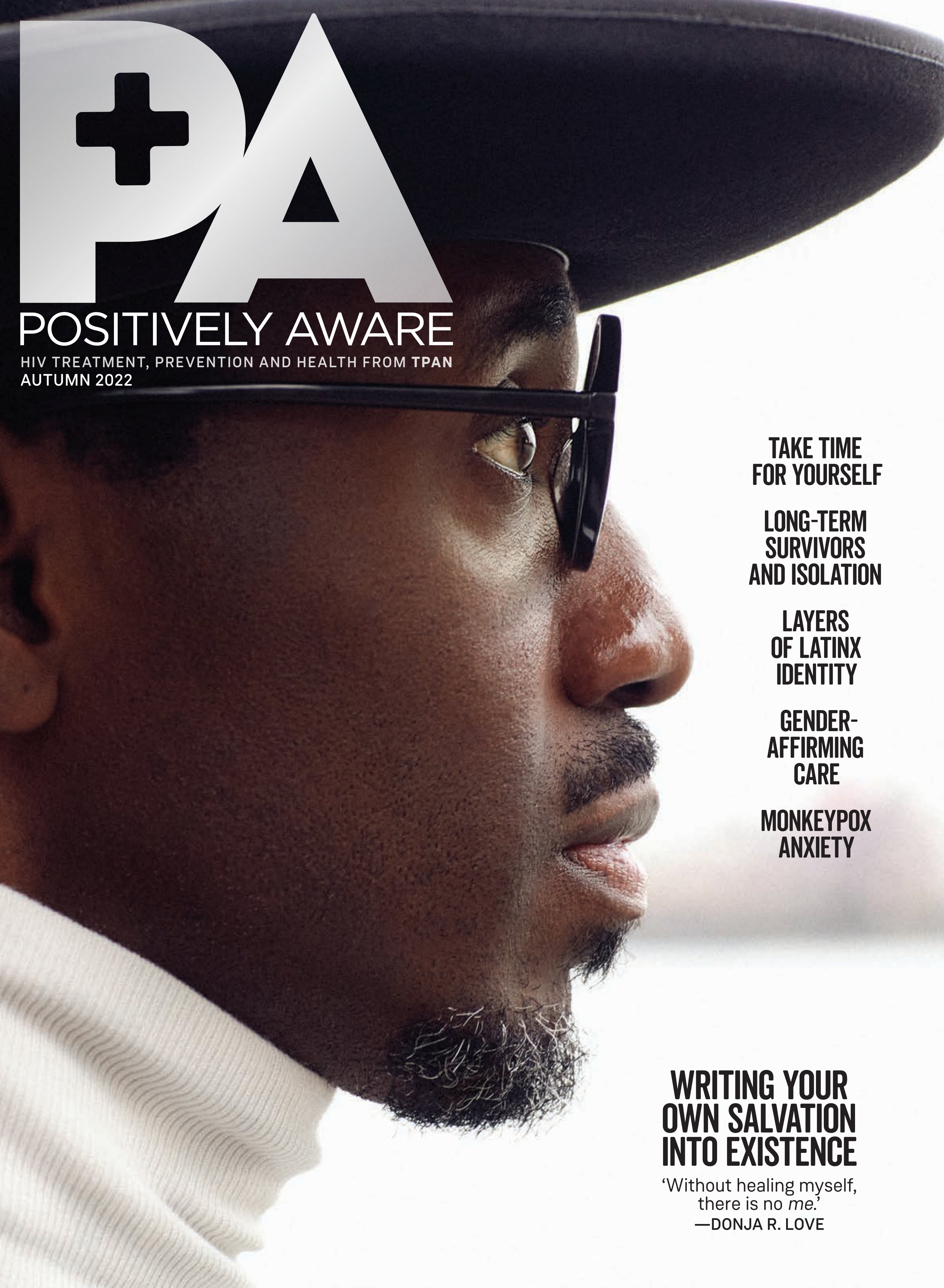

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HIV TREATMENT, PREVENTION AND HEALTH FROM **TPAN**

AUTUMN 2022

TAKE TIME FOR YOURSELF

LONG-TERM SURVIVORS AND ISOLATION

LAYERS OF LATINX IDENTITY

GENDER-AFFIRMING CARE

MONKEYPOX ANXIETY

WRITING YOUR OWN SALVATION INTO EXISTENCE

‘Without healing myself,
there is no *me.*’
—DONJA R. LOVE

AUTUMN 2022

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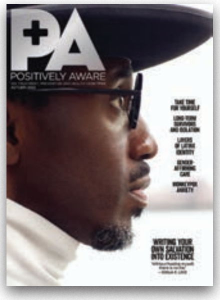

