arv/transgender-people-hiv>

UCSF Transgender Care and Treatment Guidelines–
<https://transcare.ucsf.edu/welcome>

National Center for Transgender Equality–
<https://transequality.org/>

Providing Trauma-Informed Care–
<https://www.traumainformedcare.chcs.org/what-is-trauma-informed-care/>

JAMIA Transgender Data Collection Examples–
<https://academic.oup.com/jamia/article/29/2/271/6364772>

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FEATURED LITERATURE

Sibiude J, Le Chenadec J, Mandelbrot L, et al. Update of perinatal HIV-1 transmission in France: zero transmission for 5482 mothers on continuous ART from conception and with undetectable viral load at delivery. Clin Infect Dis. 2022 Aug 29; ciac703. doi:10.1093/cid/ciac703. PMID 36037040.

French Perinatal Cohort (ANRS C01/C011) collaborators sought to revisit perinatal HIV-1 transmission rate estimates, specifically examining differences by timing of ART initiation and viral suppression. Data from 14,630 non-breastfeeding mother-infant pairs in metropolitan France between 2000 and 2017 was included. Viral suppression was defined as plasma viral load (VL) < 50 copies/mL, or undetectable if the threshold was higher than 50 copies/mL. Neonatal prophylaxis was prescribed for all infants. In cases where ART was initiated before conception, transmission rates decreased over time, from 0.42 percent in 2000-2005 to 0.03 percent in 2011-2017. In women not receiving ART at conception, rates did not differ across time periods: overall rates were 0.52 percent for women initiating ART < 14 weeks gestation, 0.75 percent for 14-27 weeks gestation, 1.67 percent for ≥ 28 weeks gestation, and 8.33 percent for women not treated during pregnancy. After stratifying by maternal VL near delivery, results were also consistent across time periods: no transmissions were diagnosed in 5,482 infants born to women treated at conception and having undetectable VL near delivery. Among women starting ART during pregnancy and with undetectable VL near delivery, transmission rate was 0.57 percent (compared to 1.08 percent for women treated at conception but with detectable VL near delivery).

AUTHOR'S COMMENTARY:

These findings affirm that the best predictor of low risk of perinatal transmission, among PWH with viral suppression at delivery, is early and sustained ART throughout pregnancy. Further, preconception maternal treatment and undetectable viral load at delivery may somewhat mitigate the effect of preterm birth on transmission. Caution has governed such that most providers are careful not to apply "undetectable equals untransmittable" (U=U) to the context of perinatal transmission, however data from this sizeable cohort are compelling. For people with HIV who wish to become pregnant, findings underscore the importance of broadening ART access and facilitating early treatment initiation with regular VL monitoring to ensure viral suppression near delivery.

FEATURED LITERATURE

Liegeon G, Assoumou L, Ghosn J, et al. Impact on renal function of daily and on-demand HIV pre-exposure prophylaxis in the ANRS-PREVENIR study. J Antimicrob Chemother. 2022 Oct 7; dkac336. doi:10.1093/jac/dkac336. PMID 36205009.

This study examined whether a reduction of exposure to tenofovir disoproxil as on-demand PrEP was associated with improved renal safety. Investigators classified participants into people who: (a) reported daily PrEP use at ≥ 75 percent of visits ($n = 499$); (b) reported on-demand use at ≥ 75 percent of visits ($n = 494$); and (c) reported alternating between on-demand and daily use and did not meet criteria for other classification ($n = 260$). Median baseline eGFR was 104 mL/min/1.73m² and 43 percent had baseline risk factors of kidney dysfunction, i.e., age > 40 years and/or baseline eGFR < 90 mL/min/1.73m². After 22.3 months mean follow-up time, mean AUC of the Δ eGFR was -1.09 in the daily PrEP group, -0.69 in the switches group, and +0.18 in the on-demand group. Compared to daily PrEP, AUC of the Δ eGFR was significantly higher in the on-demand group (this persisted after adjusting for baseline age and eGFR). In participants with baseline risk factors of kidney dysfunction, adjusted mean AUC of Δ eGFR was significantly greater in the on-demand group compared to the daily group. Multivariate analysis indicated that age > 40 years, baseline eGFR ≥ 90 mL/min/1.73m², daily PrEP and switching were associated with a higher risk of negative eGFR variation. Five participants (two in the daily group, two in the on-demand group, and one in the switches group) experienced a > 25 percent reduction in eGFR on two consecutive measurements (incidence rate: 2.5 per 1000 person-years). Fanconi syndrome was not reported. Two participants stopped PrEP because of eGFR decreases but were subsequently re-challenged without incident.

AUTHOR'S COMMENTARY:

Despite slight differences in eGFR variation over the initial two years of PrEP use (using tenofovir disoproxil fumarate), investigators concluded renal safety was favorable regardless of dosing strategy. On-demand PrEP appears to have a smaller impact on eGFR change compared to daily use, but this difference does not appear to be clinically meaningful. Further, the mean eGFR variation for the on-demand group was close to that previously described for DISCOVER trial participants taking daily PrEP using tenofovir alafenamide. As other studies have suggested, older age is independently associated with increased risk of eGFR reduction—findings from this analysis would suggest that on-demand PrEP may be a reasonable option for older adults and others at risk of kidney dysfunction.

