

THE AMERICAN ACADEMY OF HIV MEDICINE ■ FALL 2022

HIV

SPECIALIST

Caring for *the* Latinx *and* Hispanic Communities





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Testing Window Closes	September 14, 2022
Exam Results Posted	October 18, 2022

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Registration Closes	October 13, 2022
Testing Window Opens	November 2, 2022
Testing Window Closes	November 30, 2022
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By BRUCE J. PACKETT II

Executive Director, AAHIVM

Expanding our Audiences and Offerings

AS YOUR NEW ISSUE OF *HIV SPECIALIST* GOES TO PRESS, news and footage of devastating flooding and damage from Hurricane Fiona in Puerto Rico is streaming across the country, and infrastructure, including healthcare infrastructure, is compromised. Displaced HIV clients and providers on the island will inevitably struggle to have their needs met, to deliver and receive care and treatment, and healthcare resources may be generally very scarce. Now we must focus on restoring access to HIV care, treatment and prevention as quickly as possible, and do everything we can as an organization to assist those affected by HIV in Puerto Rico. It's another unfortunate setback for a country and a community of people already with an unlevel playing field compared with much of the rest of America, and already beset by other multifactor challenges.

Fittingly, this magazine issue itself centers on the impact of HIV on our Latinx and Hispanic populations. Successful interventions in the HIV care continuum require specific, non-general recognition of each community, ethnic-

ity, race or population most affected by the disease, and the Latinx/Hispanic Community certainly is a critical focus for the Academy specifically, but also generally for any targeted engagements in HIV care and prevention. Already in 2022, the Academy participated in the National Latinx Conference on HIV, HCV and Substance Use Disorder in Albuquerque, NM, presented a PrEP 101 webinar for members of the National Hispanic Medical Association, and in October we will be at the U.S. Conference on HIV/AIDS in San Juan, including as sponsors and organizers of an important community program on advancements in PrEP in 2022.

We are also very pleased to announce that this is the first issue that makes continuing medical education/continuing pharmacy education credits available for our providers and pharmacists within its pages. Responding to our readers' feedback around interest and need for continuing credits, starting with this issue, there will be at least one clinical feature with accompanying accreditation in every installment of *HIV Specialist*. I would like to personally thank John Juchniewicz and his team at the American Academy of CME for serving as our accrediting partner for the *HIV Specialist* magazine going forward. The article in this particular issue was based upon one of the most dynamic and well-received presentations at this year's ACTHIV, a conference for which John and his team provide all the CME. We are

proud to be able to support our HIV care providers with yet another way to stay current on the latest clinical advances in HIV.

And in the meantime, please enjoy the articles offered here by providers and other experts in the unique issues and challenges around HIV in the Latinx and Hispanic populations. Authors in this issue, many identified from the National Latinx Conference, explore the overarching issues in the community, including migrant and other Latinx/Hispanic clients living in the often-transitory spaces between two countries. Other writers tackle important issues facing this at-risk population, including stigma and other unique, dynamic challenges facing MSM in Latinx communities, model care delivery, sex work, mental health and other key intersectional topics to this group. We thank our experts for their dedication working with these and other communities with specific challenges.

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

IN THE NEWS

American Academy of HIV Medicine Launches New Podcast

WASHINGTON, DC: The American Academy of HIV Medicine has launched a new podcast, *The Academy Exchange: HIV Today & Tomorrow*. This podcast will explore the latest news and advances in HIV prevention, care, and treatment, as well as examine the societal and systemic issues facing people with and at risk for HIV.

The Academy Exchange: HIV Today & Tomorrow is geared toward anyone who wants to learn more about the latest advances in HIV prevention, treatment and care. Hosted by the Academy's Executive Director, Bruce J. Packett, this podcast series of interviews with clinical, research, epidemiological, public health and advocacy experts will demystify the current HIV landscape and point towards future developments.

The first episode, titled "A New Day for HIV Treatment," was released on September 6th and discussed new and novel antiretroviral therapies including single pill regimens and long-acting

injectables. Future episodes will be released biweekly and explore a variety of topics, including "Let's Talk About PrEP," and "Women & HIV." It will feature interviews with top experts in the field including Academy credentialed clinicians Dr. Brooke Stevens, Dr. Carly Floyd, and Dr. William R. Short.

"With over 37 million people with HIV around the world, it is more important than ever to provide accurate information about this epidemic," said Packett. "We created this podcast because we believe that everyone should have access to accurate information about the latest advances in HIV care and prevention, directly from the experts. We hope this podcast will provide listeners with valuable insights and facilitate meaningful conversations with medical providers who are on the front lines in the fight against the HIV epidemic."

For more information or to listen to the podcast, visit podcast.aahivm.org.



Judge Rules that PrEP Coverage Violates Religious Freedom Clause

A TEXAS JUDGE ruled that PrEP coverage under the ACA provision that requires certain preventive medications to be covered without cost-sharing violates the Religious Freedom Restoration Act (RFRA). This is a challenge to the Affordable Care Act (ACA) provision first filed in 2020 by former Trump administration officials with the intent of using the Religious Freedom Restoration Act to block coverage of STI screenings and HIV prevention that plaintiffs claim, "facilitate and encourage homosexual behavior, prostitution, sexual promiscuity, and intravenous drug use." In late July, the case finally came before a Texas judge who already has ruled against the ACA several times and was expected to again do so in this case. The Biden Administration requested that the judge reject this case and

block it from moving forward, but instead, the judge ruled today that requiring employers to provide coverage for PrEP violates their religious freedom.

The plaintiffs' foundational argument is, "The government cannot possibly show that forcing private insurers to provide PrEP drugs, the HPV vaccine, and screenings and behavioral counseling for STDs and drug use free of charge is a policy of such overriding importance that it can trump religious-freedom objections." Aside from this statement being antithetical to the purpose of the ACA in that insurers should actually cover more rather than less; this case also endangers progress the U.S. has made in expanding protections for communities who sit outside those the religious right think is deserving.

This lawsuit also comes at a time when

STI rates continue to skyrocket across the country and as we've seen an erosion of HIV testing resulting from the COVID-19 pandemic. Without ensuring coverage, we know there will be millions of people left behind – without access to prevention, testing, or treatment. By overturning *Roe v. Wade*, the Supreme Court sent a message that it would be willing to hear other cases in which fundamental, long-accepted rights were questioned. As such, we should expect more efforts to erode fundamental rights, particularly access to any services related to sexual health care. The judge in this case, Judge Reed O'Connor has a history of anti-LGBTQ rulings, both to marriage equality and to Title IX's ban on discrimination based on sex. The Biden administration is sure to appeal this decision, so it will continue to work its way through the courts.

IN THE NEWS

Long-acting Agent Resource Center Now Available

The American Academy of HIV Medicine launched a new online resource, www.hivlaa.org, to expand the knowledge base for long-acting antiretroviral agents (LAAs) used for the treatment and prevention of HIV.

LAAs are innovative new tools in the fight against HIV that come in many forms including injections, implants, and oral medication. Long-acting treatment offers an enormous benefit to people with HIV by decreasing the need to take daily medications.

The new Long-acting Agent Resource Center website is designed to be a one-stop shop for information on LAAs and helps connect patients and clinicians with those who are already successfully incorporating long-acting agents into care plans. The website contains detailed information including:

- Frequently asked questions for patients in both English and Spanish
- Prescribing guidelines
- A centralized hub of best practices and procedures
- State-specific information on LAA availability and third-party payer options
- A peer network for providers to ask questions and share best practices

“Because they do not require daily dosing, long-acting injectables are a game changer for the treatment and prevention of HIV, and expediting their use is essential,” explained Bruce J. Packett, Executive Director of the American Academy of HIV Medicine. “But, as a new treatment option, there are significant questions and concerns regarding cost, availability, coverage, and dispensing. This website was developed as a resource to navigate the process more easily.”

“HIV care providers and other clinicians looking to utilize these novel therapies need a central location that houses the most up-to-date clinical data and state-based coverage information,” said Dr. Carolyn Chu, Academy Chief Medical Officer. “Even more importantly, they need a safe environment to ask questions and identify peers who can share their experiences in providing this treatment. This site is intended to serve all of those purposes.”

“LAAs represent the culmination of years of research,” said Packett. “The Academy hopes to raise awareness and knowledge about these incredible new tools and bring us one step closer to ending the HIV epidemic.”

The creation of this resource was made possible through an unrestricted grant from ViiV Healthcare. Learn more at www.hivlaa.org.

LONG-ACTING AGENT RESOURCE CENTER

COVERAGE MAP RESOURCES PATIENT INFORMATION CLINICIAN FORUM CONTACT

Welcome!

The goal of this site is to expand the knowledge surrounding long-acting antiretroviral agents for both treatment of HIV and prevention of HIV acquisition by providing information related to the availability of products, payment coverage, and prescribing guidelines. This resource connects visitors with clinicians who successfully incorporate long-acting agents into their current practice, as well as provides a peer network in order to ask questions and share best practices.

COVERAGE MAP

PRESCRIBING GUIDELINES

PATIENT INFORMATION

BILLING, CODING & ADMINISTRATIVE

DATA & RESEARCH

LAA CLINICIAN DISCUSSION FORUM

This site is managed by the non-profit American Academy of HIV Medicine, the nation's leading independent organization of healthcare professionals dedicated to providing HIV care and prevention excellence. Our network of member and credentialed clinicians manage the health of most people with or at risk for HIV in the United States.

AMERICAN ACADEMY OF HIV MEDICINE

Coverage Map
Prescribing Guidelines
Billing, Coding & Administrative
Clinical Data & Research
Patient Information
Clinician Forum

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Feedback

Winner of the 2022 Cesar Augusto Caceres Award for Technology in HIV Practice Creates Innovative Telehealth Program with Incarcerated Individuals

THE AMERICAN ACADEMY OF HIV MEDICINE

and the Institute for Technology in Health Care have awarded the 2022 Cesar Augusto Caceres Award for Technology in HIV Practice to Dr. Hillary Liss and Dr. Jennifer Jones-Vanderleest of Seattle, Washington. Drs. Liss and Jones-Vanderleest are being recognized for an innovative telemedicine partnership between the Madison Clinic, a Ryan White clinic at Harborview Medical Center/University of Washington in Seattle, WA, and Public Health-Seattle and King County Jail (KCJ) Health Services, found to improve care of incarcerated individuals with HIV.

Providing direct patient care since January 2019 via weekly telemedicine sessions, Drs. Liss and Jones-Vanderleest, situated at the Madison Clinic and the jail medical clinics respectively, collaboratively see incarcerated patients, often involving HIV case managers at both sites. This is paired with a weekly videoconference that brings together a multidisciplinary team of medical, public health, community low-barrier clinic, social work/release planner, and community-based organization representatives to assist with adherence, outreach, linkage/engagement/retention in care, and transitions to community or prison.

"It is an honor to be recognized by the Academy and ITHC," said Drs. Jones-Vanderleest and Liss. "We are committed to developing creative approaches to better serve incarcerated people with HIV, and we look forward to



Dr. Hillary Liss



Dr. Jennifer Jones-Vanderleest

collaborating with others who work with this vulnerable population."

People with HIV are incarcerated at disproportionate rates in U.S. jails, with many missed opportunities for diagnosis, treatment, linkage to care, and help with transition to the community. Prior to the establishment of this program, incarcerated people who required specialty HIV care needed to be transported in the custody of jail officers to an outside facility which involved a number of challenges including: the stigma of being transported from jail, confidentiality concerns, short jail stays that precluded an opportunity to arrange and attend appointments, and the cost of patient transport and associated staffing, which limited the number of patients who could be brought to the outside clinic.

In its eleventh year, the Cesar Augusto Caceres Award for Technology in HIV Practice seeks to acknowledge those who have created, adapted and/or used innovative technology in their HIV practice and to share that technological knowledge with others in the practice of HIV medicine to improve patient care. The award honors the legacy of Dr. Cesar Caceres, founder of the Institute for Technology in Health Care.

Dr. Liss and Dr. Jones-Vanderleest will be hosting a live Academy webinar this summer to share their best practices and discuss program outcomes.

Greater Predicted Life Expectancy Confirms Importance of HIV/AIDS Treatment

SINCE THE INTRODUCTION of the first antiretroviral therapy (ART) drug for HIV/AIDS treatment 35 years ago, life expectancy in Sub-Saharan Africa has steadily increased. ART medications are specifically designed to help an individual's immune system fight HIV and in turn suppress HIV replication. However, there is a limited understanding of the combined effects of HIV and ART on disability and healthy longevity for individuals with the disease. Investigators from Brigham and Women's Hospital collaborated alongside international partners in South Africa to

compare people with both virally suppressed and unsuppressed HIV, with people who were uninfected with HIV. The team used data they collected in an observational, longitudinal, population-based cohort study that included baseline interviews and blood collection, as well as subsequent follow-up interviews and blood collection about four years later. Their modeling analysis found that those receiving ART medication were predicted to live considerably longer and with less disability than those with unsuppressed HIV. This research illustrates the role of ART in healthy aging, as well as the continued importance

for international global health organizations to provide HIV treatment to those all over the world, including in Africa.

"It was exciting for us to find that—at the population level—achieving high rates of viral suppression among people with HIV will not only lead to increases in life expectancy but also to healthier aging," said senior author Jennifer Manne-Goehler, MD of the Division of Infectious Diseases. "This confirms the critical importance of maintaining support for antiretroviral programs as a way to ensure the best long-term health outcomes for people growing older with HIV."

IN THE NEWS

Heart Attack Risk Increased Among People with HIV and Hepatitis C as They Aged

HIV AND HEPATITIS C STATUS associated with increased risk of heart attack, according to a study in the *Journal of the American Heart Association*

As people with HIV age, their risk of heart attack increases far more if they also have untreated hepatitis C virus, even if their HIV is treated, according to new research published today in the *Journal of the American Heart Association*.

Since the introduction of antiretroviral therapies to treat HIV in the late 1990s, the lifespan of people with HIV has increased dramatically. However, even with treatment, studies have found the heart disease risk among people with HIV is at least 50% higher than people without HIV. This new study evaluated if people with HIV who also have hepatitis C—a viral liver infection—have a higher risk of heart attack.

“HIV and hepatitis C coinfection occurs because they share a transmission route - both viruses may be transmitted through blood-to-blood contact,” said Keri N. Althoff, Ph.D., M.P.H., senior author of the study and an associate professor in the department of epidemiology at the Johns Hopkins Bloomberg School of Public Health in Baltimore. “Due in part to the inflammation from the chronic immune activation of two viral infections, we hypothesized that people with HIV and hepatitis C would have a higher risk of heart attack as they aged compared to those with HIV alone.”

Researchers analyzed health information for 23,361 people with HIV (17% female, 49% non-Hispanic white) in the North American AIDS Cohort Collaboration on Research and Design (NA-ACCORD) between 2000 and 2017 and who had initiated antiretroviral treatment for HIV. All were between 40 to 79 years of age when they enrolled in the NA-ACCORD study (median age of 45 years). One in five study participants (4,677) were also positive for hepatitis C. During a median follow-up of about four years, the researchers compared the occurrence of a heart attack between the HIV-only and the HIV-hepatitis C co-infected groups as a whole, and by each decade of age.

The analysis found:

- With each decade of increasing age, heart attacks increased 30 percent in people with HIV alone and 85 percent in those who were also positive for hepatitis C.
- The risk of heart attack increased in participants who also had traditional heart disease risk factors such as high blood pressure (more than 3 times), smoking (90%) and Type 2 diabetes (46%).
- The risk of heart attack was also higher (40%) in participants with certain HIV-related factors such as low levels of CD4 immune cells (200cells/mm³, signaling greater immune dysfunction) and 45 percent in those who took protease inhibitors (one type of antiretroviral therapy linked to metabolic conditions).

“People who are living with HIV or hepatitis C should ask their doctor about treatment options for the viruses and other ways to reduce their cardiovascular disease risk,” said lead study author Raynell Lang, M.D., M.Sc., an assistant professor in the department of medicine and community health sciences at the University of Calgary in Alberta, Canada.

“Several mechanisms may be involved in the increased heart attack risk among co-infected patients. One contributing factor may be the inflammation associated with having two chronic viral infections,” Lang said. “There also may be differences in risk factors for cardiovascular disease and non-medical factors that influence health among people with HIV and hepatitis C that plays a role in the increased risk.”

According to a June 2019 American Heart Association scientific statement, *Characteristics, Prevention, and Management of Cardiovascular Disease in People Living With HIV*, approximately 75 percent of people living with HIV are over the age of 45. “Even with effective HIV viral suppression, inflammation and immune dysregulation appear to increase the risk for heart attack, stroke and heart failure.” The statement called for more research on cardiovascular disease prevention, causes and

treatment in people with HIV.

“Our findings suggest that HIV and hepatitis C co-infections need more research, which may inform future treatment guidelines and standards of care,” Althoff said.

The study is limited by not having information on additional factors associated with heart attack risk such as diet, exercise or family history of chronic health conditions. Results from this study of people with HIV receiving care in North America may not be generalizable to people with HIV elsewhere. In addition, the study period included time prior to the availability of more advanced hepatitis C treatments.

“Because effective and well-tolerated hepatitis C therapy was not available during several years of our study period, we were unable to evaluate the association of treated hepatitis C infection on cardiovascular risk among people with HIV. This will be an important question to answer in future studies,” Lang said.

Dolutegravir-based Antiretroviral Therapies for HIV-1 Effective in Pregnancy

DOLUTEGRAVIR-BASED antiretroviral therapy (ART) for HIV-1 infection is more effective in pregnancy than some other ART regimens commonly used in the U.S. and Europe, according to a study published in the *New England Journal of Medicine*.

“Our study showed that dolutegravir-based regimens had a high probability of maternal viral suppression at delivery, and there were no observable differences in the risks of adverse birth outcomes, such as preterm birth, low birth weight, small for gestational age, or neonatal death, between dolutegravir and the other contemporary regimens,” said co-author Ellen Chadwick, MD,

First Individual Treated with CRISPR-based HIV Therapy

A breakthrough treatment pioneered by researchers at Lewis Katz School of Medicine at Temple University and developed by Excision BioTherapeutics

IN A MAJOR MILESTONE in the search for a cure for HIV/AIDS, a breakthrough gene-editing therapy for HIV infection now being tested in clinical trials has been administered to a human with HIV for the first time. The trial, designed to evaluate the safety and efficacy of EBT-101, a one-of-a-kind gene-editing treatment with the potential to change the future of HIV therapeutics, is the product of a remarkable collaborative effort between researchers at the Lewis Katz School of Medicine at Temple University and Excision BioTherapeutics, Inc.

The first individual to receive single-dose intravenous infusion EBT-101 therapy is under observation and will soon be evaluated for viral rebound if eligible to stop antiretroviral therapy under the protocol. Investigators are hopeful that if the one-time curative treatment works as anticipated, the individual will no longer require antiretroviral therapy, which currently is the standard treatment for HIV infection.

The launch of the EBT-101 Phase 1/2 clinical trial was made possible by research led by Kamel Khalili, PhD, Laura H. Carnell Professor and Chair of the Department of Microbiology, Immunology, and Inflammation; Director of the Center for Neurovirology and Gene Editing; and Director of the Comprehensive NeuroAIDS Center, and Tricia H. Burdo, PhD, Professor and Vice Chair in the Department of Microbiology, Immunology, and Inflammation at the Katz School of Medicine.

Dr. Khalili and colleagues at Temple pioneered the development of EBT-101, which is based on the gene-editing technology known as CRISPR, while Dr. Burdo and her team played a key part in advancing EBT-101 into clinical trials through their studies of EBT-101 in non-human primates.

"Nearly 40 million people worldwide suffer from the effects of HIV,

and more than 40 years after the discovery of HIV/AIDS, there still are no curative treatments," Dr. Khalili said. "EBT-101 can potentially address long-standing unmet needs of individuals living with HIV/AIDS by removing viral DNA from their cells, thereby eradicating infection."

The removal of HIV DNA from the cellular genome is essential to effecting a cure. The virus takes up long-term residence in tissue reservoirs, where it hides, evading the immune system and escaping antiretroviral therapy. HIV can persist in tissue reservoirs for years.

"The extensive preclinical work by our research teams at Temple demonstrated the effectiveness of EBT-101 in removing HIV DNA from infected cells and laid the foundation for clinical studies," Dr. Burdo said. "It is really exciting for us to see Excision BioTherapeutics take this potentially curative therapy into Phase 1/2 clinical trials."

"We are well-positioned to collect key data that will enable our efforts to translate the success this approach has shown in animal models to human clinical trial participants," Dr. Khalili added. "We look forward to investigating this hypothesis through the EBT-101 clinical program and are pleased that the EBT-101 Phase 1/2 trial is proceeding as planned."

"The official start of the Phase 1/2 clinical trials for EBT-101 brings us one extremely significant step closer to creating a potential cure for HIV/AIDS," said Amy J. Goldberg, MD, FACS, Interim Dean of the Katz School of Medicine. "This amazing milestone speaks to the exceptional research acumen and scientific knowledge of Drs. Khalili and Burdo and their teams—outstanding members of the Temple family."

The trial is taking place at multiple locations, but Temple is not one of the sites.