ON THE COVER
Donja R. Love
PHOTOGRAPHED BY
MARQUIS PERKINS

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Rick Guasco
ACTING EDITOR-IN-CHIEF
CREATIVE DIRECTOR
@rickguasco

Kenyon Farrow
GUEST EDITOR
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Enid Vázquez
ASSOCIATE EDITOR
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WRITERS
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PROOFREADER
Jason Lancaster

PHOTOGRAPHERS
Abiola Kosoko
Marquis Perkins

ADVERTISING MANAGER
Lorraine Hayes
L.Hayes@tpan.com

DISTRIBUTION MANAGER
Denise Crouch
distribution@tpan.com

LIVE LIFE POSITIVELY AWARE.
SINCE 1990, PUBLISHED BY
TPAN
5537 N. BROADWAY
CHICAGO, IL 60640-1405
(773) 989-9400
FAX: (773) 989-9494
inbox@tpan.com
positivelyaware.com
@PosAware

TPAN was founded in 1987 in Chicago as Test Positive Aware Network, when 17 individuals living with HIV gathered in a living room to share information and support in response to the HIV/AIDS epidemic. POSITIVELY AWARE is the expression of TPAN's mission to share accurate, reliable, and timely treatment information with anyone affected by HIV.

BE GREEN.
SHARE OR RECYCLE
THIS MAGAZINE.

NOTE FROM THE GUEST EDITOR

KENYON FARROW

@kenyonfarrow

Your HIV life matters

Ten years ago this November I lost a dear friend. Brandon Lacy Campos was a Black queer activist and writer who was living with HIV, living with mental illness, and who also struggled with addiction. Brandon and I met in 2006 when I was in Minneapolis for a speaking gig at a university—and before I knew I could demand hotel accommodations that should have been part of my contract—I needed a place to crash—and mutual friends put us in touch. He let me stay in his studio apartment and we were instant friends.

Brandon was very candid about his life, his writing and his activism, that he suffered from post-traumatic stress disorder (PTSD) due to being a survivor of childhood abuse (bit.ly/blog-ptsd-tragedy). Brandon, like many people living with HIV, dealt with mental health illness that most likely contributed to his seroconversion.

Despite the large amount of research demonstrating that a history of mental illness, adverse childhood events (ACEs) and trauma are all strongly associated with HIV acquisition, most of the HIV policy and advocacy work over the last decade has focused on biomedical issues relating to access to antiretroviral therapy and viral suppression. So in documents like the National HIV/AIDS Strategy, or the various state and county “end the HIV epidemic” plans, you’re most likely to see plans and an HIV care continuum that reflects concerns with the following questions:

How many people tested for HIV?
How many are diagnosed?
How many started antiretroviral therapy (ART)?
How many reached viral suppression?

In some respects, there is good reason for public health programs to be focused on these issues. The HIV care continuum is a useful measure to hold our health care systems accountable to ensure people living with HIV are accessing care and achieving success in terms of their viral suppression, which decreases the likelihood of HIV-related illness and increases the lifespan of PLWH.

But as has been pointed out by the People Living with HIV Caucus and its member organizations, achieving viral suppression is important, but it is not the only measure we should be concerned with. These groups and other activists were successful in getting a “quality of life” metric named in the 2022 National HIV/AIDS Strategy update.

Why is quality of life important? We know that even with all the success of ART helping people living with HIV lead “normal” lives akin to managing a chronic condition, there are still many issues that impact the quality of life for PLWH that supersede viral suppression. And those issues can impact their mental health and emotional well-being.