FEATURED LITERATURE

Bonacci RA, Moorman AC, Bixler D, et al. Prevention and care opportunities for people who inject drugs in an HIV outbreak—Kanawha County, West Virginia, 2019–2021. J Gen Intern Med. 2022 Nov 2. doi:10.1007/s11606-022-07875-w. PMID 36323825.

This study, conducted by collaborators from CDC and other public health agencies, examines a recent IDU-associated HIV outbreak in West Virginia. Health records and state surveillance data were reviewed for 65 PWID residing in Kanawha County who received an HIV diagnosis between January 1, 2019 and June 18, 2021—specifically, investigators analyzed health care encounter and HIV- and opioid-related service data from one year before HIV diagnosis through June 18, 2021. Median age at HIV diagnosis was 34 years; 54 percent of PWID were male, 62 percent ever experienced homelessness/unstable housing, 35 percent were ever diagnosed with a mental health condition, and 31 percent were previously incarcerated. Medical record documentation indicated illicit opioid use for 85 percent and methamphetamine use for 85 percent; overall, polysubstance use was documented for 88 percent. Eighteen percent were ever classified as having stage 3 AIDS and 30 percent were engaged in HIV care within the last three months (34 percent were ever virally suppressed). Of 496 encounters occurring over 127 person-years of follow-up, 42 percent occurred in the emergency department, 20 percent were inpatient, and 38 percent occurred in ambulatory settings. Among 291 opioid-related encounters, prescriptions for naloxone and medications for OUD were documented in 10 percent and 20 percent of encounters, respectively. No one was prescribed HIV pre-exposure prophylaxis.

AUTHOR'S COMMENTARY:

Study collaborators identified a relatively high number of health care-related encounters among PWID who were subsequently diagnosed with HIV in a single West Virginia county, highlighting several 'missed opportunities' to prevent HIV transmission and address heroin/fentanyl use as well as use of other illicit substances (including prescription opioid misuse). Authors offer multiple potential interventions—i.e., HIV screening, harm reduction services, PrEP and MOUD initiation, and care navigation (particularly from acute care and hospital settings)—that might help facilitate engagement and persistence in medical care. Findings from this analysis can help guide intensification of HIV prevention and SUD programming in other jurisdictions where prevalent IDU raises the likelihood of similar outbreaks.

FEATURED LITERATURE

Sigman EF, Ondrush NM. Utilization of bictegravir/emtricitabine/tenofovir alafenamide in patients with end-stage renal disease on hemodialysis. Am J Health Syst Pharm. 2022 Nov 14; zxac339. doi:10.1093/ajhp/zxac339. PMID 36373751.

This case series from a single U.S. medical center describes the use of co-formulated bictegravir/emtricitabine/tenofovir alafenamide (BIK) among six adult PWH with end stage renal disease on hemodialysis. Patients were identified through an electronic medical record query if they transitioned to BIK and were receiving hemodialysis between January 2018 and October 2022. Ages ranged from 51–70 years, and the average time since HIV diagnosis was 24 years. All had co-occurring cardiovascular disease. All case patients were on INSTI-containing regimens prior to starting BIK: four were taking dolutegravir once daily, one was taking dolutegravir twice daily, and one was receiving elvitegravir/cobicistat. Four patients were on a 3-class ART regimen. At one year prior to starting BIK, three patients had HIV-1 RNA levels > 50 copies/mL (three had an undetectable viral load). At one month prior to starting BIK, three patients had HIV-1 RNA levels > 50 copies/mL. Four patients were transitioned to BIK alone and two patients started BIK plus doravirine. By one year after starting BIK, five patients had an undetectable viral load, and the sixth patient had an undetectable viral load after ~2.5 years. No patient-reported adverse effects were documented in the electronic medical record after transition to BIK-based regimens, and overall patients reported adherence to their new regimens.

AUTHOR'S COMMENTARY:

Observations from this small real world case series are consistent with findings from an extension study initially presented at IDWeek 2020, namely regarding tolerability and general safety of BIK among PWH with end stage renal disease on chronic hemodialysis. For the extension study, potential participants were excluded if they had any documented history of HIV drug resistance to elvitegravir, emtricitabine, lamivudine, or tenofovir. By contrast, in this series, there was concern for or documented history of potentially relevant ARV resistance in four of six patients. Nevertheless, all but one patient achieved virologic suppression one year after ART modification to a BIK-based regimen, and the other patient suppressed after ~2.5 years. Although data from this retrospective study were gathered solely from electronic health records, findings suggest BIK may be a reasonable simplification option for ART-experienced PWH on chronic hemodialysis who desire a streamlined regimen with relatively few drug-drug interactions. **HIV**

The Silent
Epidemic:

HIV & Hepatitis C Co-Infection

People living with HIV-infection face a **higher risk of long-term liver failure** as a result of co-infection with Hepatitis C (HCV).

25%

About 25% of people infected with HIV in the U.S. are also infected with HCV

80%

About 80% of injection drug users (IDUs) with HIV infection also have HCV

3X

HIV/HCV co-infection more than triples the risk for liver disease, liver failure, and liver-related death from HCV



Compared with other age groups, a greater proportion (about 1 in 33) of people aged 46–64 years are infected with HCV

20
to
30

Chronic HCV is often "silent," and many people can have the infection for 20 to 30 years without having symptoms or feeling sick

2X

In the U.S., HCV is twice as prevalent among blacks as among whites

Investigating data and trends on co-infection care and treatment.



Co-Infection Watch



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timely updates