Director of Section of Pediatric, Adolescent and Maternal HIV Infection at Ann & Robert H. Lurie Children's Hospital of Chicago and Professor of Pediatrics at Northwestern University Feinberg School of Medicine. "This is great news, since dolutegravir also has other important benefits compared to older antiretroviral drugs."

Dolutegravir, a more recently approved antiretroviral drug, is taken once-a-day, is more tolerable, and is less likely to result in resistance mutations compared with other antiretroviral drugs.

"This is one of the largest studies to examine the effectiveness and safety of dolutegravir in pregnancy compared to regimens that have been commonly used during pregnancy in the U.S. and Europe," said co-author Jennifer Jao, MD, MPH, an infectious diseases physician at Lurie Children's and Associate Professor of Pediatrics at Northwestern University Feinberg School of Medicine. "Our results show viral suppression at

delivery in considerably more participants."

In the current observational study, the researchers compared dolutegravir-based ART in pregnancy to atazanavir/ritonavir-, darunavir/ritonavir-, and raltegravir-based regimens that are currently classified by the Department of Health and Human Services Guidelines Panel as "Preferred" for use in pregnancy in the U.S. About half of the participants started ART before conception. At delivery, 96.7 percent of the pregnancies in participants who received dolutegravir had viral suppression, whereas atazanavir/ritonavir and raltegravir had viral suppression rates of 84 percent and 89.2 percent, respectively.

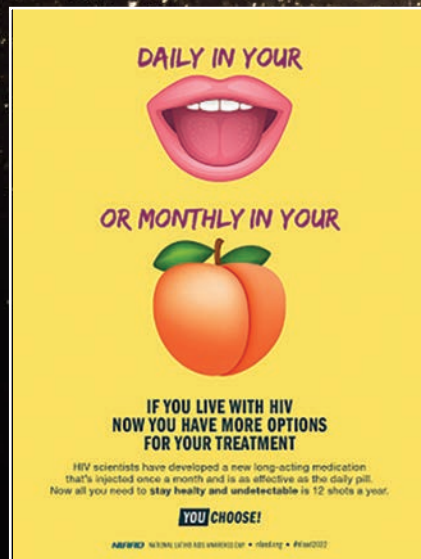
This research was supported by the Eunice Kennedy Shriver National Institute of Child Health and Human Development, National Institutes of Health, National Institute of Dental and Craniofacial Research, National Institute of Allergy and Infectious Diseases, National

Institute of Neurological Disorders and Stroke, National Institute on Deafness and Other Communication Disorders, National Institute of Mental Health, National Institute on Drug Abuse, National Cancer Institute, National Institute on Alcohol Abuse and Alcoholism, National Heart, Lung, and Blood Institute (grants HD052102 and HD052104), and Harvard Chan School for PHACS 2020 (P01HD103133), and the Swiss National Science Foundation (grant 201369).

Research at Ann & Robert H. Lurie Children's Hospital of Chicago is conducted through Stanley Manne Children's Research Institute. The Manne Research Institute is focused on improving child health, transforming pediatric medicine and ensuring healthier futures through the relentless pursuit of knowledge. Lurie Children's is ranked as one of the nation's top children's hospitals by *U.S. News & World Report*. It is the pediatric training ground for Northwestern University Feinberg School of Medicine. **HIV**

The Power of Education

BY LUIS ALBERTO MARES, LMSW



Lessons
on positive
outreach
from the
National
Latino
Commission
on AIDS

LATINX AND HISPANIC COMMUNITIES face several individual, community, and structural challenges when addressing the impact of HIV and other diseases. These include low health literacy, minimal awareness of available services and resources, sociocultural stigmatization of HIV, and higher engagement in risk behaviors.

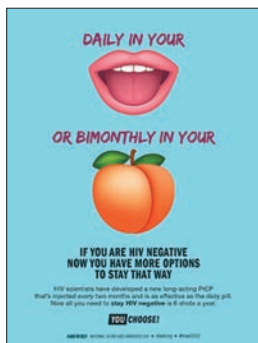
In addition, access to appropriate prevention and care is impacted by a lack of low-cost quality services, insufficient education, prevention, and screening services, lack of cultural competency to serve Latinx/Hispanic clients, and discriminatory policies and practices.

According to the Centers for Disease Control (CDC), there were 10,502 new infections within the Latinx community in 2019 in the United States. While this number decreased in 2020 to 8,285, this still represents 23 new infections daily. The Latinx community accounts for 27 to 28 percent of the new infections per year, despite representing only 18 percent of the total population of the U.S.¹ More alarming, one in six Latinos living with HIV don't know it, making HIV screening and testing a fundamental piece of the plan to end this epidemic in the U.S. by 2030 as proposed by the Ending the HIV Epidemic (EHE) Plan.² If current HIV rates persist, one in four Latino men who have sex with men (MSM), one in 48 Latino men, and one in 227 Latina women may be diagnosed with HIV in their lifetime.

Getting the Word Out

The Latino Commission on AIDS (LCOA) has proudly served the Latinx population since 1990. We spearhead health advocacy for Latinos, promote HIV education, develop model prevention programs for high-risk communities, and build capacity in community organizations. Through our extensive network of partner organizations and community leaders, LCOA works to mobilize an effective community response to meet the health challenges and address the impact of HIV/AIDS, hepatitis C and other sexually transmitted infections (STIs) in communities nationwide.

One way we engage with our communities is our National Latinx/Hispanic Awareness Day (NLAAD) campaign. Established in 2003,



NLAAD was first created as an HIV awareness poster campaign. It has evolved into a community mobilization intervention addressing various pressing issues.

Observed on October 15th, NLAAD aims to:

1. Increase awareness of health prevention, testing, and treatment and available resources and services for HIV that represent a health disparity to the Latino community.
2. Increase engagement in health screening, testing, early detection, and referral services for treatment and prevention.
3. Decrease negative sociocultural views and stigmatization of HIV and other health conditions among Latinx/Hispanic individuals and communities
4. Increase community discussions and engagement in health services

At the structural level, the awareness campaigns aim to:

1. Increase local institutional capacity and resources to conduct awareness campaigns among Latinx/Hispanic communities
2. Increase networking among local and national organizations serving Latinx/Hispanic communities
3. Increase awareness of health prevention, testing, and treatment needs among Latinx/Hispanic communities



NLAAD Event on October 15th 2019 by Chicago House, at 4 locations through Chicago IL: "Taco Tuesday": Free Tacos and Free HIV screening

Due to the differential impact of HIV among some Latinx/Hispanic subgroups, each campaign emphasizes particular at-risk sub-populations, including LGBTQ+ individuals, transgender women, Latinx youth, and older populations. In addition, to address social, institutional and structural barriers, our awareness campaigns reach out to the health workforce serving Latinx/Hispanic communities and elected and public officials at the federal, state, and local levels.

For instance, in 2017 NLAAD wanted to focus on those subgroups through a theme that empowered them to become the superheroes of this story. Young gay men, cisgender women, older adults and transgender women were present in our poster as a representation of those subgroups within our community that were being more affected by this disparity.

From the beginning, NLAAD has promoted HIV prevention, testing and care, adding through the years, pre-exposure prophylaxis (PrEP) and post-exposure prophylaxis (PEP), treatment as prevention and undetectable

equals untransmittable (U=U) education, as we showed clearly in our 2018 campaign. We wanted to not only create awareness among our community of the existence of all the available tools we have in the present to end this epidemic, but to also make it clear that it is the responsibility of all of us to end HIV. This fact was reinforced in our 2019 campaign illustrating that it is the responsibility to people with AND without HIV to end the epidemic.

You Choose!

This year, the theme is You Choose! The name celebrates that science is providing more options to prevent and to treat HIV. Now people with HIV can choose to treat their HIV orally or with an injection, the same way that people who are HIV negative can choose to take PrEP via an injection or a pill.

NLAAD Campaign Components

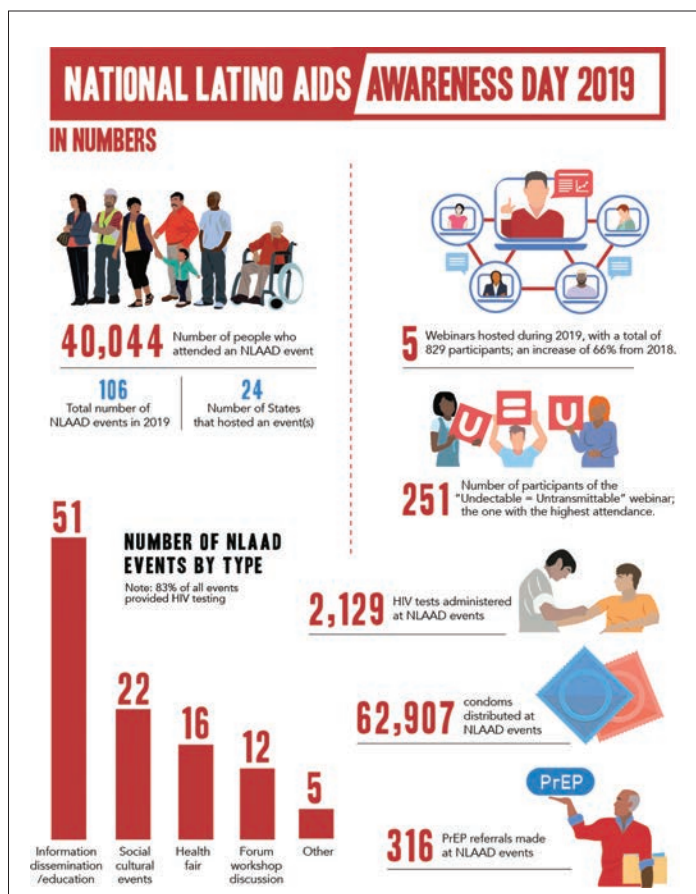
For those seeking to engage the Latinx community, consider the interrelated components of our campaign: mobilization activities, awareness campaign, educational events, and health events. These can be a guiding model for your own outreach.

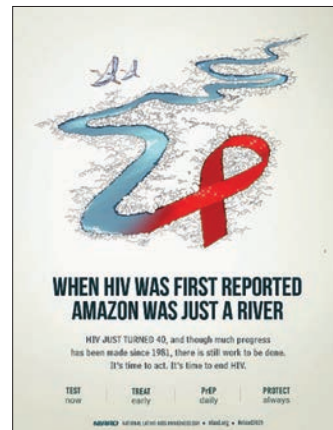
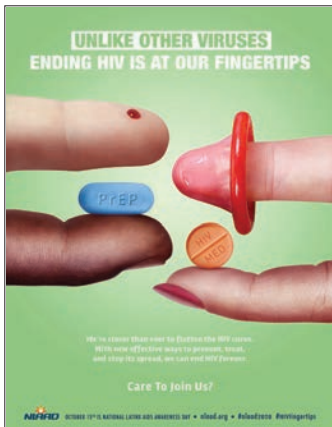
Mobilization activities: LCOA partners with organizations that share our mission and goals, including health organizations, LGBTQ+ organizations, colleges and universities, and local, state, and federal health institutions. Through our current list of professional contacts, we identify prospective institutional partners in underserved and underrepresented areas that may benefit from the introduction of NLAAD activities.

Awareness campaigns: Campaign and promotional materials are published and shared via social media platforms such as LinkedIn, Facebook, Instagram, Twitter and YouTube and regular email blasts to our list of over 9,000 contacts. We also engage media stakeholders to amplify the scope and reach of our awareness campaigns. We provide partner organizations with technical assistance to implement and coordinate activities for each campaign and campaign kits to tailor to their local communities' specific needs. The kits include resource guides, letter templates, fact sheets, posters, infographics, logos, social media resources, and videos. In addition, we provide a functional website (www.nlaad.org) to exchange up-to-date health information among partners and promote campaign-related events and services.

Webinars and workshops: We conduct webinars and workshops for community members to increase awareness of up-to-date information on the issues addressed in the campaigns. Through these partnerships, we also conduct webinars and workshops for the health workforce to increase knowledge of HIV and its impact on their local communities.

This year the webinars that have been scheduled for the campaign are focused on the advances that have been done recently in the HIV field for prevention and treatment of HIV. We will have two webinars dedicated to present the injectable forms of the new medications for treatment and for prevention. We will also have a webinar with updated information about the HIV vaccine, and another about the use of PrEP by ethnicity in the U.S.





Health events: We support, facilitate and organize health and testing events in partnership with other organizations in local communities across the U.S. With outreach efforts in their communities, organizations distribute educational and promotional materials, provide sexual health services, conduct testing and vaccination, and provide referrals to HIV services.

We will continue working on this difficult task of creating awareness among our community, to help fight the health disparity that HIV represents, and end the HIV epidemic. It has been already over 40 years of this constant struggle against this disease, but now we have all the necessary tools to do it. **HIV**



LUIS ALBERTO MARES, LMSW, is director of community mobilization for the Latino Commission on AIDS.

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Addressing the Mental Health of the Latino/Hispanic community and its correlation to HIV care outcomes

By Gabriel Silva, MSW, LCSW

THE LATINO/HISPANIC COMMUNITY is a vibrant presence in the United States. It is a diverse community with unique challenges and needs that HIV practitioners must be aware of and take into consideration when providing HIV care and other needed services, more specifically, delving deeper into the barriers impacting HIV care outcomes and its correlation with mental health.

Based on studies and research, specific strategies and interventions to consider for the Latino/Hispanic community are introduced. For the purpose of this article, the terms Latino and Hispanic will be used to include individuals who are Spanish-speaking, who identify as Latino, Hispanic or Latinx/a, and whose country of origin is in Latin America.

It is important to consider the current population trends within the U.S. Recent CENSUS data shows that Latino/Hispanics make up about 60 million of the entire U.S. population (about 18.9%) which is expected to account for 29 percent by 2060.¹ Currently the highest concentrations of Latino/Hispanic communities are found in Texas, California, Florida, New York and Puerto Rico.¹

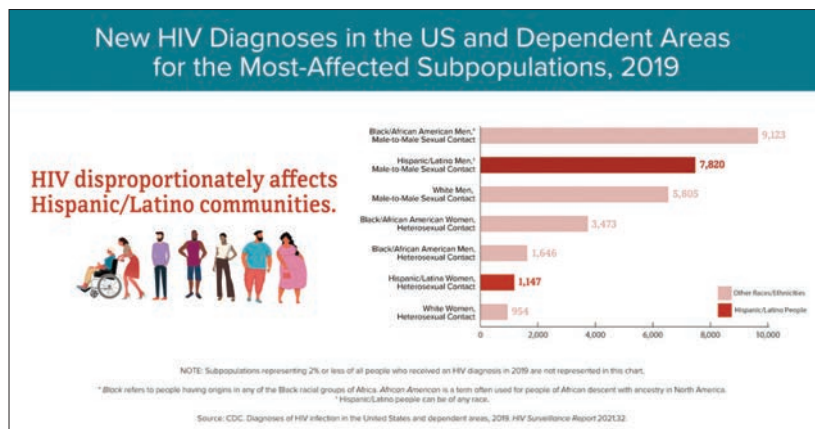
In terms of HIV, the trends among the Latino/Hispanic population vary, but are significant. Based on data from the Centers for Disease Control and Prevention (CDC) from 2019 for new HIV diagnoses in the U.S. (see graph below), Hispanic/Latino Men (Male-to-Male sexual contact) are the second highest subpopulation most affected by HIV.²

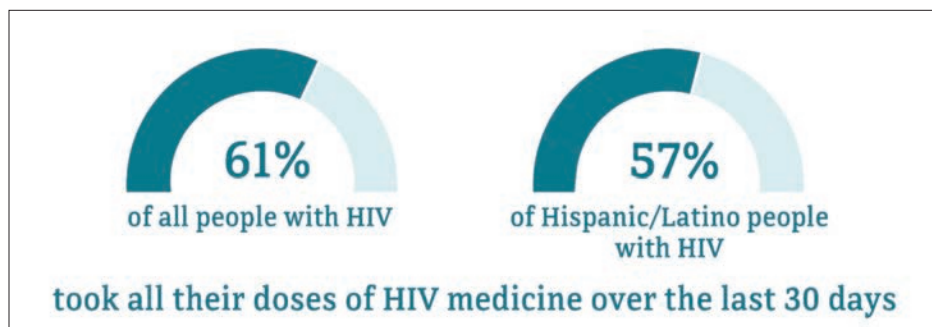
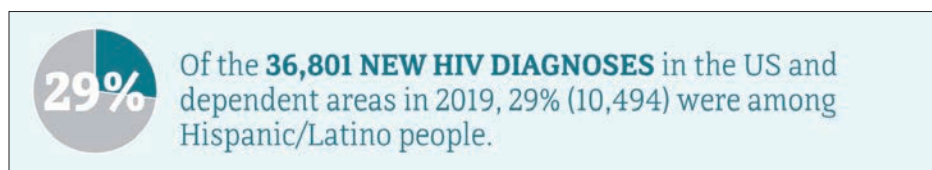
In addition, per CDC data, of the 36,801 new HIV diagnoses in the U.S. and dependent areas in 2019, 29 percent were among Hispanic/Latino people.³ Moreover, when comparing to the people with HIV, 61 percent took all their doses of HIV medication over the last 30 days, versus 57 percent in the Hispanic/Latino population, which is lower than the general trend (see graphs next page).⁴

It is also important to consider unique HIV trends within the Hispanic/Latino community. Overall, there have been declines of HIV diagnoses among heterosexual Latinas and young Latino/Hispanic ages 13–24.⁵ However, there are three sub-groups most affected by HIV: men who have sex with men (MSM), transgender females, and recent migrants.⁶

More specifically, the MSM population account for 80 percent of estimated HIV incidence among Latinos/Hispanics, and it is particularly high for ages 25–34.⁶ One out of four Latina transgender females are living with HIV.⁶ In the migrant population, those born outside of the continental U.S. account for at least one in three new HIV diagnoses, as of 2017.⁶ A majority number of migrants acquired HIV after migrating to U.S.⁶ This is significant to note due to the perception and myth that migrants are “bringing in HIV into the U.S.”

As we consider the population and HIV trends among the Hispanic/Latino community, we must acknowledge the unique challenges impacting their HIV care outcomes.^{6,7,8}





Healthcare access/Lack of insurance: Limited access or none at all to HIV care can exacerbate HIV and/or cause health complications related to HIV. Even when access is attained, either through insurance or through a Ryan White program, HIV diagnosis and/or treatment is late-term.

Fear/Stigma: There are fears of dying of HIV and feeling stigmatized living with HIV and these can be due to cultural and/or educational factors.

Homophobia within community: Traditional male/female roles within the community can influence homophobia. This can lead to isolation and alienation within the community that could further increase risky behaviors and thus, facilitate HIV transmission and/or weaken viral suppression.

Immigration status: There are significant fears of being deported if accessing HIV care. There can be a mistrust of the healthcare system and having to disclose personal information can convince individuals to not obtain needed HIV care.

Cultural differences: Cultural beliefs can formulate an idea of what it is like to live with HIV, with beliefs varying by country of origin.

Health literacy: Is there an understanding of the healthcare system? Are they aware of their rights and responsibilities as patients? Do they know how to navigate their own healthcare? Staff should make an effort to assess understanding and readiness when clients are entering HIV care.

Knowledge/Education gaps: There may be a limited lack of understanding or knowledge of HIV.

Racism/Discrimination: Systemic racism or discriminatory practices can deter people from accessing or sustaining their HIV care, or affect the care being provided to Latino/Hispanic clients.

Lack of culturally-appropriate services: Are agencies and facilities equipped with bilingual staff to better assist the communities they serve? Are consents or other pertinent documentation translated in the preferred language? In addition, is there training provided to promote cultural sensitivity/awareness about the communities being served?

Additional challenges may include rising housing costs which can cause people with HIV having to choose work over healthcare in order to maintain housing, or having to increase work hours to be able to pay rent. Similarly, inflation rates can contribute to making financial decisions that can jeopardize healthcare status. Also, it is important to determine whether culturally-sensitive gender-affirming care is accessible to individuals who identify as Latinx/e or transgender.

When considering mental health risk factors among the Latino/Hispanic population, 8.9 million Hispanic adults (over age 18) had a mental illness and/or substance use disorder, as of 2019.⁹ This was a 3.7 percent increase from 2018.⁹ For Latino/Hispanic people over the age of 12, marijuana was the most used illicit drug as of 2019⁹; however, the legality of marijuana in some states must be considered. Similar to factors impacting HIV care, there are risk factors impacting mental health within the Latino/Hispanic community:

Language barriers: If mental health services are not offered in the preferred language, clients may be less likely to engage due to an inability to properly communicate and/or express concerns when necessary.¹⁰ Consequently, if a setting does not adequately assess a client, they may miss significant information or an opportunity to help.

Cultural beliefs: What are the cultural beliefs concerning mental health overall? Utilizing religious beliefs and the importance of family dynamics as tools in the therapeutic process can be helpful.

Discrimination: Alienation or isolation as a result of discrimination can cause or exacerbate mental health symptoms.

Access to appropriate care/Lack of health insurance: Mistrust of the healthcare system can prevent people from accessing mental healthcare.

Low educational attainments: Consider the educational level of a client and its implications to mental health engagement/understanding. Those with less knowledge about mental health services may not easily engage in needed services.

Financial instability: This can lead to stress and pressure. This is significant for Latino/Hispanic individuals who are the sole breadwinners in the family.