Mental illness or other psychological stressors can be both associated with being diagnosed with HIV and often result from an HIV diagnosis. A 2014 study published in the *American Journal of Public Health* found that HIV prevalence for people in the U.S. receiving mental health services was four times higher than in the general population (bit.ly/HIV-mental-health-prevalence-study). It also found an “association between psychiatric symptom severity and HIV infection, indicating that engaging persons with mental illness in appropriate mental health treatment may be important to HIV prevention.”

> **Many of my friends, lovers and colleagues who are living with HIV have embraced their diagnosis but they still have to contend with a hostile and ignorant world.**

As much research has shown us, ACEs including exposure to violence, abuse and trauma, neglect, homophobia and transphobia can impact one’s self-esteem and ability to negotiate the terms of sex with partners later in life, which can make one more likely to then acquire HIV. A 2016 study found a strong association between ACEs and increased risk behaviors associated with HIV acquisition (bit.ly/pmr-ace-hiv-risk-study).

But it’s not just having a background of abuse or violence that creates mental health challenges for PLWH. Being diagnosed with HIV itself may cause or exacerbate mental health challenges. The stigma of having HIV is still prevalent in the U.S. and in most parts of the world, and the disrespect for people living with HIV shows up in news stories, pop culture, criminal justice systems, and too often in medical settings—which is the one place you’d expect people to be treated better than anywhere. Feeling isolated, unable to have a healthy sex life or romantic partners, the pressure to disclose one’s status or the fear of actual criminal penalties including prison for having sex can be reasons that lead to other mental health challenges.

Many of my friends, lovers and colleagues who are living with HIV have embraced their diagnosis but they still have to contend with a hostile and ignorant world. My friend Brandon also wrote in a blog post for TheBody.com two years before his death that his use and addiction to methamphetamine came as a result of his HIV diagnosis (bit.ly/queer-poz-and-colored). So, while having HIV from a medical standpoint is no longer a death sentence, many things in our society still make having HIV an extremely difficult proposition for a lot of people.

Since most people living with HIV already know the personal challenges and stigma the virus carries with it, this issue of POSITIVELY AWARE is mostly focused on the things people can do, and are doing, to take care of their mental and emotional well-being. I sincerely hope that these feature articles, personal stories and tips help you know that you’re not alone, and there are some strategies and resources to help support your overall mental health and emotional well-being.

In the name of my friend Brandon Lacy Campos, your HIV life matters.

In Struggle,

ISTOCK

How monkeypox has triggered social anxieties and historical fears

Monkeypox causing you additional worry? Some tips on keeping your cool

BY **NATHANIEL CURRIE, DSW, LCSW**

The sudden emergence of the monkeypox virus (MPX) has been explicitly felt by queer and HIV communities. Stigma, misinformation and fear are reminiscent of the U.S. HIV/AIDS epidemic, and the even more recent COVID-19 pandemic. People living with HIV are especially vulnerable to both the emotional anxieties and to acquiring the disease itself. As a Black queer person (and therapeutic provider), my peers, colleagues, clients and I have had many conversations about the monkeypox outbreak, its effects on our social and sexual health, and where and how to seek health care. I noticed early in this outbreak that fear and anxiety were especially palpable among queer people and people living with HIV.

Black and Brown queer people especially feel vulnerable in times of disease outbreaks as we have seen priority access to preventative and treatment interventions offered to White queer people over our communities. Several of my clients and team members feared they would be exposed to MPX before their social and intimate partner circles were offered access to vaccines. And recently we've begun to see data published by big cities like New York, Atlanta and Washington, D.C. demonstrating that Black and Brown gay, bisexual and other men who have sex with men are disproportionately being diagnosed with monkeypox, while a majority of vaccinations have gone to White gay and bisexual men, even as Black and Brown men reported actively trying to get a vaccine appointment.

A lot of my work recently has been teaching patients, community member, and friends how to maintain their emotional health and well-being while also working harder than most to seek equitable access to preventative health care and treatment intervention for monkeypox. I am writing this piece in hopes that it will continue our communities' hard work to secure our emotional and physical health, and to offer some ways we can each hold that onus.

Reality test: Do I have real reason for concern?

Self-reflection is powerful, and a good place to start in managing fear and anxiety. Ask yourself the following:

> "Are my worries rational?"
> "Is this a projected or actual danger?"
> "Am I able to keep myself safe?"
> "What tools do I need to keep myself safe and free of worry?"