Undocumented status: Fear of “being caught” or afraid of being deported because one is accessing mental health services. Additionally, having to disclose substantial personal information to mental health agencies can deter people from accessing care.

Taboos around mental health: Consider the negative connotations about mental health, both a client’s perception and their community’s response to mental health.

Degree of acculturation: Those individuals who have longer time to assimilate into U.S. society are more likely to recognize mental health risk factors and access the appropriate services if needed.¹⁰

Machismo culture/Beliefs: Be aware of machismo beliefs among the Latino/Hispanic community and how it can impact conversations about mental health; what it means “to be a man” may be ingrained in a client’s perception, which can involve no display or discussion of emotions.¹²

Now that risk factors have been explored, we must analyze how mental health and HIV are correlated. Undiagnosed and/or untreated mental health conditions can impact HIV care outcomes in significant

Consider any childhood trauma and how its effects may be present in the client. For those individuals who may have had a migration journey into the U.S., be mindful how the journey could have been traumatic: having to leave family, escaping violence or crime in country of origin, or witnessing or experiencing assault.



Take into consideration the collective nature of the Latino/Hispanic community. Be creative in using group therapy and/or peer-led group discussions. This can promote camaraderie and accountability as validation from peers is significant. Using these strategies promotes personalismo—preference of personal contacts over institutional ones, and sympatia—valuing of pleasant and approachable demeanor.

ways. First, the presence of depressive symptoms, psychosis, persistent drug use, and high levels of anxiety can lead to an inability to take antiretrovirals (ARV) as prescribed or to take consistently. Impaired judgment and/or weak perception of self can affect decision-making. Secondly, stigma is already significant for people with HIV and adding a mental health condition or diagnosis can further exacerbate this feeling. Also, poor self-esteem/self-worth can cause thoughts and feelings of not being worthy to live, therefore, choosing not to take HIV medication. Having passive suicidal ideations can also cause individuals to stop their HIV medication.

Now we need to consider effective strategies/interventions to address mental health concerns for the Latino/Hispanic community in order to address the risk factors that have been discussed. It is important to highlight that mental health treatment, at its core, aims to lessen human suffering while also striving for empowerment and healthier coping.

When it comes to culturally-appropriate services, Latino/Hispanic individuals are more likely to engage in mental health services if these are accessible in their preferred language and include culturally relevant elements.¹⁰ Most importantly, be aware that people from Latin America distinguish themselves based on nationality rather than terms such as Latino, Latina, or Hispanic. In addition,



avoid generalizations and stereotypes about Latino/Hispanic clients. Remember, the community is heterogenous and diverse. In terms of communication, using phrases like “illegal client” or “client who is illegal” provokes more negative stereotypes compared to the term “undocumented”.¹³

Incorporating spirituality into practice may be a necessary and beneficial tool. Consider that a significant proportion of the Latino/Hispanic community identify as Catholic or adhere to the Catholic faith. Encouraging the use of prayer and/or attending mass can be coping mechanisms. For example, the use of prayer can promote self-reflection and mindfulness, or time to disconnect from stressful environments. Consequently, studies have shown those who had not engaged in mental health counseling indicated higher levels of belief in spirituality than those who reported seeking counseling.¹⁰ Also, it is important to acknowledge the culturally-specific illness manifestation and/or use of folk treatments. Those who attribute their psychological distress to supernatural force are more likely to turn to spiritual and traditional healing practices.¹⁰ Logistically, consulting with a folk healer (curandero) can be done in Spanish and may spare the complicated paperwork, high cost, need for identification and long wait times.¹⁰

As mentioned before, there are several risk factors determining outcomes on mental health, when it comes to unresolved trauma which can lead to long-term effects such as PTSD, detrimental interpersonal relationships or unhealthy coping mechanisms. Overall, Latino/Hispanic individuals are found to have a higher prevalence of symptoms of PTSD.¹⁰ Consider any childhood trauma and how its effects may be present in the client. For those individuals who may have had a migration journey into the U.S., be mindful how the journey could have been traumatic: having to leave family, escaping violence or crime in country of origin, or witnessing or experiencing assault. A recent study conducted at the Mexico/U.S. border showed that 83 percent of respondents identified violence as a reason to migrate from their country of origin, and at least half had been exposed to a traumatic experience.¹⁴ It is important to note the substantial research

on trauma therapy or trauma-informed therapy and consider trainings and workshops to become more knowledgeable and familiar with this form of intervention.

Take into consideration the collective nature of the Latino/Hispanic community. Be creative in using group therapy and/or peer-led group discussions. This can promote camaraderie and accountability as validation from peers is significant. Using these strategies promotes *personalismo*—preference of personal contacts over institutional ones, and *sympatia*—valuing of pleasant and approachable demeanor.¹⁰

Other specific interventions to consider:

Liberation psychology: It calls for acknowledgement of history, a move away from neutrality in the face of injustice and recognition of collective trauma. It may be particularly useful for those individuals who may escaped poor treatment by oppressive regimes.¹⁰

Testimonio: A therapeutic tool for bearing witness to and supporting in the speaking of the unspeakable.¹⁰

Family Constellation Therapy (FCT): It allows the individual to address a problem by connecting with ancestral roots to uncover trans-generational situations they are not aware of. It is trauma-focused, incorporates spirituality, and resonates with people of color.¹⁰

Culturally-competent group cognitive-behavioral therapy: It incorporates elements of group therapy with a cognitive-behavioral approach in Spanish.

In summary, the Latino/Hispanic community is a diverse and vital community that is uniquely impacted by the interplay of mental health factors on HIV care outcomes. As the Latino/Hispanic community continues to grow in the U.S., it is critical for healthcare, mental health and social work practitioners, and other professionals to glean an accurate understanding of the unique characteristics and challenges faced by this community. Culturally-competent and effective strategies must be put in place in order to empower and facilitate healthcare outcomes. Utilize information from this article to become more aware of the needs of the Latino/Hispanic community, and consider further expanding expertise and knowledge for some of the concepts discussed. **HIV**



GABRIEL SILVA, LCSW graduated with Master of Social Work in 2013 from the University of Georgia. He started providing mental health therapy for children and families involved in foster care. In 2014, he joined Positive Impact Health Centers (formerly AID Gwinnett) as a bilingual Medical Case Manager, then becoming the Medical Case Management Team Lead in January 2017. Currently, since 2020, Gabriel is serving as Assistant Director of Client Services. Gabriel has been in the HIV field since his start at PIHC. He has also presented at the National Conference on Social Work and HIV/AIDS in 2020 and 2021 on topics relating to improving HIV care outcomes, as well as the 2022 National Ryan White Conference on HIV Care & Treatment. In addition, Gabriel is currently in private practice providing individual therapy, specializing in depression and anxiety. He has been a licensed Clinical Social Worker, by the State of Georgia, since 2016.

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NAVIGATING CRITICAL SERVICES

for those with Co-occurring Disorders and Multiple Disabilities

A first-hand account of a clinical social worker getting creative

By Briana Mandel, LCSW

THE WAY WE NAVIGATE SERVICES FOR AND WITH OUR HIGH NEEDS CLIENTS is often shaped by the systems in which we're forced to operate. Engaging with some of the most vulnerable individuals in Los Angeles, Calif. and navigating a system that was built broken, has forced a type of creative advocacy in my work that I was not expecting when I first became a social worker.

In March of this year, I presented at the National Latinx Conference on HIV/HCV/SUD on this topic and used a case study to illustrate these complexities. The room was full of service providers who introduced a multi-layered conversation about our healthcare system. We engaged in rich discussions about barriers for clients, self-doubt as providers, and anger at the injustice of the system, just to name a few. It was clear that providers from all over the country are having similar experiences and coming together to creatively talk out these issues was a process that was both invigorating and inspiring.

I'm presenting this case study here, in hopes that you'll find new, inspirational, and creative ways to work through these systems with your colleagues and your clients and patients.

A Brief Background

I am a licensed mental health clinician with Outpatient Care Services (OCS), a department of mental health contracted program, housed in a medical setting adjacent to various providers (medical, dental, occupational therapy, chiropractic, nutrition, phlebotomy, and pharmacy). We provide therapy, mental health case management, and psychiatry services, employing traditional and non-traditional mental health interventions, all stemming from a trauma-informed, harm-reduction, power-with "do-whatever-it-takes" approach. Our community clinic is in downtown Los Angeles in the heart of Skid Row.

Barriers, Barriers, Barriers

In our program, we often pour over the barriers that our clients face as consumers, and those we face as providers. According to research by Placzek et al.¹ and from what we as clinicians, case managers, and advocates have observed, client barriers to engagement may include, but are not limited to the following: accessibility, lack of trust and rapport with providers, distrust of the system and disbelief that it could actually work, acute and chronic trauma, learned helplessness, mental health, substance use, medical challenges, communication and cultural challenges, and a reluctance to engage in a process that can be overwhelming and intimidating.

Equally important are the barriers that providers face when advocating for clients including self-doubt, self-blame, countertransference, uncertainty, status and our own intersections, trauma, fear of failure, education level, fear of doing more harm than good, cultural challenges, ethical dilemmas, and language/communication. Further, the systemic barriers providers face when advocating include the criminal justice system, under resourced communities and agencies, red tape and bureaucracy, poverty, institutional racism, sexism, and health disparities.

For these reasons and more, service delivery needs to be proactive, intentional, and creative, and advocacy for clients must be enthusiastic, loud, and unapologetic.

Carlos: A Case Study

I've been working with Carlos² since he was referred to our program in May 2019. Carlos is a 62-year-old cisgender Hispanic male who emigrated to the United States at age 16 and settled in Los Angeles as a resident of Skid Row. When Carlos was referred to our program, he displayed symptoms of depressed mood, self-blame, shame, emptiness, frustration, irritability, and sleep disturbances. During his intake, Carlos revealed extensive trauma both in childhood and adulthood. He became blind in early 2019. Until then, he had use of his left eye (His right eye was damaged in his early 20s.), however, he was attacked by a former partner which left him totally blind. His other medical challenges include diabetes, hypertension, reduced liver function, nerve damage due to alcohol use, and impaired mobility which often forces him to use a wheelchair. Carlos also presented with functional impairments including lack of social and family support, lack of stability with finances, lack of meaningful activities, and poor hygiene. Additionally, he reported instances of paying for sex work, putting him at greater risk for HIV, hepatitis, and other sexually transmitted infections (STIs).

Building Trust with Carlos

Developing trust and rapport with clients is incredibly important and can sometimes take years. Providers can offer incredible services with top-notch research to back it up, but if our clients don't trust us, they won't engage. With Carlos, it was a long process that took over a year, and that process eventually revealed some incredible strengths. Carlos has proven repeatedly that he can handle anything that comes his way, is determined to not give up, genuinely cares for others, and has a stellar sense of humor. When I asked Carlos how he started to trust me, this is what he said:

"From the get-go you showed me you really wanted to help me get my act together. You started talking to me like no one ever talked to me: down to earth. You were really trying to help me. I didn't even know if I needed help, if I wanted help. I was in LaLa Land. It was like that for years. I didn't know how to get help because I wasn't used to none of that. When I noticed you were trying to help me, I was too busy drinking to care. Both of us got frustrated at one time or another, but that was because of me messing up what I was doing. I never experienced nobody going out of their way to help me and get a relationship. Usually, people just look out for themselves. I had never seen the other side."

As Carlos and I began to trust one another, the real healing work began.

Creative Resource Navigation

To provide the level of care Carlos needed, his mental health case managers and I navigated at least 11 service organizations which included care coordination with over 50 service providers. When this level of service is needed, creativity is not an option; it is a necessity.

My creative brain began working overtime when Carlos had surgery to potentially restore his vision in January of 2021. Up to this point, Carlos was living in a single room occupancy (SRO) in the heart of Skid Row with a project-based section 8 voucher (PBV). Although SROs are not ideal, before Carlos lost his vision, it was a manageable living situation. However, when he became blind, certain residents of the building and others in the community knew that he couldn't see and



began to take advantage of this new vulnerability. People stole his keys to make copies so they could easily enter his unit, all electronics were stolen from his unit, meals provided by local agencies were stolen from his refrigerator, cash was stolen when he was sleeping, and when he was sitting in his wheelchair outside his unit, his mattress was stolen and replaced with one infested with bed bugs.

It was clear that after surgery, he would not be able to return to his unit, and safe, alternative housing was needed. During his surgery, I sat in the UCLA surgical waiting area, calling numerous recuperative cares hoping that there would be at least one available bed at a facility that took his insurance. I located a bed, and through an honest conversation with the clinical social worker, I shared that this was a new process for me, I needed help with next steps, and any guidance would be appreciated. My own vulnerability opened a conversation about the complexities of service navigation especially for a high-needs client, and the clinician and I developed a plan to advocate for insurance approval for Carlos to stay in recuperative care throughout his recovery.

Post-Surgery, Post-Vision, All Progress

Insurance approved the recuperative care stay, but sadly, the surgery did not restore Carlos' vision, as the damage to his retina was too extensive. Carlos always knew this might be an option and he was ready for what he called "Plan B." Plan B was enrolling in school through the Braille Institute and focusing

Developing trust and rapport with clients is incredibly important and can sometimes take years. Providers can offer incredible services with top-notch research to back it up, but if our clients don't trust us, they won't engage.

on his education as he officially adjusted to the world as a blind person. Additionally, he asked for referrals to physical and occupational therapy so that he could start moving more independently. His acceptance of the situation seemed almost super-human.

As Carlos and I began talking about this transition in therapy, he noted that he knew this outcome was a possibility, and it was his choices that brought him to this point. Because of this knowledge, he felt ready to accept the outcome and move forward. Carlos shared that if he hadn't become blind, he may have "drank myself to death," and often says that becoming blind saved his life. He identified that he was "done drinking," had goals to pursue, and has been sober ever since.

Eight months after the surgery and into plan B, Carlos called me and described a dream he had where he saw his entire family on a train as the train and his family quickly passed him by. We processed this dream and the emotions he felt, and then he asked: "So, if I wanted to find someone on Facebook, how would I do that?" This launched a three-day project where we created a Facebook profile for him and began contacting people with names he recognized. Carlos couldn't see the pictures, so he was relying on my descriptions and names only. It was a fascinating process.

In a short 72 hours, Carlos reconnected with his brother, two sisters, and most notably, his 46-year-old daughter who he hadn't spoken with in over 20 years. They had all been looking for him for decades. Within the first week of reconnecting, Carlos and his daughter decided that they would like to meet in person. She lives in Oakland, Calif. Neither had the means to travel to see the other person, and Carlos had never been on a plane before. However, knowing that we needed to be creative with Carlos' treatment, my director and I submitted a request for funds so that I could fly with Carlos from Los Angeles to Oakland to facilitate a reunion.

The first response we received from corporate was a strong "NO, ABSOLUTELY NOT." But that wasn't the answer that would best support Carlos' emotional and mental health healing, therefore we advocated loudly, enthusiastically, and unapologetically. For this, we employed the help of our program manager and program director, who used their positions of power to explain to corporate why this trip was crucial for the client. After all, if Carlos was able to reunite with his family and potentially move away from Skid Row, that would be a huge success. The support we provide is temporary and we are always looking for more permanent solutions. The next answer we received was, "Well, there's nothing in our insurance that says the therapist can't fly with the client." That was all we needed to hear, and we booked the tickets immediately.

Carlos' trip to see his family was beautiful, messy, and eye-opening. Everyone learned that although they wanted a relationship with one another, it would take time, and the healing process would be a journey.

Here We Are

Since his surgery, Carlos has progressed from using a wheelchair, to a walker, to learning how to use a white cane, to navigating the streets of Skid Row in almost complete independence. He went from financial instability to being able to pay for his own cell phone plan and a new phone with much needed accessibility features. He is enrolled in classes to learn Braille and independent living skills, schedules all his own transportation, attends all appointments, and participates in extra-curricular activities including bike riding, hiking, fishing, and going to baseball games (Go Dodgers!). Carlos continues to work on his mental health, moving through the guilt and shame of his past to build the supportive, independent future he desires.

The relationship that Carlos and I have built over the past three years is one of mutual respect, trust, and tons of laughter.

When I say things like, "Looking forward to seeing you tomorrow," he responds with: "I can't wait to SEE you!" And when we go to appointments together, he wears the tee-shirt his grandkids recently got for him that says, "I'm legally blind. If you don't like my driving, get off the sidewalk!" I couldn't be prouder of Carlos and how far he's come. When I asked Carlos about this journey with me as his therapist he said:

"The rude awakening was when the trip came up, and you said you were tagging along. I knew I would never be able to pay you back for that. Just the way you were conducting yourself, the way you were transparent. Basically, that's how I learned to trust you. I don't know where I would be without you right now."

I'm not crying, you're—yea, ok, I'm crying.

This is why we do what we do. I didn't enter this field thinking that it would change me as much as it has. Providing critical services for individuals who are vulnerable, high needs, and medically complex is exhausting and amazing work. And because the nature of this work can feel so isolating, we need to call on the vulnerability and radical honesty it takes to successfully and creatively collaborate in this messy system to help our clients achieve success. If I'm not doing this, call me out! And I challenge you to be open to the same because that is where the real change happens. **HIV**



BRIANA MANDEL is a licensed clinical social worker at Wesley Health Centers working on Skid Row in Los Angeles, CA with some of the most vulnerable and incredible humans on

Earth. With a background in theater and customer service, Briana brings a unique and creative perspective to her clinical work in mental health, substance use, and trauma with unhoused communities. Briana currently serves on the Board of Directors of All Saints Los Angeles, an LGBTQ+ inclusive church, and the Board of Directors of Strike for Our Rights (strikeforourrights.org).

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2. Client's name has been changed to protect his identity. Client chose the alternate name for this article.

a magical place
where one feels safe;
a place from which one's
strength of character is drawn;
a place where one feels at home.



DEGA

A Love Letter

By Anthony Martinez, MD, AAHIVS, FAASLD



FOR THE PAST DECADE, *La Bodega* at Erie County Medical Center in Buffalo, New York, has provided care for individuals with the hepatitis C virus (HCV) and addiction disorders. The program is a macro model of HCV elimination based on community outreach and co-localization of HCV and addiction management. Located on the hospital's first floor, the clinic is nothing more than a bullpen-like area where the staff spends 10 hours a day together, surrounded by eight exam rooms. The front window has a pull-down metal gate reminiscent of well, a bodega which is in part, how the clinic derived its name. Bodegas are also considered community gathering spaces and our small clinic is a space where all are welcome. A large black and white flag, embolic of our philosophy and visible from the front window declares "Come One, Come All." *La Bodega* is a personal dream realized and what I hope, is a place where all people find strength, comfort, and some degree of peace.

Screening is the first pillar of HCV elimination followed by linkage to care and treatment initiation. Our staff spends innumerable hours in the community working with our community partners in addiction medicine clinics, corrections, sexually transmitted infection (STIs) programs, foster care, shelters, and everywhere else that HCV may live, educating and developing screening protocols based on available resources to each referral site.

One of the major barriers to HCV linkage to care is system navigation, and we have worked to eliminate this by navigating the system for patients and referring providers. Once a patient is identified, one of our team members is notified by secure email or text. No additional labs are required of the referring provider. Our team contacts the patient to schedule them, arrange transportation if needed, and essentially, navigate the system for them. As a result, eight thousand patients will pass through our doors annually. When a patient comes to us, we take a co-localized approach. HCV therapy is initiated immediately, along with medically assisted therapy as required. Counseling services are available on-site, along with HIV and primary care. There are no incentives to come, yet the clinic show rate is over 80 percent. I've long believed that the greatest incentive for patients is to feel that they are authentically loved and respected.

Luckily in New York, we no longer have restrictions around sobriety, fibrosis stage, or prescriber type. The World Health Organization (WHO) aims to eliminate HCV by 2030, a target that the United States is currently not close to hitting.¹ While these restrictions continue to fall nationally, many states still have them in place. Sobriety requirements are especially troubling. Imagine withholding chemotherapy from a patient with cancer until they quit smoking. Or insulin from a person with diabetes until they modify their diet.

Simply put, we cannot eliminate a disease if we are not allowed to treat it. Seventy percent of new infections in the U.S. are acquired via injection drug use, yet less than 10 percent of patients with active use have received treatment.² Left untreated, one individual will potentially infect 20 others within the first three years of the initial diagnosis.^{3,4} The COVID-19 pandemic has only poured gas on the fire. Screening declined 73 percent, and new treatment starts declined 22 percent.^{5,6}

Additionally, rates of opiate-related overdose increased 30 percent, with more than 100,000 overdose deaths in 2021.⁷ There is a clear correlation between opiate-related overdose, treatment admissions, and incident cases of HCV. Treatment facility admissions for injection opiate



use have increased by 622 percent in individuals ages 18-29, with a subsequent 400 percent increase in incident HCV in the same age group.⁸ Fueled by the injection drug use epidemic, new cases are far outpacing treatment starts. If we are to achieve elimination, we must do more to reach this population for both addiction and HCV management.

Since the arrival of direct-acting antivirals in 2014, *La Bodega* has treated close to 4000 patients for HCV, most of whom are active injection drug users. A modified rapid start approach is part of the care model. Patients have their basic labs drawn on the day of the visit, if not yet done previously, and we have an on-site pharmacy with medications readily available. There is no wait time, and we frequently initiate medication-assisted treatment (MAT) simultaneously with HCV therapy. One of the major barriers to the engagement of active substance users for HCV care is concern regarding adherence and reinfection. Lack of adherence to HCV therapy has long been part of the narrative among people who use drugs despite evidence to the contrary. The growing body of literature over the years dispels these myths. Our model has demonstrated a 90 percent adherence rate for HCV therapy among those who actively inject with a sustained virologic response rate of 98 percent. A recent meta-analysis reports a reinfection rate of 5.9 percent among patients with recent injection or non-injection drug use.⁹ To date, the reinfection rate among our patients is 1.4 percent which we attribute to retention in care for uninterrupted MAT and continued harm reduction measures.



This is a nutshell description of the model, and it's simple enough, really. But what *La Bodega* truly is, is far more complex. At its core, *La Bodega* is a visceral experience where one tastes, smells, hears, sees, and feels what human nature has to show us about survival and redemption. It is the embodiment of meeting people where they are. This concept is frequently discussed as it relates to HCV elimination, and in some cases, it may be considered in a literal sense. For example, deploying mobile units or street outreach to reach patients. While we also utilize those strategies, the concept is a bit more abstract. Meeting people where they are involves establishing a truce with a reality that is not your own and then willingly immersing yourself into that reality. For many years we have focused on a "patient readiness" approach to HCV management with an emphasis on the "challenges" and "barriers" such as active substance use, housing, or food instability, and psychiatric co-morbidities. But for many patients, this has long been their reality and they may never approach a level of readiness or stability that providers are comfortable with. To increase uptake into care, we as providers must be willing to meet patients where they are in every way and work to overcome our discomforts and perceptions.

I've been asked many times why *La Bodega* works. It starts with the staff. Every member of the *La Bodega* has been hand-picked, each bringing their unique personalities and skills, working as a greater whole, and contributing to what we consider a mission. It's rare that in your life and work, you catch lightning in a bottle and get surrounded by some of the most beautiful souls in the universe. It is a small, dedicated team that operates as a family. Our patients' lives are better because of these people. I know that mine sure is.

The staff is also essential to the patient's sense that they are in a safe, stigma-free environment. That sense of safety and comfort is critical for individuals to build trust. There are no white coats allowed in the clinic. There are a lot of tattoos and denim, however. Everyone goes by their first name, and the hierarchy of titles is non-existent (I can't tell you how many times patients ask the staff after I've left the room when they're seeing the doctor. If you met me, you probably wouldn't

believe me either). Patients have our cell numbers and emails. You would be surprised how knowing that they can reach you for that emergency buprenorphine script over the weekend works toward building a relationship. Do you occasionally get that midnight call from jail? Sure. But that can also mean a missed day of HCV medication being avoided.

The schedule is also crucial. We have one, but it's more of a suggestion, a rough guide. There's no 15-minute grace period, no three missed appointments, and you're out of luck rule. Show up an hour or two days late? We still see you. I remember when I was a first-year medical student in Guadalajara, Mexico working in a rural clinic about two hours outside the city. The clinic had closed for the evening, and my attending, Dr. Guyton, was outside smoking a cigarette. I was cleaning the clinic. Three weeks prior, I was a professional janitor and had no discernable medical skills, but I could clean with the best of them. Around 9 p.m., a woman showed up, well past her 11 a.m. appointment time. She explained that her bus never came and she had to walk to the clinic. Dr. Guyton stubbed out his cigarette, turned the lights on and told me to bring her into the office. He also sent me across the street to get her food and water. Three weeks into my medical career, in the middle of nowhere Mexico, I learned what remains the most valuable lesson of my career. Meeting people where they are is the true essence of medicine.

One of the most beautiful aspects of *La Bodega* is the ceremony we have when patients find out that they are cured of HCV. After an individual is cured, they sign the walls of the clinic. The messages vary from just their initials to long notes of gratitude, even some thumbprints. The names and notes cover every space on the clinic's walls. After they leave their mark, the patients ring a cure bell. The original was a mounted dinner triangle-type bell, but one exuberant lady pulled it right out of the wall. The hole is still there (We put a sticker over it.). After that, we got a legitimate cowbell, a massive upgrade, and significantly louder. Every time they ring it, there's not a dry eye in the place. HCV cure and that small ceremony means many different things to patients. It's empowering for some, a positive step forward. For others, it symbolizes closing out a chapter



One of the most beautiful aspects of *La Bodega* is the ceremony we have when patients find out that they are cured of HCV. ...After an individual is cured, they sign the walls of the clinic. ... After they leave their mark, the patients ring a cure bell. ...Every time they ring it, there's not a dry eye in the place.

of their life, a weight lifted, allowing them to leave a dark part of their life behind.

This place sounds amazing, no? The truth is that the raging opiate crisis continues to overwhelm us. Sometimes *La Bodega* exists as a sort of no man's land between fertility and dust, where progress is slow, and everyone struggles to survive. Some days it feels like the last stop on earth. The stories of trauma and destruction are overwhelming, and the dark attempts to snuff out everything in its path. It can be hard to find hope in the sea of destruction. But that these people are there at all, sitting with you, still trying, is the true reminder. I often wonder if they know how much they give us, how much they teach us, and how they make us better.

"How did you feel the first time you came into the clinic?" I asked one of our long-standing patients as he was signing the wall. "I loved it. I've loved it ever since. This is the first place I've even come for help that actually saw me as a person and treated me like a human. It helped me find strength. This clinic is the reason I'm still alive." Then he rang that bell like he was trying to crack the earth in half. The echo, signaling the promise of hope.

As I write this, *La Bodega* is quiet, the gate pulled down. Even in the calm, there is an unmistakable energy here. The names on

the walls are a testament to resilience and redemption.

I don't know what the destiny of *La Bodega* is, but I know that it strives toward service to the greater good. Drawn forward by some invisible force, we walk together with our patients, knowing that we have all come with a purpose. Our mission is rooted in love, and all that love is defined by—passion, awe, allegiance, respect, justice, and compassion. No matter what comes, there will be no compromise. *La Bodega* represents something different to all who are connected to it. It is my *querencia*, and I owe my life to every person who has walked through its doors. **HIV**



DR. MARTINEZ is an associate professor of medicine at the University at Buffalo and the medical director of Hepatology at the Erie County Medical Center. His clinic "*La Bodega*" has been recognized both nationally and internationally as a novel co-localized model for the management of viral hepatitis and addiction disorders. His team's work has been presented at the annual liver meeting of the American Association for the Study of Liver; the annual conference of the International Network On Viral Hepatitis in Substance Users and the International Liver Congress. Dr. Martinez is a Fellow of the American Association for the Study of Liver Disease; a member of the American Academy of HIV Medicine; the European Association for the Study of The Liver; the American Society of Addiction Medicine; and he is co-chair of the Chronic Liver Disease Foundation HCV Committee.

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Women
Empowering
Women

MUJERES
Empoderando
MUJERES

Addressing HIV and Substance Use among Female Transgender and Cisgender Transactional Sex Workers in the Rio Grande Valley, South Texas

By Gustavo Adolfo Morales Correa and Samantha Montemayor

IN THE RIO GRANDE VALLEY BORDER AREA OF MEXICO and the US, women's life might as well be expendable. Women are murdered and regularly disappear. Unfortunately, many of their cases are never resolved. Poverty and income inequalities increase the vulnerabilities in women, which can increase their engagement in risky transactional sex and may lead to unimaginable harms, such as substance use and human trafficking.¹ At the Mexico-U.S. border, financial need is a major motivation for women to initiate and continue trading sex.² Females trading sex in the boarder of the Rio Grande Valley from Brownsville to McAllen have been found to have low-educational attainment, low literacy, multiple financial dependents, inconsistent knowledge of HIV and sexually transmitted infections (STIs), and to have traveled from distant locations (e.g., Matamoros to Reynosa Tamps Mexico) in hopes of getting to the United States.³

Call me Samantha Montemayor

Before we move forward there are quite a few things I'd like you all to know about me, the first one is that I am a chingona!⁴ This word has historically been used to describe women who are "too aggressive," while the masculine version of the word "chingon" is used as a way to compliment men. In recent years, Latinas have made efforts to reclaim the word and used it as a way to empower themselves, similarly to how the LGBTQI community has taken back the word "queer."⁵ For the past 5 years I've been a fierce Human Rights Activist who believes that LGBTQI+ Rights, Trans Rights, and the rights of People with HIV (PWH) are Human Rights, period. I'm also a proud Trans Latina Woman of Color from the Rio Grande Valley who has lived with HIV for the past 12 years. Most importantly, I'm all of these and much more, but you may call me Samantha Montemayor.

As a person raised in the border town of Donna, TX, I became used to straddling multiple societal, political, gender, linguistic and cultural borders. When you spend your formative years in the Rio Grande Valley, it seems that you never get to be enough. I wasn't Mexican enough because I was raised this side of the border, yet I wasn't American enough because I was born that side of the border. I wasn't woman enough because of the sex I was assigned at birth, and I wasn't important enough because I was a woman. I was not Latina enough due to my limited Spanish and I wasn't "American" enough because of ethnicity. Very few times I got to enjoy spaces where I just could be me, I decided that would stop with me.

Growing into my wings

Interestingly, yet not uncommonly, the realization that a better space for the women in the Rio Grande Valley could be possible, came to me while I lived in New York City, funny how sometimes we need to crawl away from what we know, find a safe space and metamorphosize to learn what we are capable of. In NYC I was a participant of MujerT, a PrEP Navigation and HIV Testing project of the Oasis LGBTS Wellness Center that prioritized women of color. In MujerT, women were brought together to address their needs and discuss options for HIV prevention, regardless of them being cis or trans. In this space we were empowered to take ownership of our sexuality not because we were cis or trans but because we were Women, a wholly new concept for me and my fellow participants who until then were taught that trans and cis issues were mutually exclusive. For the first time I was just a woman, no other prefix attached. At Oasis I also learned to believe in myself and become a stronger person and activist. The leadership development retreat "Construyendo tu Yo ideal" (Constructing your ideal Self) gave me the metaphorical wings I needed to fly back into the Rio Grande Valley and help my community.

We are women! And we matter!

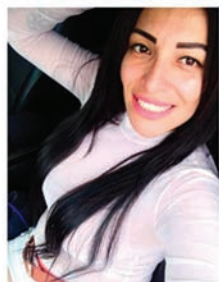
You see, at the end of the day Cisgender and Transgender women who engage in sex work face similar issues, the problem is that not leveraging these commonalities stops us from uniting our voices and that minimizes our chances

of effectively advocating for ourselves. The vast majority of women sex workers choose to do sex work because it is the best option they have. Many sex workers struggle with poverty and destitution and have few other options for work. Others find that sex work offers better pay and more flexible working conditions than other jobs. Some pursue sex work to explore and express their sexuality.¹



Who is Kimberly:

She is a Brownsville native who went missing May 13, 2017. With the help of the Valley AIDS Council and the Brownsville Police Department, the reward money for information on her disappearance has reached \$10,000. Family members urge the public to report any information on Avila's whereabouts to Brownsville Crime Stoppers at (956) 546-8477.



Who is Yareli:

She was a 32-year old Cisgender Female who was found dead in her apartment Monday, December 28, 2021. She was a mother, a daughter, a friend. Family and friends raise their voices together to demand justice.

In Brownsville Kimberly Avila, a Transgender Transactional Sex worker went missing on May 12, 2017. As of today, we haven't had any answers regarding her whereabouts. Yareli Chin, a cisgender Transactional Sex Worker was murdered by her boyfriend on December 27, 2020. He fled to Mexico and again the police has not done anything to resolve the case.

We demand justice and our women are important!

For us Kimberly and Yareli were mothers, daughters, sisters, friends, and someone who our Rio Grande Valley community loved and misses. For the society, providers, and authorities both were women, sex workers, and Latinas, a trifecta of intersectionalities that in the Rio Grande Valley basically renders you invisible. Transphobia is rooted in misogyny and misogyny feeds transphobia, violence, discrimination, and machismo. While we demand attention to both cases, one is

a Missing Person Case the other a Murder Case, 5 years, and 2 years old respectively, we also recognize that something had to be done to empower women in the Rio Grande Valley.

Doing something about it.

The alarming increase in HIV & STIs amongst the transactional sex worker community of the Rio Grande Valley, exacerbated by homelessness, lack of education, lack of employment, self-esteem issues, machismo, and immigration led to the efforts of hosting a series of workshops for women, regardless of them being cis or trans. Between October 2018 and February 2019, while working for Valley AIDS Council (VAC) the Director of Education, Oscar Lopez presented me with the opportunity of creating two, eight-session workshops for Transgender and Cisgender Transactional Sex Workers. Workshops were delivered in the McAllen-Reynosa and Brownsville-Matamoros border towns in the Rio Grande Valley south Texas Border region. A small grant in the amount of \$7,000 was secured and it allowed VAC to reevaluate our approach for working with Spanish or English-speaking Transactional Sex Workers from a one-time cookie cutter intervention to a more tailored "think outside the box" when it came to developing a bilingual and replicable two-city training for Cisgender and Transgender Latina Transactional Sex Workers on the U.S.-Mexican Border. The concept which became a reality allowed us, with support from auxiliary staff and community guest speakers to empower two regional sets of sex worker communities, one from McAllen, Texas and one from Brownsville, Texas both sister cities located some 70 miles apart, and each within two of the busiest international border crossings nationwide in the two poorest regions of the United States. The women who participated identified as Cis, Trans and Gender Non-Binary.

Mujeres empoderando Mujeres offered female transactional sex workers educational workshop sessions, on sexual health, their rights as individuals, self-defense, and better quality of life outlooks. As an integral part of these sessions, when an individual participated, access to HIV/STI care, linkage to care, Case Management, Sexual Health Education and Testing was provided.

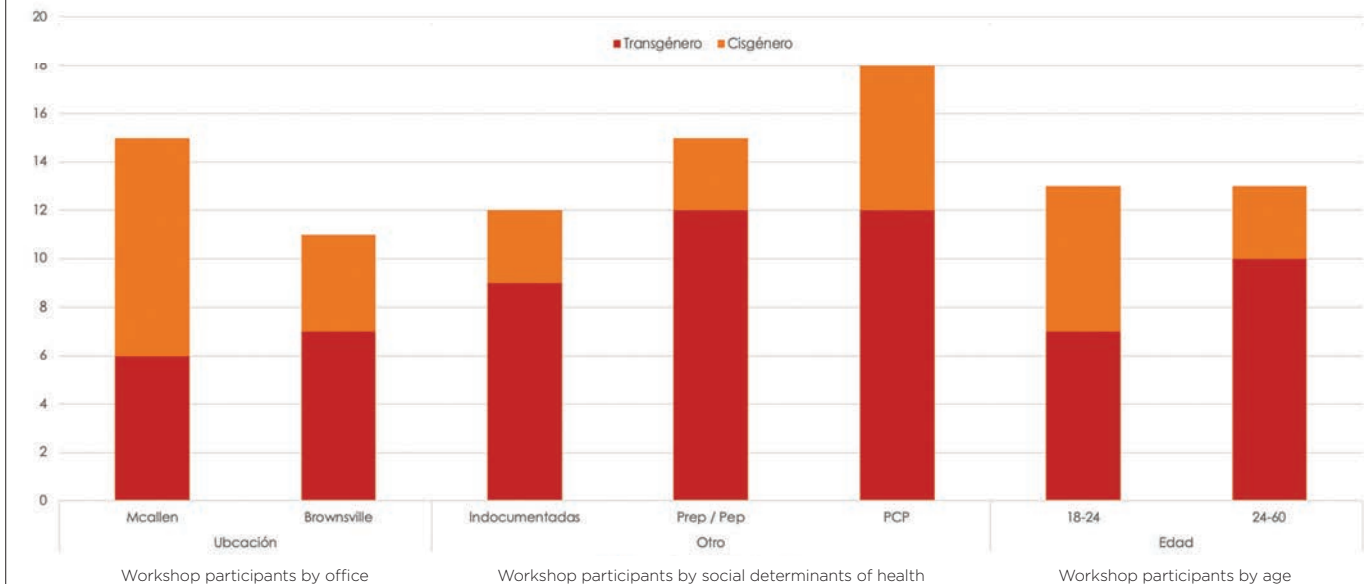
In total, twenty participants graduated from *Mujeres empoderando Mujeres*. All of them were ready, willing, and able to be engaged. They were each living in poverty, on the cusp of poverty, or struggling with poverty and income inequality. They voiced their increased concern for making rent, for caring for children, their gratitude for the lessons learned during our trainings and the money earned without having to swallow anyone's load, or thankful for being able to put food on the table without any fear of potentially contracting HIV or an STI. They were all savvy about condoms and PrEP but they also knew they would get paid more without condoms or by engaging in substance use, even if they ran the risk of an STI.

They also knew there were risks associated with rejecting the advances of someone wanting aggressive, violent sex or sex that included substance use. If they accepted the 'date' there were risks and if they rejected the person(s) it could worsen. Their decision to engage in transactional sex was ALWAYS risky, and for some of the participants it had already led to horrific harm, such as physical violence, rape, forced substance abuse, exploitation by police and a physical attack that left one participant at death's doors beaten by a golf club until she was unrecognizable and in a coma.

Workshops were developed to address Self Care. For these workshops we relied on the expertise of motivational speaker Maria Limon who was tasked with developing a curriculum bringing into focus the reality that women, cis or trans, experience Domestic Violence, Sexual assault, Police Discrimination & Abuse among other issues in similar ways and provided women tools and skills to work together when addressing these issues.

The participants in both groups also completed two "Know your Rights" workshops were then Officer Garza, an ally within the police force, was able to gain the trust of the participant and taught them how to and where to report crimes committed against them while engaging in their trade. Crimes against sex workers, some of them perpetrated by police officers, usually go unreported due to fear. Officer Garza became the main point of contact for the participants if they ever became victims of a crime and enforced the concept that the fact, they are engaging in sex work does not

Demographic breakdown of workshop participants



exclude them from accessing justice.

We were also able to create a Self Defense workshop where the girls were taught techniques to be able to protect themselves from a client who could become aggressive towards them. On our last workshop we were able to provide Health Prevention and Testing to our participants.



The Participants were able to gain a \$100 incentive for each workshop with a total gain of \$800. Participants were both Street and Cybersex workers. Ages ranged from 21-56 years old, both groups had a ratio of six cisgender and 7 transgender females. In the McAllen group it was more Cyber-sex workers and in Brownsville it was more street-based sex workers.

This first of its kind training on the Texas–Mexico Border with Transactional Sex Workers it only was it needed by the women who participated, but that cis and

transwomen could build community together. The training showed that transactional sex workers wanted, needed and appreciated self-defense training from potential tricks as well as police, the training showed that women in this field of work wanted and were deserving of respect from organizers, police, HIV orgs, each other, and that an opportunity had to be created, and indeed all the women benefited, as well as the community that they inhabit as we as their families and support systems. This is a program that Valley AIDS Council currently delivers today. **HIV**



GUSTAVO MORALES is a skillful Sexual Health Counselor/Facilitator currently servicing the community of New York City as the Director of Access to Care and Services Department of the Latino Commission on AIDS. Most recently he was a member of the “High Impact Prevention & Engagement” Workgroup of the NYC HIV Planning Group and has presented on the 2016 Creating Change Conference and at the 2012 U.S. Conference on AIDS a Social Marketing strategy developed on Puerto Rico to enhance outreach efforts and enroll young MSM to get tested. He comes with 17 years’ experience on the HIV field including volunteer, counseling, multiple DEBI facilitator and HIV tester roles.



SAMANTHA MONTEMAYOR is a Sexual Health Counselor currently servicing the community of New York City as the Oasis Case Manager of the Latino Commission on AIDS. Most

recently she was a member of the “Activate and Elevate Fellowship” Workgroup of the Human Rights Campaign and has also been in the Elevate program of NMAC. She has been a community Activist since 2017. She has been the House Manager for Casa Anandrea the only Trans Shelter in the State of Texas. Has been the Board Secretary of GENTex, a Trans led organization based in the Rio Grande Valley in South Texas.

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LGBTQ Communities, Interse **Ending the HIV E**



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By Corey Prachniak-Rincón, JD, MPH,
and José M. Zuniga, PhD, MPH



ISTOCK/ PEOPLE IMAGES

LAST YEAR, we led a global survey of 275 key informants who work in areas relating to the health and well-being of lesbian, gay, bisexual, transgender, queer (LGBTQ) and related communities.¹ We included respondents from 50 diverse localities that are part of the Fast-Track Cities network, a group of more than 400 cities and municipalities that have committed to ending HIV as a public health threat by 2030.

The results were sobering, if not a total surprise to those of us who are part of (and serve) this population. Quality of life for LGBTQ people was rated at just 3.2 on a scale of one (poor) to five (excellent), with many cities in the United States like Miami (3.3), New Orleans (3.3), and Chicago (3.4) scoring right around the global average. Access to primary care was rated at 3.1 on that same scale, while mental health-care (2.8) and gender-affirming care (2.7) fared even worse.

If there was a bright side amidst these results, it was with respect to HIV services. Key informants scored access to HIV prevention and care as being better for their local LGBTQ community than any other health service, weighing in at 3.8 on the same scale. While this left considerable room for improvement, it nonetheless reaffirmed that HIV service providers were relative leaders for LGBTQ inclusive care in many communities.