This is called reality testing. Reality testing is an objective assessment of an emotion or thought against real life. Is this thought based on reality? We have very creative minds that are capable of coming up with all types of scenarios. Understanding what is real, as in what is happening to you in the present, versus what could happen, is a thought process most likely to keep you from creating unnecessary worry or anxiety for yourself.

So if you are concerned, even deeply fearful of contracting monkeypox, one thing to do is to breathe and ask yourself, why am I afraid? Have I actually done anything to be potentially exposed to monkeypox?

Seek out reliable sources of information to assess your real risk.

Another way to combat fear and anxiety is to seek out reliable information and to be proactive about your health. This can help create a sense of safety and empowerment. Fear and anxiety are greatly reduced when we as people feel safe. Reading some of the risk assessments from trusted sources such as the Centers for Disease Control and Prevention (CDC) or your local health department is a good way to assess whether your anxiety is well-founded, or whether you may be triggered by the last few years of the COVID pandemic, or by living with HIV in a world that regularly stigmatizes us, or blames people living with HIV, people of color, immigrants or poor people for infectious disease outbreaks.

Get vaccinated against monkeypox if you are able.

For some people, that can mean seeking out getting vaccinated against monkeypox as a way to decrease anxiety around disease acquisition. I received the first dose of the MPX vaccine in July 2022 through Fulton County Board of Health in Georgia, where I live. Access to MPX vaccines was very limited in the first few months of the outbreak in the U.S., with the bulk of available vaccines being concentrated in urban areas or more vulnerable populations, including people living with HIV. In my own experience, I was unsuccessful getting a vaccine appointment for the first month I attempted to secure one. Open appointment links were full in a matter of minutes, representing hundreds of vaccine slots.

Raise any questions or concerns you have with a medical provider.

Upon receiving my MPX vaccine dose I met with a provider who answered all my questions about the vaccine before I received my dose. I highly encourage readers, especially anyone anxious about vaccines or needles, to prepare for your appointment by writing down your questions and bringing them with you to your appointment. Part of health care is not just getting shots or pills, but also getting accurate health information from providers, so feel empowered to ask any and all questions, and to take your time until you feel comfortable.

> **Part of health care is not just getting shots or pills, but also getting accurate health information from providers, so feel empowered to ask any and all questions, and to take your time until you feel comfortable.**

During my vaccination appointment, my vaccine provider, an infectious disease physician, answered my questions. She told me the MPX vaccine is a series of two shots separated by 28 days, with full protection at two weeks after the second dose. It is uncertain if there is partial protection after one dose. The vaccine is either administered through a small needle into the fleshy or fatty part (tissue) of the back of your arm, or just underneath the skin. I was told I would feel a slight prick followed by some soreness. The soreness or itchiness could last a few weeks. Mine lasted three weeks and appeared as a hard, warm, red bump at the injection site. The bump was expected and is not the result of an allergic reaction. Some people feel tiredness or fatigue shortly after receiving the dose, explained my provider. I did not, however. Having this information, knowing what to expect, was incredibly helpful, as I have been known to become anxious when faced with health concerns. You won't lead yourself down a rabbit hole of *what ifs* if you know what to expect.

During my appointment, I learned monkeypox originated in Africa, and historically had been contained to that continent. There have been some intermittent outbreaks here in the U.S., with the last outbreak associated with the importation of animals from Africa. The current outbreak is of a different strain from the original strain in Africa and is thought to be transmitted through skin-to-skin contact. You can visit the CDC's website if you want to track the number of cases, learn more about the history, symptoms, and spread of disease, or how to lower your risk during sex, at cdc.gov/poxvirus/monkeypox.

This resource was shared with me by my provider during my vaccine visit. She went on to explain that MPX is not spread so much by the exchange of bodily fluids, but more by bodily contact (touching, rubbing, kissing) as well as by surface contact, for example, the sharing of bed sheets, towels, and equipment that has been exposed. Hot water is enough to kill the virus, so no need to trash your belongings if you have been exposed to MPX; just wash them well in very hot water. Again, information and care instructions are helpful in reducing fear and anxiety surrounding monkeypox. This information may also help you build confidence in your ability to keep yourself safe.