Of course, these topline numbers do not tell the whole story—first, because there is great diversity and disparity within any given LGBTQ “community,” and second, because underlying sociopolitical dynamics make healthcare access just a small part of overall health and wellness. As we delve into these topics, it quickly becomes apparent that not only can we not end the U.S. HIV epidemic without a focus on intersectionality and populations such as LGBTQ Black and Latinx people who face the greatest inequities, but also that to end the epidemic, we will need to address (if not entirely upend) the underlying structural dynamics that have facilitated the situation we face today.

Intersectionality and HIV

The term “intersectionality” was coined by Kimberlé Crenshaw more than thirty years ago to help us understand how discrimination facing women of color is more than just a sum of parts of the discrimination encountered by women on the one hand and people of color on the other. Rather, the interplay between these marginalized identities creates unique experiences of discrimination and resulting challenges.² In the years that have followed, Crenshaw has also applied the concept to people of color within LGBTQ communities, who not only face unique forms of marginalization within society at large, but who are also systemically marginalized within LGBTQ communities.³

This concept is critical in understanding, and ending, the U.S. HIV epidemic. Sexual minority men make up about two-thirds of new cases of HIV each year, despite the fact that this population represents only two percent of the U.S. population. However, equally important is that the vast majority of those cases are among Black and Latinx sexual minority men, who make up just under half of all new cases of HIV annually.⁴ Data is more limited on transgender individuals, but in a study of seven cities, the Centers for Disease Control and Prevention (CDC) found that 62 percent of Black transgender women and 35 percent of Latina transgender women were living with HIV, compared to 17 percent of White transgender women (still a hugely disproportionate burden compared to the general population).⁵

In seeking to address and end the HIV epidemic, we cannot take an “either/or” approach in which we focus on LGBTQ individuals or Black and Latinx communities. Not only does this miss the epidemiological mark, it also minimizes the identities of Black and Latinx LGBTQ individuals and ignores the factors that explain and maintain the inequities that they face.

For example, pre-exposure prophylaxis (PrEP) has been found to reduce the risk of HIV transmission by up to 99 percent, but Black and Latinx sexual minority men were more likely not to be aware of PrEP, to have discussed it with their provider, or to have initiated PrEP than were their White sexual minority peers.⁶ While 61.1 percent of White individuals with indicators for PrEP have been prescribed it, that is true of only 13.7 percent of Latinx individuals and a mere eight percent of Black individuals.⁷ As such, White individuals make up just over two-thirds of those who have been prescribed PrEP, despite accounting for under a quarter of those with indicators.

It should not be shocking that without targeted outreach and education, Black and Latinx sexual minority men would be not only less likely to know about PrEP, but also to feel comfortable speaking to their provider about accessing it. But we must layer on top of that issues of social determinants of health, because Black and Latinx individuals are also less likely than their White peers to even have access to a healthcare provider, as well as to things like transportation and housing that facilitate adherence to PrEP (or to other forms of care).

How Inequities Shape LGBTQ Health and HIV

Globally, the 275 key informants included in our study said that discrimination against LGBTQ people holding multiple marginalized identities, including racial and ethnic minorities, was the most problematic form of discrimination facing their community. Almost three in four respondents (74%) said that this was either a “serious” or “moderate” problem. One in 14 respondents (7%) said that it was not a problem at all. Of course, racial and ethnic minority communities are very different across cultural contexts, yet a majority of respondents in every region of the world said that this type of intersectional discrimination was a problem for their LGBTQ community.



Data on both Latinx and LGBTQ identities is notoriously bad, given both the inherent complexities of each (much less the two combined together) and the frequent indifference or outright opposition shown to counting these populations by decision-makers.

The same was also true with respect to criminal justice issues. More than six in 10 respondents (62%) said criminal justice issues facing LGBTQ racial and ethnic minorities, was a “serious” or “moderate” problem, with only one in 10 (10%) saying it was “not at all” a problem.

These concerns specific to intersectionality and LGBTQ health were raised in conjunction with a wide range of challenges that we know disproportionately affect Black and Latinx LGBTQ people here in the U.S., including housing, employment, food security, and criminalization of HIV transmission and nondisclosure. All of these were noted as problems by a majority of respondents in our study across regions, including in the U.S., despite our standing as one of the world’s wealthiest countries. For example, 58 percent of respondents in New Orleans said that food insecurity among LGBTQ people was a “serious” problem, versus just 13 percent globally. New Orleans respondents were also almost three times as likely as respondents globally to say that criminal justice disparities facing LGBTQ racial and ethnic minorities was a “serious” problem. In contrast, San Francisco—known as an epicenter of LGBTQ culture and history—scored above global averages on many metrics, but nonetheless showed room for improvement. This was especially true with respect to housing access for LGBTQ people, which was labeled as a “serious” problem by every key informant surveyed.

While we did not inquire specifically about immigration, many key informants noted LGBTQ migrants as a population facing unique challenges and needs in their cities. This was true with respect to discrimination and legal barriers, but also in having adequate education and outreach on LGBTQ health issues (including HIV) to make services accessible.

To End HIV, We Must Address Inequity

In July, we traveled to Montréal to present further findings from our work that found an association between various aspects of LGBTQ health equity and progress on reaching the global HIV targets: that 905 percent of people living with HIV know their status, that 95 percent of those who know their status are on treatment, and that 95 percent of those on treatment are virally suppressed.⁸ We found that cities that had made the most progress on those 95 targets had better LGBTQ policies in place (like antidiscrimination laws, marriage equality, and access to documents matching one's gender identity), had lower levels of LGBTQ discrimination as reported by key informants, and had higher reported quality of LGBTQ primary care and HIV care.⁹ While this does not prove causality, it does show that progress on LGBTQ equity and ending local HIV epidemics go hand in hand.

Our study focused on LGBTQ life at the urban level in order to show the challenges and opportunities that exist to improve LGBTQ equity in individual communities. As members of the global Fast-Track Cities network, the political leaders of these cities and municipalities have signed onto the Paris Declaration on Fast-Track Cities. This includes commitments to achieving the global HIV goals and also to engaging with key populations and working to end stigma and discrimination. Research such as ours highlights both the common themes and potential solutions for LGBTQ health and HIV responses across the globe, while also centering the unique opportunities in each local community.

The U.S. Latinx LGBTQ community provides an excellent example of one with both national and local dynamics. It is also a timely example, with National Latinx HIV Awareness Day occurring on October 15. While awareness is needed for the Latinx population in general, and especially LGBTQ Latinx individuals, "awareness" often seems even more lacking when it comes to those in power failing to adequately account for the Latinx populations' needs with respect to HIV and general health. Data on both Latinx and LGBTQ identities is notoriously bad, given both the inherent complexities of each (much less the two combined

together) and the frequent indifference or outright opposition shown to counting these populations by decision-makers. The Latinx population also varies greatly between and even within states, just as LGBTQ challenges in New York City will look different than they do in rural Appalachia.

Nevertheless, many of the same strategies that we recommended in our report and that Fast-Track Cities utilize more broadly can apply regardless of the unique circumstances of local communities. These include having quality, comprehensive, and inclusive data at the local level, in order to inform responses and increase transparency; ensuring that marginalized and key populations have not just a seat at the table, but leadership roles in decision-making processes; tackling stigma and discrimination, since these factors can inhibit not just access to care, but also participation in shaping health systems and HIV responses; and educating healthcare, social services, and government workforces on the needs of LGBTQ communities, especially Black and Latinx LGBTQ individuals.

Globally and here in the U.S., LGBTQ rights remain in a tenuous position, and the COVID-19 pandemic and other factors have put at risk the hard-won gains we have made in tackling HIV.¹⁰ We cannot end HIV without addressing inequity, including with respect to LGBTQ identities and racial justice. Even reaching the 95 targets will be a bittersweet victory, at best, if the five percent who remain undiagnosed and untreated represent the most marginalized among us. But LGBTQ communities and HIV responses are both remarkably resilient, and if those most affected by these issues are centered and supported with financial and political capital, it is still possible to achieve our goals of achieving LGBTQ health equity and ending HIV as a public health threat by 2030. **HIV**



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Entre MACHO y Maricón

The complex relationship dynamics of Latinx MSM relationships

BY ELIAS DIAZ, LMFT

FOR OVER FOUR DECADES, we have made enormous strides in medicine and research to address the HIV epidemic. We have mobilized an entire nation to move toward social, racial, and economic justice and advocate for equity. And we have identified some gaps in our care continuum to secure funding and developed strategic plans to reach those populations that have been left behind. But for those of us that identify as Latinx, the intersectional oppression of HIV stigma, machismo, homophobia, and limited access to healthcare converge to create complex dynamics for our romantic relationships with other men.

That complexity creates a problematic dynamic for HIV services and prevention. According to the Centers for Disease Control and Prevention (CDC), of the 34,800 estimated new HIV infections in the United States in 2019, 24 percent were among Latinx men who had sex with men (MSM).¹ Hispanic/Latinx men accounted for 89 percent of new HIV infections among all Hispanic and Latino people in the U.S. in 2019, with 87 percent of those infections attributed to male-to-male sexual contact.²

Contextualizing our Identity

Feeling invisible is a theme that is all too familiar in my life. I grew up in a colonia in Eagle Pass, Texas where our roads were not paved, we did not have trash pickup services available, and we did not have access to potable water lines. Colonias are geographic areas along the U.S./Mexico border

where low to very low-income families, most of which are recent immigrants, lack safe and sanitary housing.³ Coming from this place can sometimes make you feel insignificant, discounted, or forgotten.

I remember feeling that I didn't quite belong there. I realized early on that I was not like other boys, and as I developed a strong attraction to other boys the fear inside me grew that I was in fact what others would call me. That internal struggle grew throughout the years as I would try to mask my femininity to conform to my machista culture. I fought the feelings of same sex attraction until I felt suffocated by the thought of having to continue to hide it.

In a culture that values the essence of family above self, and what Henry Carrillo (who is he? A writer?) describes as "sexual silence," in his research, my need to be out and open presented a sharp and problematic contrast with the



tradition and values of my Latinx culture.⁴ My mother begged me to be quiet in order to avoid my father's violence. The shame of my sexuality reverberated through our small town and made my father very angry. It was the first time that a man would try to make me erase a part of my identity through violence, but it would not be the last. He would beat me in his efforts to teach me how to be a macho. But, while I was afraid of my father's heavy fist, I was more afraid of losing my autonomy.

This attempt at erasure of identity is not specific to my generation. My people have experienced the pain and aftermath of colonialism and conquest for centuries. Our native tongues have been erased. Our Spanish colonial ancestors cloaked us with Catholicism to erase our religious identity and force binary gender norms. I inherited the fight of my ancestors, and it fights for visibility in a world that demands assimilation.

We are a child of the conquered, the native Meso Americans, as well as the Spanish conquistador. That violent clash of cultures is a part of our genetic makeup and it sets a backdrop to the multilevel trauma we endure throughout our lives. In fact, according to Salud America! 78 percent of Latino kids suffer at least one adverse childhood experience, such as poverty, neglect, abuse, or some form of household dysfunction. I was among the 28 percent that suffer four or more adverse experiences. I survived emotional, physical, and sexual abuse as a child.⁵

My teenage years were dark as I turned my anger and depression inwards. It manifested in the form of various maladaptive coping mechanisms, some of which accompanied me into adulthood. I longed for the day in which I could leave this small town and have a real shot at being me.

Dynamics of Power

In spite of the constructs of our early lives, the Latinx community persists. We grow despite family rejection, internalized messages of homophobia and racism, and multilevel trauma. El maricón forges through the world making space and demanding visibility.

We seek guidance and insight from the community as a means to survive. Yet, that series of early internal struggles we go through, shape the relationships we form with other gay and bisexual men. I remember the first time I was afraid of contracting HIV. I was 16 and in a relationship with a man in his early thirties, and my friends called me to tell me to be careful with him. They had found out his previous partner had died of AIDS and they were concerned for my well-being. That was the first time I felt afraid of a partner, but it was definitely not the last.

According to the CDC, "Hispanic/Latino gay and bisexual men are more likely to report that their last sex partner was older, compared to White or African American gay and bisexual men." The research shows that older partners may increase the likelihood of HIV exposure because an older partner is more likely to have had more sexual partners or other risks and is more likely to have HIV.⁶

My fear of contracting HIV was highlighted by several barriers that were in place preventing me from even addressing the issue. I remember not knowing where to get tested for HIV in my town. I feared disclosing my concerns to my parents, mostly because I was not out to them, yet. I now know that even if I did ask them for help, their ability to help me would have been limited by what they knew about healthcare in this town. In retrospect, I remember that I probably didn't even have health



insurance at that time ... it would remain that way until my mid-20s.

Developing Relationships

As I reached adulthood, I remember clinging on to the fear that my next relationship or sexual encounter might give me HIV. I spent the majority of my adulthood feeling as if I was playing roulette every time I had a sexual encounter. I carried my shame like a backpack as I wove in and out of relationships and sexual encounters. I saw my friends grieve as they acquired HIV and wondered when it would happen to me. But as I navigated relationships with men living with HIV and men not living with it, I realized that fear had always been my primary partner.

My childhood experiences had left me feeling afraid to be vulnerable. I lacked confidence in my ability to choose the right partner as I experienced varying forms of physical and emotional violence in every one of my relationships. I scrambled through my early memories of masculinity and identity to find parts that fit me. I found solace in

I remember feeling that I didn't quite belong there. I realized early on that I was not like other boys, and as I developed a strong attraction to other boys the fear inside me grew that I was in fact what others would call me. That internal struggle grew throughout the years as I would try to mask my femininity to conform to my machista culture. I fought the feelings of same sex attraction until I felt suffocated by the thought of having to continue to hide it.

my work and ascertaining financial independence. And while fear was my primary partner, money became a worthy mistress.

Machismo taught me that hard work was the trademark of a man. I remembered idolizing my father for his work ethic, and excusing his emotional disconnectedness with his work. It was a worthy excuse that I felt entitled to inherit. I missed birthdays, anniversaries, and dinners in my quest to ascertain my manhood through my financial stability. I found value in my bank account, and never put anyone before my work. While I longed for a true connection, I found myself engaging in behaviors that would prevent me from getting that.

Re-authoring our Stories

We have endured such losses. Some of us lose our friends or families of origin through coming out. We lose people through patterns of immigration. We lose people through the criminal justice system. We seek out chosen families in hopes of preventing hemorrhaging of loss only to find ourselves losing our people to death from HIV, being murdered for their LGBTQ identity, or succumbing to substance abuse or suicide. But perhaps one of the most poignant losses was the one that we so often repeat, the loss of love. Yet, it is the stories that we tell ourselves that have the power to moderate the impact that our stressors have had on our lives.

We make believe that we can quell our fear of loss through things we can control. We invest in our bodies, we seek out financial success, and we immerse ourselves in the best parties all at the expense of forming real relationships. But what if we learn to deconstruct these stories in a different way?

Research on couples' narrative therapy on sexual minority couples outlines steps

to externalizing and naming the problem in order to facilitate a conversation on how the problem is defined, what stories we make up about the problem, and how different stories are told in relation to the problem.⁷

We've inherited this existential crisis from a generation of men that survived daily trauma. These men have seen their lovers die in their arms. They've been to more friends' funerals than they'd care to count. Their shared grief was ignored by a nation that looked the other way. The penance of survivor guilt loomed over their shoulders as they forged on, forming the habit of separating the "us" from the "them" in a game of pure survival. It is our time to deconstruct these stories, to honor their experiences by giving their stories new meaning, but most of all to recognize the beauty of resilience.

While machismo is associated with aggression, dominance, and emotional disconnectedness, it is also synonymous with "bravery, honor, and pride." Perhaps the key to our survival is that which has hurt us the most.⁸

The Latinx gay man, el maricón, is the essence of survival. My activism is about recognizing that fight for the right to exist, and recognizing it in others, but most of all, to recognize that the fight is not with ourselves or with each other. After years of enduring the pain of what felt like perpetuity of failed relationships, I've found a partner in the fight.

I learned about vulnerability, self-respect, and dignity as I taught about what I knew about the effects of trauma, the context of the LGBTQ community, and levels of accountability. Together, we collaborate to find a space that was safe for both of us and centered each of our needs. (The preceding sentences do not make sentence. Who is the partner he is referring to?)

We have cut through varying levels of oppression to be present in this space, here and now. With a holistic approach to healing and with a fresh perspective on recognizing the complexities of our identity, we can change the landscape of HIV for Latinx men living in the U.S.

For all those men that didn't make it this far, let's learn to love each other. Let's learn to love ourselves enough to redefine our stories. Let's honor our bodies by looking at all of our options for treatment and prevention. For those men that came before us, let's learn to recognize that our identity lies somewhere on the beautiful spectrum entre macho y maricón, (again, maybe not the best word to use). **HIV**



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REPRESENTATION MATTERS

By Pedro Goicochea, MSC, MA and Tasia Baldwin, MSC, MA on behalf of the Latinx Caucus*

PROVIDER-CLIENT RELATIONSHIPS have the potential to increase the participation of Hispanic and Latinx individuals in HIV clinical research trials. Representing populations from Central and South America, and the Caribbean, the Hispanic and Latinx communities are racially, culturally, and linguistically diverse. Providers can learn more about these populations to facilitate conversations about research participation. When initiating conversations, providers have the opportunity to enhance the provider-client relationship and contribute to the overall goals of evidence-based medicine. As part of this discussion, we will highlight the importance of increasing the trial participation of Hispanic and Latinx individuals by addressing factors that impact trial participation using approaches suggested by experts in our literature review.

Participation of racial and ethnic minorities and other vulnerable groups is essential and required in clinical trials to assure the generalizability of research findings and their applicability to the broadest range of the population.²⁻⁵ This is particularly true for HIV clinical research.

HIV incidence in the United States is decreasing, however, Hispanic and Latinx communities remain the second most impacted group by the HIV epidemic after the Black and African American population. Hispanic and Latinx individuals account for 19 percent of the U.S. population and are the second fastest growing ethnic group in the country. Census Bureau projections predict that this group will account for 28 percent of the country's population by 2060,⁶⁻⁸ emphasizing how important it is to address the HIV incidence among Hispanic and Latinx individuals, who accounted for 29 percent of the new HIV diagnoses in 2019.[†] One in four people with HIV in the U.S. is Hispanic or Latinx.⁹ Despite the disproportionate impact of the HIV epidemic on the Hispanic and Latinx communities, their representation in HIV clinical research remains low in comparison with non-Hispanic or Latinx White individuals,^{3,10-14} mostly due to challenges that limit their participation.

“...That certain minority groups make up a small percent of the US population is not an acceptable justification for underrepresenting those groups in clinical research.”

D. Vigil, *et.al.* in *Ethics and Human Research* (2021)¹

*The Latinx Caucus is a working group of the Legacy Project of the Office of HIV/AIDS Network Coordination (HANC) aimed at increasing the representation and participation of Latinx in HIV/AIDS clinical research. Members of the Caucus provided feedback to this manuscript:

- Moises Agosto-Rosario (NMAC, formally National Minority AIDS Council)
- Tasia Baldwin (HANC)
- Jorge Benitez (Columbia Clinical Research Site)
- Russell Campbell (HANC)
- Daniel Castellanos (Latino Commission on AIDS)
- Rafael Gonzalez (HIV Vaccine Trials Network)
- Angel Luis Hernandez (HIV advocate)
- Jean Hernandez (AIDS Alabama)
- Jahn Jaramillo (PhD candidate, University of Miami)
- Brian Minalga (HANC)
- Carlos Rodriguez-Diaz (George Washington University)
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[†] We are using data from 2019 since data for the year 2020 are likely skewed by the effects of COVID-19 on access to HIV testing, care-related services, and case surveillance activities in the state and local jurisdictions as stated by CDC in their updated surveillance report released in May of 2022.

***How Providers
Can Increase
Hispanic and Latinx
Representation
in HIV Clinical
Research***



The Participation of Racial and Ethnic Minorities in Clinical Research

A recent meta-analysis conducted by Turner et.al. reviewed 20,692 U.S.-based trials and found that, in those that reported ethnicity and race, the majority of enrollees were White individuals (median 79%), and the median combined enrollment of minority race and ethnicity groups (Black/African American, Hispanic/Latinx, Asian, American Indian, and Other/Multi-racial communities) was below census estimates (median 27.6%). Furthermore, only 43 percent of clinical studies reported any ethnicity or race.¹⁵

Similarly, the participation of racial and ethnic minority groups in HIV clinical research mirrors the low participation rates in trials for other diseases when race and ethnicity are reported. Nonetheless, results from trials with such underrepresentation are implemented in the broader population under the assumption that their outcomes are generalizable, even when that broader population is more racially and culturally diverse than the study sample.^{3,10,16-18}

In 1993, the U.S. National Institutes of Health (NIH) issued the NIH Revitalization Act requiring that clinical research include women and minority groups. Likewise, in 1998, the U.S. Food and Drug Administration (FDA) released the Demographic Rule that required that New Drug Applications (NDA) and Investigational New Drugs (IND) present effectiveness data by gender, age, and racial subgroups.¹⁹⁻²⁴ Despite these recommendations, minority groups continue to be underrepresented in clinical research, and the required reporting on disaggregated effectiveness of the research outcome does not always occur.

Factors Affecting Hispanic and Latinx Participation in Clinical Research

External and internal factors impact the clinical research participation of Hispanic and Latinx individuals. External factors are defined as participant-centered factors providers should be aware of that affect an individual's decision to volunteer for clinical research. Internal factors are provider-centered factors we recommend addressing to

A MATTER OF TERMINOLOGY

Hispanic, Latino/a, Latinx

The U.S. Office of Management and Budget (OMB) requires federal agencies to use a minimum of two ethnicities in collecting and reporting data: Hispanic or Latino and Not Hispanic or Latino. OMB defines “Hispanic or Latino” as a person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin regardless of race.⁴²

The term “Latinx” describes “Latino” and “Latina” in a gender inclusive way. The Merriam-Webster dictionary included the term in 2018.⁴³

support effective conversations with Hispanic and Latinx clients about research participation.

EXTERNAL FACTORS—CLIENTS

Systems of discrimination (e.g. racism, sexism, classism), both structural and interpersonal, negatively impact research participation due to stigmatization, mistrust, distrust and fear.^{13,25-27} Historically, research procedures implemented by healthcare and research institutions provided minimal humane consideration for culturally and ethnically diverse populations, reducing the willingness to participate over time.²⁸⁻³⁴ Since then, robust bioethical guidelines have been implemented to oversee the conduct of research (e.g. Nuremberg Code, Belmont Report principles, and Common Rule) to support ongoing progress to dismantle systems of discrimination by institutions and providers working within them. A recent article by Kaiksow et al., showed that Asian, Black, and Latinx American individuals were more likely to participate in HIV studies, if asked, despite relevant historical narratives of discrimination and stigma.^{13,27} This is an encouraging finding and suggests that while systems of discrimination are a barrier to participation, there are other circumstances to consider (e.g. inviting clients to participate in research).

Socioeconomic factors, both structural and personal, drive individual decision-making in research participation. Common attributes that affect Hispanic and Latinx individuals' participation in clinical research are related to education, income, access to healthcare and insurance, research site location, transportation, and child care.^{13,35} These are important considerations, and where significant barriers exist, require action to remediate barriers to research participation. Each factor is unique to each individual, so learning about these considerations from clients can help guide discussions about how barriers can be appropriately addressed.

Cultural factors describe a way of living. Health and research data on Hispanic and Latinx participants are often reported in aggregate, promoting the assumption that all Hispanic and Latinx individuals share homogenous cultural experiences and identities. Understanding that Hispanic and Latinx individuals represent a vibrant multicultural and multi-experiential community with a rich longstanding history in the U.S. and other countries of origin is important because it can shape provider-client conversations. Additionally, recognizing and respecting the cultural, linguistic, and racial diversity that exist within the larger Hispanic and Latinx community can positively shape the way that providers relate to clients, which can subsequently affect the tenor of conversations about research participation.¹³

Language is an expression of culture that enables people to communicate. Federal laws recognize the legal right to culturally and linguistically appropriate services for individuals with limited English proficiency, although these laws are not adequately operationalized.³⁶ In Hispanic and Latinx communities where no or limited English proficiency or literacy exists, language barriers limit access to healthcare resources and information. It is important to note that bilingual speakers of either Spanish or Portuguese and English may prefer to use both languages interchangeably when given the option, as a form of expanded expression.* Therefore, providing access to Spanish, Portuguese, and English language resources is important—these options can reach a broader base of Hispanic and Latinx clients who might benefit from clinical research and support broader research generalizability that better serves these communities longer-term.

Individuals with immigrant status interested in participating in clinical research may need additional support. Many immigrants of Hispanic and Latinx communities have no formal health services in the U.S. and are likely unaware of their rights to informed consent and federal limitations that limit compensation amounts for those with immigrant status. Furthermore, for those individuals with immigrant status, fear of deportation for themselves, family members, or community networks, can become a crucial factor impacting participation.^{35,37} However, at least one publication reported that individuals of immigrant status would consider research participation if it helped a close family member with a disease, afforded access to healthcare, or if they could work with staff from their own racial or ethnic group.⁸³⁵

INTERNAL FACTORS—PROVIDERS

Discussing clinical research trials is an important opportunity providers have to help clients make decisions about whether to volunteer in clinical research. Learning about the social, cultural and structural factors a Hispanic or Latinx client has is helpful information to guide discussions that can address their questions holistically (e.g. client eligibility, barriers and other constraints like time). Additionally, discussions can help clients understand and learn

‡ The Latinx Caucus noted that this is an issue that requires careful consideration when it comes to service provision to Hispanics and Latinx.

§ The Latinx Caucus noted that the absence of Social Security Number or Tax Identification Number, limits clinical research trials volunteers' compensation for their participation, affecting their decision to enroll in a clinical study.

about options that support their healthcare choices.

Discussions with clients should include information about the study and, when applicable, describe what medical care and clinical research do and do not provide.³⁸ Learning about research happening locally is a great way to stay updated on open studies. For clinicians who have interest in research but may not conduct it themselves, this is a way to increase their own engagement and better support engaging their Hispanic and Latinx clients who might benefit from participating.³⁸

Other considerations for providers to address is their own research and client bias. There is some evidence showing that providers, can be biased when choosing whether or not a discussion about clinical research is appropriate. Factors specific to whether a physician engaged their patients in conversations about clinical research were found to be based on individual characteristics, practice

HIV/AIDS Research Infrastructure

The Office of HIV/AIDS Network Coordination (HANC) coordinates the science and operation of the U.S. National Institutes of Health's HIV/AIDS clinical trial networks. HANC promotes effective representation of communities with which the networks conduct research by addressing the factors that influence the underrepresentation of historically underrepresented communities in HIV/AIDS clinical research.



patterns, physician knowledge and perceived barriers of the client.³⁹ Understanding how personal bias influences the willingness to have conversations about clinical research should be assessed. Resources by Project Implicit and Learning for Justice can help identify personal attributes or tendencies that may act as barriers.

Lastly, providers work in a busy and time limited environment. In 1999, Jenkins et.al., reported that when assessing physician-patient conversations about randomized clinical trials, conversations lasted about 10.5 minutes.⁴⁰ Not all providers have this time and not all conversations will result in a client deciding to enter a clinical research trial. However, these brief conversations can offer clients more autonomy and increase community knowledge by providing more information about what healthcare options exist. Such discussions can be accomplished using shared decision making (SDM), and literature shows that physicians who use a rational decision-making style and patient-centric

approaches are more likely to incorporate SDM into clinical practice.⁴¹ We share these physician-patient findings in hopes that these approaches (i.e. SDM, and discussion times) can be considered across the provider-client spectrum.

Increasing the participation of Hispanic and Latinx clients in HIV clinical research trials can help ensure that research is applicable to those that can benefit most, as well as ensure the democratization of the research process. Providers play an important role by having these conversations because they foster client autonomy, provider-client relationship, healthcare literacy, generalizability and applicability of research findings, and medical care. **HIV**



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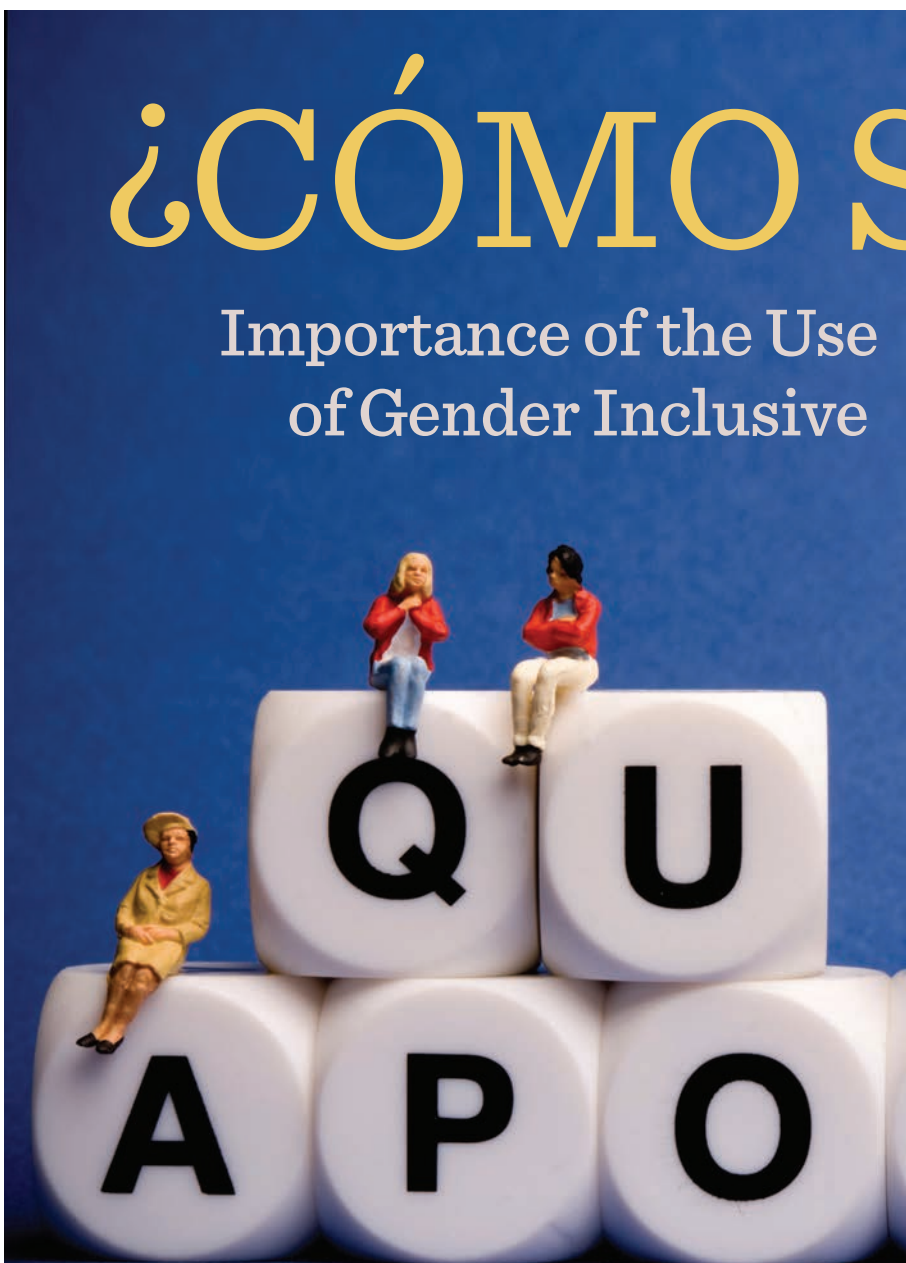
INCLUSIVE LANGUAGE AND PRONOUNS are growing in different English-speaking agencies, communities, and organizations. With new movements and despite the resistance of some conservative organizations, the diversity in the language is being utilized in most places around the country. One specific case is the use of pronouns. This helps the LGBTQI+ affirm the presence of the non-binary and trans communities. However, inclusive language is almost non-existent in Spanish-speaking clinics, organizations, and communities since there are not enough studies to help with this work, or our Spanish-speaking communities are dealing with more stigma due to cultural context.

The trauma experienced by members of the Spanish-speaking community from homophobia, transphobia, and LGBTQI+ phobia is amplified by the lack of preparation many clinics, organizations, and agencies demonstrate around diversity and inclusion. Even doctors, nurses, educators, and staff who work directly with clients try to be sensitive about Spanish use to communicate with them. However, the major problem is finding the correct translations. The binary terms that we have in Spanish, which are problematic nowadays, do not exist in English; therefore, the problem is more notorious because the pronouns do not apply only to human subjects but subjects in every single sentence.

The Spanish use of the generic masculine in a plural and singular form continues to affect our communities, further marginalizing those most vulnerable to discrimination (LGBTQ+ individuals and women). In Spanish, and according to the *Real Academia de la Lengua Española*, you can use masculine pronouns to talk about something that does not have a gender or when a plural form needs to be used. Academically you are supposed to say *Latinos, pacientes, clientes*, etc. There are some words that, by default, are gendered under the feminine pronoun but are less common and not existent with all the terms. Predominantly, the masculine is present in the language, accepted, and more used. Feminine is also present but as a second option. There is no other term; no pronouns are dedicated to being outside the binary world.

Our community, especially the LGBTQI+ community, does not have a sense of belonging or feel welcomed in clinics and healthcare agencies, given that they are not

fully recognized or respected there. The term non-binary is not well known among LGBTQI+ people that consider themselves Latinx. But that does not mean that people within the Latinx community do not consider themselves part of the non-binary, gender-fluid, or alternative sense of gender. The other problem is that we tend to speak as we see; if we see someone that looks like a woman or if someone looks the opposite, the terms that we use are going to be based on what we see, not on what the person desires or wants to be called by. According to Spanish language rules, someone that lives under the trans umbrella needs to be either on the masculine or feminine side.



To avoid this situation and validate our clients' experiences, I will offer some recommendations to follow when working with individuals that are part of the trans umbrella (non-binary, gender-fluid, alternative gender, or agender).

1. Always ask and never assume. This is a fundamental starting point. This does not mean you will ask only people who look like they are part of the LGBTQI+ community. This must go beyond your list of patients or clients. The best way to start this question is to introduce yourself, always including your pronouns and how you would like to be called. (The best alternative pronoun for

non-gendered in Spanish is *elle*). Do not assume how the person would like to be called. This is a problem since many clients and patients haven't changed their names on their official documents.

2. Instead of using active sentences that refer to the other person,

try to use passive voices and yourself as the active agent, at least while you figure out the gender of the person. For example, instead of saying, "Welcome!" you say, "We are welcoming you." This makes sense in Spanish. Rather than "*Bienvenido o bienvenida*," dices "*Le damos la bienvenida*." You are not assuming gender, and you are using a neutral tone. You are speaking from your point of view; you still share the same excitement as in this case but without assuming anything. The point is to always focus on the person that is speaking, and the passive voice will be the subject that you are talking or referring to.

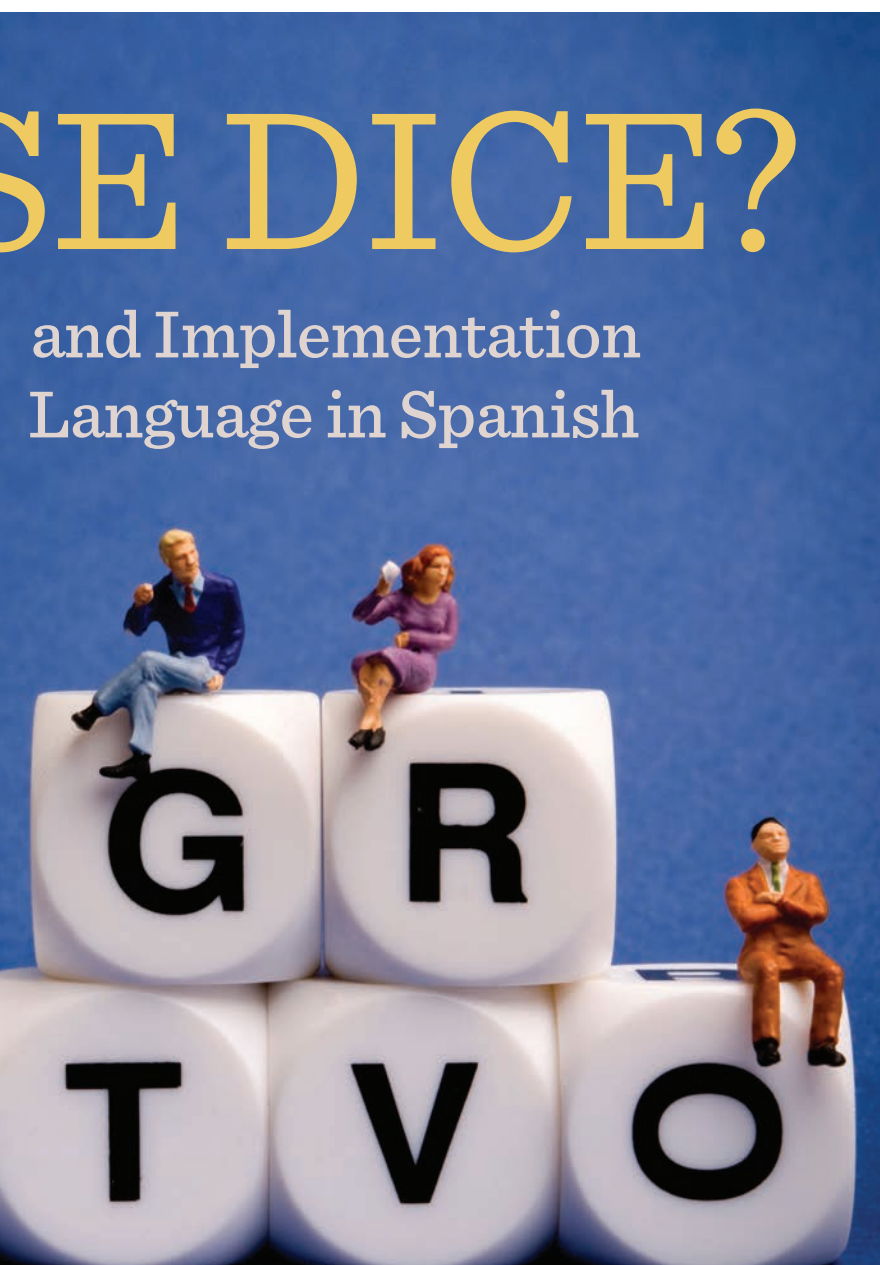
3. Instead of speaking in the third person, try to talk as much as possible in the second person and directly to the patient. Since the moment that the front desk is calling the patient, this is important. Sometimes people are not by themselves or alone, so this will make more sense. Also, when you have a colleague with you, and you want to talk about the patient, try to focus on the patient or client and give them the importance they deserve. When you say, "*tu or usted*" it is better than saying, "*el or ella*."

4. Normalize the use of the e instead of a or o. In Spanish, generally, when you are using the masculine, it is an "o" at the end of the word, and for the feminine, it is an "a." A new proposal in the Spanish-speaking community is using an "e" instead. The pronoun more used for the non-binary community is *elle*. *Elle* would be the translation of they/them pronouns. This applies to subjects and helps to avoid the use of gender in words, for example, *elles*, *no ellos or ellas*; *invitades no invitados or invitadas*; *enfermes no enfermos or enfermas*.

If you are in doubt, always ask and validate everyone. This is a work in progress, and we are all learning together; it is normal to make mistakes. What is not normal is to keep repeating them or ignoring them intentionally. Our communities are the heart of our work, and we can help them continue accessing care without more trauma. The choice is in your hands. **HIV**



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Innovations in Supporting Underserved Populations

Using funding of last resort for
HIV care and prevention



By Andrés Cordero, Jr., MBA, ACS, PhD Candidate



ONE OF THE KEY CHALLENGES in reducing HIV transmission rates and improving treatment engagement rates is dealing with the complex nature of accessing medication for people with HIV (PWH). Absent any support or expertise, patients are often left alone to navigate a confusing network of medication financial access programs that involve complicated relationships among insurance companies, pharmaceutical programs, federal and state programs, medication discount programs, and funding of last resort programs.

This patchwork system can be incredibly intimidating to patients. It can be confusing, frustrating, and at times even intentionally or unintentionally deceptive. Add to this barriers related to language, affirming and competent support needed by the sex and gender minority (SGM) population, and keeping up with changes in the complex and convoluted nature of insurance coverage in the United States, and many patients often give up on access altogether.

For almost five years, I was involved in patient navigation/patient advocacy for a major provider offering sexual health and wellness, as well as gender-affirming care, in Austin, San Antonio, and the Central Texas region. Our vision as a team was to establish a system that demanded nothing more of patients than simply picking up or receiving their medications and taking them as prescribed—in short, to maintain adherence to their care.

In this article, I offer an overview of the challenges and opportunities faced by those providing medication access-related care to PWH, patients seeking HIV prevention services, and patients seeking gender-affirming care. I hope it is beneficial to both individuals actively engaged in delivering medication access assistance directly to patients (patient navigators, patient advocates, medical and non-medical case workers) as well as decision makers seeking to understand the opportunities and challenges their staff may face in supporting their patients.

Comprehending Access to Health and Medication Coverage Insurance

Your patient advocates and navigators, and other care providers, should have a general understanding of the insured status of your patient populations, including the type of insurance coverage and medication benefits. In addition to helping your agency make operational decisions such as resourcing, operational flows, and staffing,

understanding the insured status of the populations, you can help inform your efforts when advocating for additional assistance from federal, state, and local resources, pharmaceutical companies, and health-focused grant organizations. The Kaiser Family Foundation manages a database that includes date of health insurance coverage of different populations. You can access this database at kff.org/statedata.

In addition to insured population information, the Kaiser Family Foundation also offers a variety of statistics related to HIV/AIDS. Advocates and navigators seeking to learn more about funding available for PWH can visit the foundation's site at kff.org/state-category/hiv/aids and scroll down to "HIV/AIDS Funding" and "AIDS Drug Assistance Program (ADAP)." Funding available through the ADAP program varies from state to state, and is based on many factors. Each state's program operates with a different level of efficiency, so examine these statistics relevant to your state. This can help your advocates and navigators determine eligibility factors and timing to approval and access of medications. Time to access medications is vital and thus requires your team to map out alternative strategies to deliver medication in the interim.