In review

So, let's briefly recap. To manage fear and anxiety, especially around health concerns, first self-reflect and reality test. Seek out accurate information and guidance. Love on yourself by being confident in your abilities to manage negative or panic-based thoughts and pause emotion to make sound decisions. Invest in being proactive with preventative care like vaccination and treatment. You are your best coach, friend, advocate, and leader. Having information, an ability to use that information prior to making decisions, an understanding of your emotions and thoughts, and skills in managing them, will keep you safe, well, and healthy.

DR. NATHANIEL CURRIE, DSW, MSW, LCSW, is a clinical social worker and educator with more than 14 years of social work experience in mental health and HIV. He is an associate professor of social work and social justice at the Whitney M. Young, Jr. School of Social Work at Clark Atlanta University. He is an active social science researcher, keynote speaker and yoga instructor. He and his terrier, Jackson, and French bulldog, Sebastian, split their time between Los Angeles and Atlanta. **FOLLOW HIM** on Twitter: @AskDoctorNate.

Writing your own salvation into existence

Playwrights Donja R. Love and Troy Anthony ‘Write It Out’ to fight HIV stigma in themselves and others

BY **JUAN MICHAEL PORTER II** • PHOTOGRAPHY BY **MARQUIS PERKINS**

Living with HIV can come with its own unique mental health challenges, particularly as it relates to stigma. Stigma is a form of discrimination against people with specific characteristics and is often based upon erroneous biases. And stigma can also take the form of self-stigma, or the way in which a person who is discriminated against can internalize that outward stigma and shape the way they view themselves, which can impact their own behavior and thinking. The ways this self-stigma appears can include ambivalent feelings towards sex and self-hatred, such as internalized homophobia. With HIV, stigma often manifests through the flawed rationale that simply living with the virus means that one is at fault.

What is important for people living with HIV (PLWH) to remember is that all people are worthy of love, respect, dignity, and support regardless of their status—whether they are seropositive, seronegative, undetectable, out of treatment, or seeking access. But arriving at this understanding can take a great deal of work and self-interrogation, especially for anyone who feels traumatized by their diagnosis.

“Receiving an HIV diagnosis can be traumatizing for many people because it represents a loss of the life that they once knew,” says Nathaniel Currie, DSW, LCSW, a psychotherapist, social worker and assistant professor of social work at Clark Atlanta University (see page 2). “And it’s important for people living with HIV to acknowledge that change is important, if only to recognize that things will be a little different than they were before and to work on moving forward, towards their new life.”

'Without healing myself, there is no *me*.'

For Donja R. Love, the award-winning Afro-Queer playwright who bears his HIV status openly, that work did not happen overnight. He admits that while coming to terms with his diagnosis, he struggled with depression as well as a dependency on alcohol. What helped him return to a sense of worthiness was having a strong support system of friends and family as well as the realization that writing can be therapeutic.

Stories about PLWH rarely appear on television, in movies, or in plays. And even when stories about HIV are included, they are often stigmatizing, filled with gross misinformation, or used as lazy plot twists to create scandal and disgust—rarely to educate or to make PLWH full human beings (TV shows such as *Law & Order* and Tyler Perry’s films have long been critiqued for their stereotypical HIV storylines). While in the midst of his own career as a

successful playwright who focused on the stories of queer romance between Black people during different points in history, Love decided to correct that imbalance by focusing on how he came to terms with his diagnosis.

Originally, Love was inspired while contemplating the then-upcoming tenth anniversary of his diagnosis. At the time, he says that he was gripped with feelings of depression even though he had overcome so much and was thriving.

“I still had some healing to do,” he says.

Without knowing why he was doing it, Love says that he pulled out his iPhone and began to write a play on his Notes app. The result, *one in two*, premiered Off-Broadway in the fall of 2019, produced by The New Group at the Signature Theatre. The title *one in two* refers to the Centers for Disease Control and Prevention’s (CDC) oft-cited 2018 statistic that if current diagnosis trends continue, one in two Black men who have sex with men will acquire HIV in their lifetime.

Rather than focus entirely on that upsetting figure, Love decided to show audiences how it might look to process an HIV diagnosis and slowly decide that there is life after seroconversion. This included aspects of Love’s own story—seeking treatment, engaging with family, overcoming a dependency on alcohol, and being open to receiving love.