Social safety net and social determinants of health are factors that can affect a patients' ability to successfully navigate barriers to access care and medication. Emory University's Rollins School of Public Health, in partnership with Gilead Sciences, Inc. and the Center for AIDS Research at Emory University (CFAR) offers a highly valuable resource to learn more about issues, opportunities, and challenges faced by PWH and patients engaged in HIV prevention treatment. The resource, AIDSvu.org, includes online mapping to visualize the state of the HIV epidemic in communities and regions across the United States. To learn more about those resources, visit AIDSvu.org.

Knowing More about your Populations in Need

Although every patient is unique, some populations face unique circumstances when they encounter barriers to medication access. These populations include: PWH; people of color, including Latino and Black people; non-English speaking people; trans and gender-expansive people; insured people who encounter temporary gaps in their existing coverage; and people who need privacy and confidentiality in their access to HIV or other sexual health and wellness care.

Despite resources that are available for people with HIV, several factors can represent barriers to patients' effective access to care. Stigma, access to knowledgeable providers, access to critical social services support including mental health, and other factors can make engagement in care and adherence difficult. Biomedical intervention is an essential and fundamental component to supporting patients, but often patient challenges in engaging in care are also economic and social-cultural in nature. They require support beyond biomedical intervention. Many agencies have effectively used technology, simplified clinical flows, and input from community advisory boards to drastically reduce time to initiate care. Regardless of these improvements, some barriers still exist.

Many studies indicate people of color (POC) often encounter more barriers to HIV care as compared to the general population. Young Latino and Black gay men, heterosexual Black women, and Black trans women have significantly higher rates of HIV transmission as compared to the general population. In these populations as well, biomedical interventions represent a vital, and yet only part, of comprehensive engagement in care. Although research continues, non-white populations in general face significant institutional, societal, and structural barriers that make it more challenging to initiate and maintain engagement in care and adherence to medication.

As the U.S. population continues to diversify, institutions and providers of all types must continue to deliver care and services in languages other than English. The annual percentage growth of non-white populations continue to grow, led in many parts of the U.S. by Latino people. In most major population

centers, Korean people, Vietnamese people, and other communities continue to expand significantly. Although not all members of these populations are monolingual non-English speakers, several are. And even for those who are bilingual or multilingual inclusive of English, several prefer communication in a language other than English. This shift, therefore, requires that medical providers, including those providing HIV care medication access support to deliver services in languages other than English.

Even though the SGM population, including persons in the LGBTQIA2+ spectrum experience considerable barriers in access to care, trans people as a population experience stigma, violence, hostility, and aggression at rates far above members of other marginalized populations.

According to GLAAD, a national non-profit organization that advocates for the LGBTQ community, more than 19 percent of transgender people lack any form of health insurance, including Medicaid. More than 15 percent live in poverty, and gender-affirming care (which includes hormone replacement therapy) is sparsely available and not uniformly covered by insurance plans. Research proves, however, that when trans people get the supportive and affirming care they need, they experience improvement in their mental health. Trans people experience one of the highest rates of suicide of all populations. Despite recent changes, trans people continue to struggle to access competent and affirming providers, uniform and consistent coverage for gender-affirming surgery (if needed by the patient), and affordable access to medication. Other factors make access to care, including HIV care for trans people, very challenging.

When it comes to sexual health and wellness services including HIV care, some patient populations have a considerable need for privacy and confidentiality when it comes to access to medications and care. Some of these patient populations include members of the SGM population, members of the LGBTQIA2+ community, victims of sexual assault including rape, and patients who are members of a culture or religion that stigmatize sexual behavior that can lead to family rejection, community repercussions, and even death. In many instances, members of these population require assistance in accessing medication to protect them from disruptions in family or intimate relationships, hostile treatment at home, at school, or at their place of employment, loss of housing and access to food, and even violence or death.

Medication Access Programs and Strategies

Barring any unique circumstances, there are some basic strategies you can use to assemble financial components that make access to medications possible. These components depend on the patient's insurance status, and usually involve some combination of insurance coverage, patient-funded or pharmaceutical company-funded copays, pharmaceutical company-based medication access programs, medication discount programs, and funding of last resort.

In patient navigation and advocacy, there are often exceptions to even the most basic of patient situations. In most situations where PWH have employer-based or ACA-based insurance coverage, some funding is available to cover medications for HIV care as well as pre-exposure prophylaxis (PrEP) for HIV prevention. In these

situations, a patient's insurance coverage, in addition to a copay card, issued by a pharmaceutical company, can cover 100 percent of the cost of their medication. In some instances where generic brands of medications are available, no copay card may be available, but the cost of the generic equivalent to the medication can be minimal and affordable to many patients.

In the case of PrEP in particular, the introduction of generic equivalents to the medication Truvada has resulted in many insurance companies rejecting claims for the brand-name medication, or requiring prior authorization documentation. Prior authorizations are often documents demanded by the health insurance company to justify dispensing brand-name medication over the generic equivalent. In many cases, prior authorizations are denied, and patients are required to use the less costly generic brand.

For insured patients accessing gender-affirming care, in some cases prescriptions for hormone replacement therapy (HRT) medication are covered by their insurance plan. If their plan does not cover HRT medication, patients often reduce their costs by using a medication discount card. One common medication discount card is known as GoodRx, although others exist as well. In many instances, the cost of HRT is financially accessible to patients even without a discount, so they choose to pay for 100 percent of the costs "out of pocket."

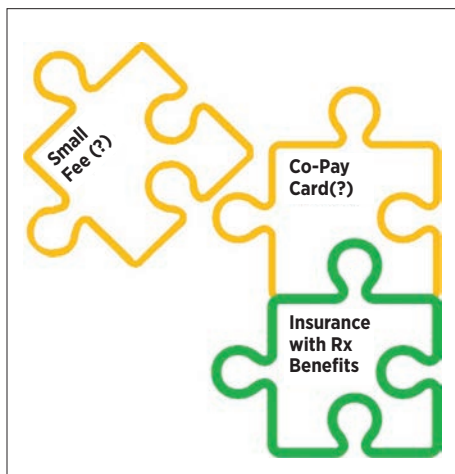


FIGURE 1 Assembling Assistance for Insured Patients



FIGURE 2 Assembling Assistance for Uninsured Patients

Assembling Access for Uninsured and Underinsured Persons

In most situations where PWH are uninsured, programs established by pharmaceutical companies will pay for 100 percent of the cost of the medication for the patient, provided they meet income and other eligibility requirements. For PWH, if their declared income indicates they are eligible for enrollment in the state's ADAP Program, the pharmaceutical company will only pay for their medication for a pre-determined time period, during which the patient must apply to the ADAP Program to continue access to the medication.

Unfortunately, depending on the state, some patients may experience significant delays in enrollment in their state's ADAP program. Some programs have complex documentation requirements. Others require disclosure of data requests that are perceived as invasive by patients, particularly if they have been recently diagnosed and are dealing with considerable challenges in disclosing their HIV status. In other programs, distribution flows require pharmacies to only dispense medication physically shipped by the program, rather than using identical medication already stocked at the pharmacy. This adds time to delivery, making access to medication cumbersome and complicated.

For uninsured patients accessing gender-affirming care, patients often reduce their costs by using a medication discount card. In many instances, the cost of HRT is financially accessible to patients, so they choose to pay for 100 percent of the costs "out of pocket."

Special Situations and Considerations

Assessing patient coverage status prior to accessing care is critical for a variety of reasons. Patients who mis-state or misrepresent their coverage situation can often experience significant delays in accessing their medication, as insured/uninsured coverage status dictates specific processes to follow and programs to access. Denials due to incorrect status declaration add additional time to research, correct, and re-process eligibility and enrollment. In addition, some patients may be covered in ways that further complicate access.

For new patients, it is vital that any and all medication insurance coverage should be identified thoroughly and accurately before the provider initiates care. In some rare but critical situations, patients seeking care must visit an in-network provider and receive prescriptions only from that provider. Some people such as those that work

in the military or for the government, and in some Medicaid programs, and in other “closed networks” will have coverage that limits their benefits to prescriptions written only by in-network providers. Because of the high-cost of HIV medication, patients who do not visit an in-network provider and have their prescriptions written by an in-network provider may be confronted with unreasonable costs for their medication at their pharmacy.

For this reason, it is best practice that patients identified as being in closed networks be directed immediately to an eligible provider. Otherwise, they should be informed that they will be responsible for the full out-of-pocket costs of their medication. Reliable estimates of out-of-pocket costs of medications (medications paid with no eligible coverage) are available on GoodRx.com. No patient assistance programs will make exceptions to this situation, so no additional funding will be available.



People with coverage in “closed networks” can only use medication benefits **for prescriptions written by in-network providers**. Patient Assistance Programs (PAPS) consider those people covered, and thus ineligible for any financial assistance.

FIGURE 3 Out-of-Network Disqualification

Some patients on Medicare who move between states should immediately visit their local social security administration office and initiate the process of cancelling their Medicare coverage in their state of origin, and initiate Medicare coverage in their new state.

Similar to the previous situation, patients who fail to cancel their Medicare coverage in their state of origin are still considered covered for medication coverage purposes, but only if they receive care from a provider in their state

of origin. If the patient fails to cancel enrollment in their state of origin and re-enroll in their new state, prescriptions written in that new state will not be covered by the program.

Because HIV medications are often expensive, patients will find themselves unable to access their medication. No patient assistance programs will pay for medications for patients who find themselves in this situation. Their only option, other than completing the transfer process, is to return to their state of origin to see their previous provider and to affordably access their medication in that state.

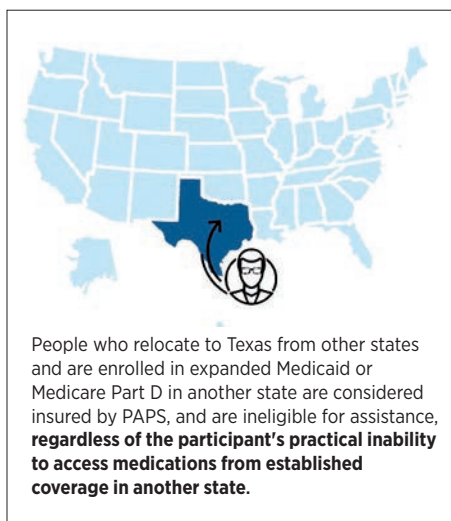


FIGURE 4 Existing Coverage Disqualification

Bridging the Gap: Patient Advocacy

Creating or enhancing medication access programs in a clinical setting often requires adjustments or changes to the patient care flow process, particularly for patients visiting a clinic for the first time. This section outlines some of the factors to consider when establishing your facility's flow to improve medication access and ultimately, level of patient care quality and adherence to treatment.

One best practice to improve the rate of access and adherence to medications and treatment is for an agency or organization to hire patient navigators, patient advocates, non-medical or medical case managers, or community health workers. These individuals should be fully trained in access to

medication assistance programs, access strategies, delivery of patient education related to medication assistance, and resolving special situations or circumstances in medication access. These individuals should be assigned to patients, and processes should be created so that these individuals are informed promptly if patients encounter medication access issues.

Creating a trusting, productive relationship between a patient and their assigned advocate/navigator is vital for improving medication access and care adherence. Patients should be invited to contact their advocate/navigator whenever they encounter an issue or problem. The patient and advocate/navigator should work together to help the patient learn more about how to access their relevant programs. If changes to a patient's insurance status, income, employment, or need for social services emerge, the advocate/navigator should work with the patient to resolve these issues, or refer them out for further assistance.

Patient advocates/navigators should receive continuous and regular training on the myriad of assistance programs. They should also learn how to assess and re-assess a patient's medication access needs at least annually, as programs and situations can change regularly. Advocates and navigators should maintain a proactive communication relationship with their patients. Patients should receive updates from their advocates/navigators even if issues are not resolved, so that the patient is at least aware resolution is in progress. Advocates and navigators are also often in a position to assess quality of care, and can resolve problems or situations before they damage the patient/agency relationship. This skill requires the advocate/navigator to maintain effective working relationships with staff in all parts of the clinic operation.

Using 340B Funding to Address Gaps in Existing Programs

The federal 340B funding program is a program created by Congress that allows community health organizations and agencies to expand their capacity to serve a larger population of patients than they normally would. They do this by working

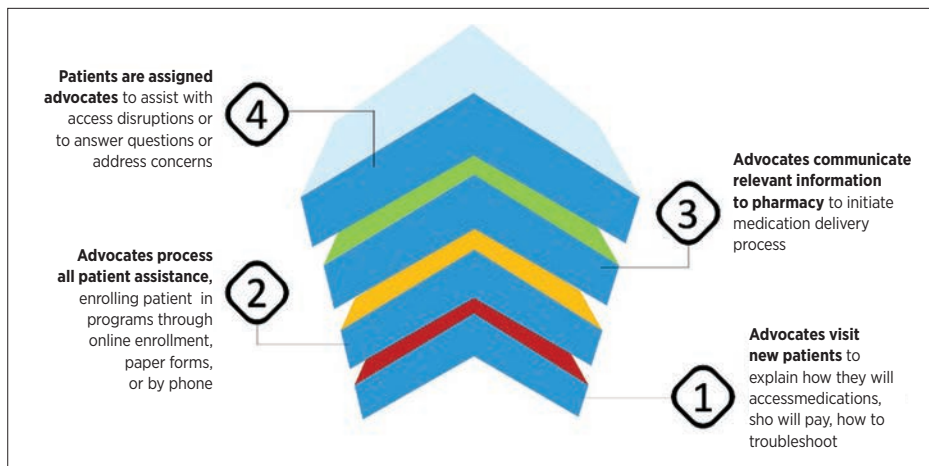


FIGURE 5 Establishing Medication Access at First Visit

with pharmaceutical companies and participating partner pharmacies to redistribute funds to support more patients. Through this program, clinics and agencies are able to generate funds that they then can use to cover costs for medication and medical services for uninsured patients.

Although the program helps to support more patients, there are several criticisms regarding the program. These programs often incentivize pharmaceutical companies to maintain the high cost of medications, for example. Participating community health clinics and agencies, however, have used this funding to create funding of last resort programs for patients when no other funding is available.

How do medication assistance programs structured through the use of 340B programs help patients? And what are the less-well known situations where such programs can contribute effectively to a patient's continuing care and adherence? Below are a few examples.

■ Making Gender-Affirming Care Medications More Affordable

For patients accessing gender-affirming care, many are unable to pay for the cost of their HRT medication, even with relatively low costs. Large portions of trans and gender-expansive patients are unemployed, uninsured and/or experience stigma in accessing medical care and employment. In these instances, funding of last resort programs can be used to pay for HRT medication.

■ Protecting the Privacy of Sex and Gender Minority Youth

Many lesbian, gay, bisexual, trans, or gender expansive youth find themselves in circumstances where they are unable to disclose their gender identity or sexual orientation to family, friends, employers, or others due to stigma, being ostracized, being rejected by their families (thus becoming homeless with no financial resources), or even having their lives threatened if they belong to communities or cultures that are hostile to the SGM population. In these cases, funding of last resort programs can be used, particularly for those patients still dependent on coverage paid for by parents or guardians. Funding of last resort programs can pay for medications related to HIV care, HIV prevention, or gender-affirming care.

This approach minimizes the danger a patient may experience if they are outed or discovered.

■ Protecting Privacy for Post-HIV Exposure Patients

Patients seeking care for potential exposure to HIV after the fact often find themselves in difficult circumstances. They may be victims of sexual assault, victims of intimate partner violence, or in unfortunate circumstances due to engaging in activities placing them at higher risk of exposure to HIV. In many of these situations, patients fear disclosure through insurance claims or due to other factors. In these cases, using funding of last resort can give these patients peace of mind that their circumstances remain confidential.

Helping Uninsured or Underinsured Patients Experiencing Short-Term Disruptions in Access to Medication

In some cases, patients may find that their existing coverage is inadequate, or they may be transitioning between insurance plans between employers. Often, there may be delays in processing paperwork, and patients find themselves in vulnerable situations without access to necessary medication. In these situations, funding of last resort programs allows clinics and healthcare providers to temporarily pay for medication until situations are resolved.

Due to the structure of the Medicare drug assistance program, many patients experience a gap in coverage for medication often described as being in the "donut hole." During this period, patients may encounter a drastic temporary increase in copay costs for medication that makes access unaffordable. Bridging that "gap" successfully results in eventual "catastrophic coverage," meaning that medications are available at no cost. Unfortunately, that gap may represent more than \$4,000 in out-of-pocket costs. In these situations, Medicare patients can benefit from funding of last resort to get them past this gap without experiencing a financial crisis.

Sometimes patients may find themselves in rare situations where an insurance plan will not pay for HIV medication for care

or prevention. Other patients may find they are uninsured. This occasionally happens, for example, if a patient becomes ineligible for ACA coverage due to failure to pay their premium, and are prohibited from re-enrolling in ACA until the next formal enrollment period. As a result, patients may enroll in sub-standard insurance plans that provide very limited benefits and highly curtailed coverage. In these situations, funding of last resort can be used to assist patients in accessing their medications until a better resolution is identified to more effectively support the patient.

Access Success In Action

Although programs can change eligibility requirements, funding availability, and administrative procedures frequently, several organizations and agencies have successfully established programs using 340B funding to support their patients in much needed important and innovative ways. Below are a few examples.

Kind Clinic and Texas Health Action



Some clinics have successfully used funding of last resort programs funded by 340B programs to further support enhancing the types of services they offer to patients.

"Assistance programs for our patients include helping us pay for medication, labs, transportation, and insurance premium assistance," said Matt Phebus, director of Patient Support Services for Texas Health Action, an organization that operates Kind Clinic locations in Austin, San Antonio, and Dallas, Texas. "Financial barriers to healthcare are a major structural source of disparate outcomes. Our use of the 340B program is helping us bridge these gaps and address inequities in outcomes."

Recent changes to the 340B program have challenged this agency to find new ways to inform patients of how they support the program. According to Phebus, in January of 2022, the program became more limited, as funding received through the program for uninsured patients was eliminated. Prior to that time, the agency was able to receive funds for uninsured as well as insured patients whose prescriptions were filled by partner pharmacies. "Unfortunately, we have also seen some insurance companies and drug manufacturers become more hostile to the program—so much so, that they have been refusing to participate," said Phebus. Despite these challenges, however, Kind Clinic/Texas Health Action continues to provide culturally-affirming services in a safe and supportive environment, regardless of their ability to pay.

ASHwell Sexual Health + Wellness



At ASHwell in Austin, Texas, patients have greatly benefited from their innovative use of funding of last resort generated through the agency's 340B program.

"Since starting our program in 2018, we grew from a staff of eight to a staff of over 30," said Ben Walker, MGPS, director of Client Services. "Our funding allows the organization to be far nimbler in our operation and take advantage of

new opportunities to support our patients. We offer ride share and other transportation options, and even provide supportive therapies such as acupuncture and massage." According to Walker, this funding allows ASHwell to offer services beyond those they were able to offer through more restrictive Ryan White program funding.

Walker also pointed out the disparity of care due to the lack of a universal healthcare system in the U.S.

"In some parts of the country, there are robust health safety net systems," said Walker. "In other states, there is barely any support for people without private insurance coverage. In these states, the 340B program is one of the few strong tools available to support and sustain medical care for historically marginalized populations."

Despite these challenges, Walker's perspective is positive. "In states like Texas, we're really just doing the best we can to utilize the 340B program with the resources we have."

Conclusion

Ongoing dialogue continues, highlighting both the benefits and disadvantages of using the 340B program. Many agencies use such funding to provide more comprehensive and less restrictive services to underserved populations. In sexual health and wellness organizations, funding is used to supplement their offerings. These offerings help patients to remain consistent in engaging in their care and to remain adherent to their medications.

As advocates and navigators work together to stay informed and learn of new and different ways to cobble together the variety of programs and services available, patients are able to focus more on focusing on staying healthy and engaged. Regardless of what the future holds for HIV care, sexual health-care, and underserved populations, we must continue to encourage institutions engaged in all aspects of the care delivery spectrum to lend a hand financially and operationally to minimize barriers and maximize their reach to patients in need. Together, these agencies can continue to help all patients to live longer, more healthy lives through highly engaged biomedical interventions, an abundance of supportive resources, and accurate sexual health and wellness information. **HIV**



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Learn more at <http://www.ecstaticlifepath.com>.

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Patient Assistance Programs

The following are some programs offered by pharmaceutical manufacturers, non-profit organizations, and other agencies to patients seeking financial support to access medications used in HIV care and prevention, sexual health and wellness, and gender-affirming care. This is not an exhaustive list.

HIV CARE

INSURED PATIENTS

- Gilead Copay Card <https://www.gileadadvancingaccess.com/copay-coupon-card>
- VIIV Connect <https://www.viivconnect.com>
- Patient Advocate Foundation [<https://portal.copays.org/#/login>] <https://portal.copays.org/#/login>
- Good Days Copay Card <https://www.mygooddays.org/apply>

UNINSURED PATIENTS

- Gilead Advanced Access Program (iAssist / First-Time Applicants) <https://advancingaccess.iassist.com/login>
- Gilead Advanced Access Program (Paper / Re-Apply)
- VIIV Connect <https://www.viivconnect.com>
- AIDS Drug Assistance Program (ADAP) <https://adap.directory>

PrEP CARE

Care for Pre-exposure Prophylaxis (PrEP)

INSURED PATIENTS

- Gilead Copay Card <https://www.gileadadvancingaccess.com/copay-coupon-card>
- Patient Advocate Foundation <https://portal.copays.org/#/login>
- Good Days Copay Card <https://www.mygooddays.org/apply>

UNINSURED PATIENTS

- Ready, Set, PrEP <https://readyssetprep.hiv.gov>
- Gilead Advanced Access Program (iAssist / First-Time Applicants) <https://advancingaccess.iassist.com/login>
- Gilead Advanced Access Program (Paper / Re-Apply)

RESOURCES

- PrEP Locator <https://preplocator.org>

PEP CARE

Care for Post-exposure Prophylaxis (PEP)

INSURED PATIENTS

- Gilead Copay Card <https://www.gileadadvancingaccess.com/copay-coupon-card>
- VIIV Copay Card <https://www.viivconnect.com>
- Good Days Copay Card <https://www.mygooddays.org/apply>

UNINSURED PATIENTS

- Gilead Advancing Access Program (Must Call) - 800-226-2056
- VIIV Connect (Must Call) - 844-588-3288
- Gilead Advanced Access Program (iAssist / First-Time Applicants) <https://advancingaccess.iassist.com/login>
- VIIV Connect (VIIV Patient Assistance Programs for Uninsured Patients) <https://www.viivconnect.com>

GENDER-AFFIRMING CARE

Including Hormone Replacement Therapy (HRT)

INSURED PATIENTS

- Good Rx <https://www.goodrx.com>

UNINSURED PATIENTS

- Good Rx <https://www.goodrx.com>

Mental Health and Substance Use in PWH

A Review of Diagnosis and Treatment for the HIV Care Team

BY ALEXANDRA CANETTI, MD

NEARLY 50 PERCENT OF PEOPLE LIVING WITH HIV (PLWH) report current or a history of substance use disorders. The rate for mental health disorders has been estimated to be even higher. Studies have showed that as many as 13 to 23 percent of PLWH have been diagnosed with a substance use and a psychiatric disorder.² Therefore, it is important for members of the HIV care team to consider patients' mental health and substance use needs during their assessments to better support their clients and offer referrals as needed.

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Scope of the Challenge

Antiretroviral therapy (ART) adherence is lower and viral loads and mortality rates are higher among individuals diagnosed with HIV, substance use and psychiatric disorders, as compared to those without.³ Specifically, substance use in PLWH often contributes to rapid progression of the illness, development of drug resistance, falls and injuries, and premature death. In those affected by mental health illness, lower adherence to antiretrovirals (ARVs), increased frequency of emergency room visits and hospitalizations, and lower adherence to treatment in general have all been observed.³ By working together to address mental health and substance use disorders, members of the care team can help improve patient health outcomes and quality of life.

Depression is commonly seen in PLWH. The prevalence estimate of major depressive disorder in this population is between 20 to

37 percent as compared to five to 12 percent in the general population. Many factors contribute to these high rates including the disease itself, the medications and their side effects, and psychosocial stressors that affect PLWH in disproportionate ways.⁵

There is also an increased rate of anxiety in PLWH as compared to the general population.⁶ And as seen with symptoms of depression, anxiety disorders negatively impact patients' adherence to treatment and quality of life.

The continuing COVID-19 pandemic has and will continue to impact PLWH. Some of these impacts include:

- disruption of their usual medical care and observation,
- instability to maintain a stable supply of medications,
- insufficient follow up of physical symptoms,

- mental health and substance use problems being ignored,
- decreased access to HIV-related social supports,
- fear that living with HIV and its comorbidities increases the risk of contracting and developing severe complications from COVID-19, and
- re-experiencing trauma from earlier HIV experiences.

The Centers for Disease Control and Prevention (CDC) describes alcohol, opioids, methamphetamine, crack cocaine and inhalants as the most common substances used by PLWH.⁷ Other studies point to tobacco, cannabis, alcohol, and cocaine as the most prevalent.⁸

As the CDC notes, it is important for care team members to keep in mind HIV risk behaviors associated with use of these



substances by PLWH. Some of these include risky behaviors like needle sharing and risky sexual behaviors (i.e., condomless sex, sex with multiple partners). Specifically related to crack cocaine, the CDC describes how its use can generate a cycle where people spend all their resources and may engage in sex trade in exchange for drugs or money.

Screening Strategies

Because mental health issues and substance use disorders in PLWH negatively impact their daily activities and care, the care team should work together to ensure strategies are in place to assess for these in PLWH. Patients should receive baseline and ongoing assessments of mental health disorders including depression and suicidal ideations during every visit, and anxiety and post-traumatic stress disorder (PTSD) at least annually. For alcohol and substance use, the care team should be screening at least once a year. Individuals who are at high risk for drug and alcohol use, for example those with a family history of alcohol or other substance use disorders, should be screened more frequently.

Currently, many screeners are included in electronic medical records facilitating their use. They are also easily accessible to the care team online. The National HIV Curriculum is an AIDS Education and Training Center Program lead by the University of Washington. On their website [<https://www.hiv.uw.edu/>], under “Tools & Calculators” you will find the Patient Health Questionnaire-2 (PHQ-2) and Patient Health Questionnaire-9 (PHQ-9) to screen for depression, the Generalized Anxiety Disorder 2 and 9 items to screen for anxiety, and the Primary Care PTSD Screen for DSM-5 (PC-PTSD-5) to screen for post-traumatic stress disorder. If the screening tool is completed on the website, it will provide the score, illness severity and proposed treatment actions (watchful waiting, consider counseling, active follow up or immediate initiation of psychotherapy).

The PHQ-9 is a screening tool that is helpful for diagnosing, assessing, and monitoring the severity of depression. It can be used in patients ages 12 and older. It can be self-administered by the patient or by a clinician or staff verbally asking the questions. The PHQ-9 is available in 49 languages (It is important to note that it has not been validated in all these languages).

The CAGE questionnaire is a simple screening tool used to help identify alcohol use disorder. It has four questions related to the consequences of drinking. Like the PHQ-9, it can be self-administered or administered by a care team member. If the patient has a score of two or more, it is clinically significant for an alcohol use disorder, and the clinician should consider referring the patient for alcohol use treatment.

The four questions are:

1. Have you ever felt you needed to **C**ut down on your drinking?
2. Have people **A**nnoyed you by criticizing your drinking?
3. Have you ever felt **G**uilty about drinking?
4. Have you ever felt you needed a drink first thing in the morning (**E**ye-opener) to steady your nerves or to get rid of a hangover?

Another tool clinicians may consider is the Screening, Brief Intervention and Referral to Treatment (SBIRT). This is an evidence-based approach intended to provide early intervention for people who may be at risk of developing alcohol or other substance use disorders. During the screening the clinician aims to recognize unhealthy use. It is estimated that about 15 to 25 percent of patients will fall in this category. The brief intervention, which may take up to 15 minutes, provides feedback and education, and increases the patients' insight and strengthens motivation to support behavioral changes. Lastly in the referral to treatment, clinicians help patients who may need a higher level of care get connected to services. Only about five percent of those screened will need a referral for substance use treatment.



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Treatment Considerations

When speaking about providing mental health and substance use treatment to PLWH, Conway and colleagues describe barriers and facilitators to mental health and substance use disorders.³ They organize the barriers by challenges accessing services, individual factors and interpersonal difficulties with service providers. These include finances and poor access to transportation, unstable housing, and social isolation. When describing difficulties with service providers, patients may feel uneasy with case managers or when interacting with unpleasant staff. Other system barriers include an elaborate referral process and limited access to appointments, stigma and racism. Some facilitators that help PLWH establish mental health and/or substance use disorder treatment include having a provider, closeness between the clinician's and the case manager's offices, provider knowledge about HIV diagnoses, stable housing and finances, access to transportation and the ability to establish trust and rapport with their treatment provider.⁹⁻¹⁰

Treatment strategies for mental health and substance use disorders include psychopharmacology, and individual and group psychotherapies, at times, and depending on the severity of their symptoms, a combination of the above. Some of these interventions include cognitive-behavioral therapy (CBT), psychodynamic psychotherapy, interpersonal psychotherapy and motivational interviewing, harm reduction therapy and mindfulness treatments. Members of the HIV care team should familiarize themselves with selective serotonin reuptake inhibitors (SSRIs)¹¹ as these are first-line treatments for depression and anxiety and some, like sertraline, have few drug-drug interactions with ARVs and when started at low doses (25mg in the case of sertraline), are well tolerated. Family history of treatment for depression and anxiety can also help guide treatment choices (i.e. if the patient's mother had depression and responded well to a particular SSRI). For smoking cessation, varenicline is a first-line treatment and doubles the chances of smoking cessation at six months as compared to

QUESTIONS

1. What is the prevalence of PLWH who also suffer from mental health and substance use disorders?
 - A. 15-25%
 - B. 13-23%
 - C. 20-37%
 - D. 5-12%
2. How often should you assess your patients for symptoms of depression:
 - A. During every visit
 - B. Every six months
 - C. Once a year
 - D. Only if the patient express feeling of sadness
3. What is an integrated model of care
 - A. In this model of care, multiple providers collaborate frequently to streamline care to PLWH who are also diagnosed with mental health and/or substance use disorders.
 - B. It is a model of care where providers educate their patients about smoking cessation and encourage them to exercise regularly and follow up with their nutritionist.
 - C. It is a model of care where a multidisciplinary team is co-located to provide HIV services as well as mental health and substance use treatment and psychosocial support.
 - D. In this model of care there is a fragmentation of care where the providers interact minimally with each other, concentrating on their specialty.

placebo.¹² It is a partial agonist of the nicotinic acetylcholine receptor $\alpha 4\beta 2$. It has no significant drug-drug interactions.

It Takes a Team

An important factor that helps facilitate treatment is having an integrated model of care. This model of care is composed of a multidisciplinary team which aids in reducing stigma and fear. When PLWH receive care that is in an integrated setting, they present with improved psychiatric symptoms, lessening of substance-use related behaviors, increased medication adherence and decreased immunosuppression and viral load replication.¹³ It also improves linkage and retention.¹⁴ This model of care incorporates HIV and medical management, psychiatric care, psychosocial support including case management, and substance abuse treatment while considering patients' culture and intersectionality, paying special attention to LGBT individuals.

Mental health and substance use can have a significant impact on whether PLWH achieve optimal health outcomes. It is therefore crucial for the care team to be on high alert and that they work together with their patients to address them as part of their efforts to provide comprehensive HIV care.

As we strive to provide the best care to PLWH, the care team should familiarize themselves with the most common substance use and mental health comorbidities affecting this population. Patient care can be enhanced by multidisciplinary teams providing collaborative and integrated care. Being able to screen, begin treatment if possible, and refer to mental health and substance use treatment centers in your community will positively enhance patient care and quality of life for our patients. **HIV**



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She joined the training faculty at the Columbia HIV Training Project and AIDS Education Training Center of NY/NJ and has interest in culturally competent family-based care to children and youth with medical illnesses. She currently serves as the Program Medical Director of the Special Needs Clinic, where she treats the mental health needs of individuals and families affected by medical illness, and of the School-Based Mental Health Program.

HELPFUL RESOURCES

1. [AIDS Education and Training Center Program](https://aidsetc.org/) <https://aidsetc.org/>
2. <https://psychology-tools.com/test/cage-alcohol-questionnaire>
3. <https://www.hiv.uw.edu/>
4. <https://www.samhsa.gov/sbirt>

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Mental Health and Substance Use in PWH—A Review of Diagnosis and Treatment for the HIV Care Team

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FACULTY: Alexandra Canetti, MD, Assistant Professor of Psychiatry, Columbia University Medical Center

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 presentation on which this article is based was selected by ACTHIV 2022 conference attendees and the conference planning committee as being among the best sessions of the conference. The goal of this article is to help members of the frontline HIV care team to be better able to:

- Identify the most common mental health and substance use disorders among people with HIV
- List screening tools for these disorders which can be integrated into practice
- Identify barriers and facilitators to treatment for mental health and substance use disorders
- Explain the opportunities an integrated care model offers for improving mental health and substance use disorder treatment in people with HIV

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UPDATE

CAROLYN CHU, MD, MSC, AAHIVS

AAHIVM Chief Medical Officer

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% 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:

D'Amico R, Ceno Gomez S, Moodley R, et al. Compassionate use of long-acting cabotegravir plus rilpivirine for people living with HIV-1 in need of parenteral antiretroviral therapy. *HIV ed*. 2022 Aug 9. doi:10.1111/hiv.13370. PMID 35945163.

This study describes participants and outcomes of a compassionate use program involving long-acting cabotegravir plus rilpivirine. Patients (n = 35) were adult PWH with no key CAB or RPV-associated mutations and needed parenteral ART due to malabsorption syndrome, dysphagia, or psychological conditions preventing oral ART; had prolonged non-adherence to oral ART with progressive HIV disease; or had some other compelling reason for compassionate use. Sixty-six percent received a 4-week oral lead-in and maintenance doses were administered every 4 weeks for all. 28/35 (80%) entered the program with viremia ≥ 50 copies/mL (median 60,300 copies/mL). At data cut-off, 22/35 (63%) achieved (16/28) or maintained (6/7) VL < 50 copies/mL (of the other patients, 2 had not yet received injections and 1 had initiated the program < 4 months before data cut-off). Out of 11 participants who had perinatally-acquired HIV, 8 experienced virologic suppression. 7 patients stopped LA CAB/RPV because of incomplete virologic response; at time of discontinuation, 6 had NNRTI resistance-associated mutations not observed at program initiation (2 of whom also had INSTI resistance-associated mutations). Although injection site reactions were the most commonly reported side effect, no participant discontinued LA CAB/RPV because of injection site reactions. 1 participant reported two pregnancies while receiving LA CAB/RPV and continued LA dosing (details available in Appendix S1).

AUTHOR'S COMMENTARY:

Initial results of this LA CAB/RPV compassionate use program were presented at the International AIDS Conference in 2020, and additional details provided in this manuscript shed further light on the role of LA CAB/RPV for PWH with viremia who have been unable to achieve or maintain virologic suppression on oral ART. Safety-related outcomes were similar to those previously described in clinical trials. A few of the participants who experienced incomplete virologic response on LA CAB/RPV were able to transition to a protease inhibitor-based oral regimen with eventual virologic suppression. As observed in clinical trials, NNRTI and INSTI resistance-associated mutations may emerge in PWH who do not experience virologic suppression on LA CAB/RPV, and therefore close laboratory monitoring is warranted to ensure early detection of virologic failure and HIV drug resistance among PWH receiving LA CAB/RPV—this may be especially important for PWH with complex ART histories where complete information on pre-existing resistance associated mutations is not available and/or case scenarios involving known factors for potential virologic failure.

FEATURED LITERATURE:

Girometti N, Byrne R, Bracchi M, et. al. Demographic and clinical characteristics of confirmed human monkeypox virus cases in individuals attending a sexual health centre in London, UK: an observational analysis. *Lancet Infect Dis.* 2022 July 1: S1473-3099(22)00411-X. PMID 35785793.

This retrospective analysis describes confirmed cases of MPX virus infection observed at four sexual health centers in London. Demographic and clinical characteristics, and sexual history information, were retrieved from patient records and an internal sexual health dashboard. Confirmed cases all had laboratory-detected infection via an in-house, pan-orthopoxvirus RT-PCR assay. Between May 14 and May 25, 2022, MPX was confirmed in 54 individuals (among 4500 patients seen): all were MSM (2 identified as bisexual). Ninety-six percent were unaware of having been in contact with a known case. Median time between reported symptom onset and testing was 7 days, and median time between symptom onset and last sexual contact was 2 days. Twenty-four percent were people living with HIV, all of whom were receiving cART with CD4 > 500 cells/mm³. Eighty-five percent had plasma RNA < 50 copies/mL within the previous 90 days, and 15 percent had viral loads between 200-500 copies/mL (these individuals had recently initiated cART after a new HIV diagnosis). Ninety-five percent of HIV-negative patients were taking PrEP. All individuals presented with skin lesions, although presentation varied according to stage of MPX infection. Over two-thirds endorsed at least one recent systemic symptom such as fever, fatigue/lethargy, or myalgias prior to lesion onset: most systemic symptoms were mild and lasted less than three days. Ninety-four percent presented with at least one lesion in the genital or perianal area. Lymphadenopathy (usually inguinal) was present in 56 percent. Lesions were noted in more than three sites in 22 percent HIV-negative individuals compared to 54 percent PWH (authors indicate no other relevant clinical differences were observed between these groups). Five required admission due to evolution of genital or perianal lesions into coalescing ulcerations (one had disseminated infection), many with superimposed cellulitis requiring antibiotics and analgesia (one person received tecovirimat)—all reported intense pruritus at the start of the eruptive phase. Median length of hospital stay was 7 days.

AUTHOR'S COMMENTARY:

As exciting coverage from **AIDS2022** continues to be released, MPX cases continue to climb, with the CDC and public health partners reporting 5,189 cases across 47 U.S. states, D.C., and Puerto Rico as of July 29. Findings described in this study shed further light on the clinical presentation and course of MPX and can help providers ensure appropriate clinical evaluation and follow-up. Of particular note, the CDC released a "Dear Colleague" letter on July 27 highlighting that pain management should "remain a cornerstone of treatment" for MPX virus infection. For HIV care providers, additional information on clinical considerations, treatment, and vaccines is available at www.cdc.gov/poxvirus/monkeypox/clinicians/people-with-HIV.html.

FEATURED LITERATURE:

Mohareb AM, Larmarange J, Kim AY, et. al. Risks and benefits of oral HIV pre-exposure prophylaxis for people with chronic hepatitis B. *Lancet HIV.* 2022 July 8: S2352-3018(22)00123-0. doi: 10.1016/S2352-3018(22)00123-0. PMID 35817068.

HIV prevention among people with chronic HBV can prevent poor health outcomes associated with HIV-HBV coinfection, such as accelerated liver disease, higher hepatocellular carcinoma rates, and increased all-cause mortality. However, many initial PrEP clinical trials excluded people with HBV—therefore limited data and published evidence are available to help guide clinical decision making. Benefits of sustained tenofovir-based PrEP use in people with HBV include improved long-term HBV control with lower risk of liver-related complication, however potential challenges include lower likelihood of HBsAg loss compared with people with untreated HBV. By contrast, risks of oral PrEP discontinuation include HBV DNA reactivation, hepatitis flares, and acute liver failure although emerging data suggest tenofovir-based PrEP cessation in some people with HBV (i.e., HBeAg-negative) may be associated with higher incidence of HBsAg loss. Because real-world PrEP encompasses many scenarios—both potentially anticipated and unanticipated—including short-term and/or unmonitored PrEP use and multiple dosing options including new long-acting injectable cabotegravir, integrated systems or processes for HBV screening, monitoring, and treatment within newer PrEP programs may be helpful, especially in settings where HBV is relatively undiagnosed and/or untreated. Authors recommend all people with HBV initiating tenofovir-based PrEP undergo close follow-up and lab monitoring of HBV DNA, aminotransferases, and select HBV serologies. Indefinite use of tenofovir-inclusive PrEP should be considered in people with chronic HBV mono-infection. For people who have discontinued PrEP, authors recommend monitoring HBV DNA and aminotransferases at a minimum frequency of every 3 months for at least 1 year.

AUTHOR'S COMMENTARY:

As authors note, uncertainty regarding PrEP safety with HBV and inconsistent antiviral use may play a role in preventing broader PrEP roll-out, despite many potential benefits in HIV prevention among people with HBV infection. Authors of this narrative review provide a useful synthesis of the benefits, risks, and key practical considerations regarding oral PrEP use in people with chronic HBV who do not meet anti-HBV treatment initiation criteria—and highlight important research priorities to address regarding PrEP use in people with chronic HBV. **HIV**

Researcher Workbench

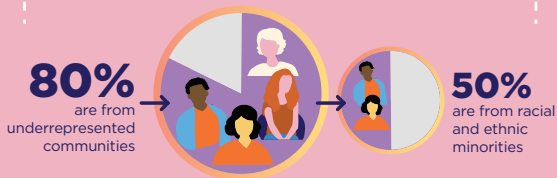
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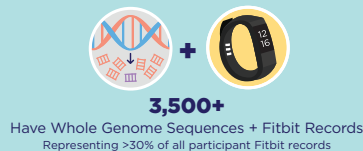
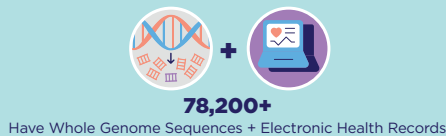
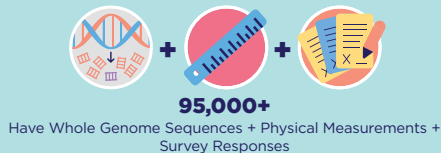
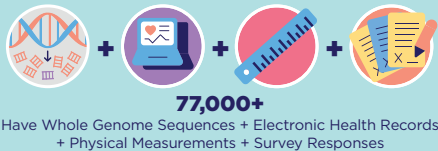


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- Education
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Data as of March, 2022

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