Since *one in two*’s successful premiere, it has been staged across the country as an encore digital production featuring the original cast, and was streamed globally as part of Playbill.com’s Pride Plays series.

Love has always been honest with the fact that he writes “to save my own life. Because without healing myself, there is no *me*.” Writing his own “salvation into existence and representing the community of Black Queer HIV-positive folks” has helped Love realize that he can share that joy with others. He started to do so in 2020 by creating an ongoing, fully funded fellowship for writers who are living with HIV called *Write It Out!*, followed by a cash prize for one distinguished playwright—the first of its kind.

Write It Out! is now in its third year and has created a diverse community of supportive writers with HIV—some of whom had never written a play prior to joining the program but who have gone on to be published and begin writing careers. By spreading the love, Love has not only helped himself but created a network of writers whom he believes will “write stories that honor our community and show the world and each other that we are more than our trauma, that we are worthy and whole.”

Since discovering his status, writer and composer Jerome A. Parker had been wary of being known as “an HIV-positive artist.” He says that when he became a member of the second cohort of *Write It Out!* in 2021, he was fearful of what that would mean not only for his art, but for himself.

“It was one of the most frightening challenges because I had never confronted what it means to live with HIV,” says Parker. “Previously, I was always trying to hide it.”

Meeting a community that understood where he was coming from helped him see that he was not alone and that there was more to him than living with HIV.

‘It is not enough to show how we live; I have to show that we can thrive as well’

“Part of the beauty of being in *Write It Out!*,” he says, “is that it took me from a place of isolation and into a community that was very diverse in how we processed our feelings and supported each other, while figuring out that HIV does not define who we are.”

Helping PLWH to see that they are more than a health condition is an ongoing passion for Love. In March, The New Group presented his digital theatre series, *i need space*. Love wrote and directed the piece to show how a group of PLWH were processing their depression during the forced isolation periods of the COVID pandemic.

“I needed my community to see that they would make it through COVID-19, even though it felt like the rest of the world had forgotten about us,” Love says.

In his most recent work, the critically acclaimed *New York Times* Critic’s Pick, *soft*, Love expanded that perspective by focusing not only on HIV, but on suicide and the structural barriers that expose so many Black men to dire health conditions. By putting onstage the real life circumstances that many Black people face on a daily basis, Love was following the edict of his spiritual mentor Joseph Beam—that “visibility is survival.” He was also creating a roadmap for overcoming those outcomes.

“It is not enough to show how we live; I have to show that we can thrive as well,” Love says. “Because we do. Even if the world likes to ignore it. But in my work, the community sees it and hopefully sets that as their new standard instead of the *cough-cough* trauma porn that we usually get. Because we are more and we deserve more. And seeing us with more gives me so much light.”

Writing to ‘remind myself that I’m here choosing life’

Love is not alone in believing this. One creative who has been inspired by Love’s bravery in sharing his status with the world is the award-winning composer and theatre-maker Troy Anthony. In June, while talking to the blog site Theatrely about *The Revival*, a Black and queer-led, community healing choral movement that is being presented and sponsored by The Shed, Anthony says, “I don’t want Donja to feel like he’s the only one out there when there are so many of us who are living with HIV.”

After sharing his status in the blog, Anthony revealed that doing so had been freeing and healing, and had opened up many conversations. He compared the healing that came from no longer hiding his status to the spiritual rejuvenation that he feels from writing.

“By healing ourselves, we also put a stop to inherited collective trauma, and heal our ancestors as well,” says Anthony.

He noted that he came to this realization after receiving a spiritual reading, during which he was told that “you have ancestors who had to stay quiet about who they were. Who couldn’t rock the boat. But you don’t have to do that.”

Hearing that message instilled in Anthony what he calls “a responsibility to undo generational curses by breaking the silence.” His most recent work, *Champs*, a musical set at a roller-skating rink in his native Louisville, Kentucky, has evolved from “writing to be seen” into “choosing to love yourself over loving toxic people, and learning how to be in a relationship with someone else who’s also healing from trauma.”

“I had to give my family the opportunity to learn how to love me,” he says.

After years of hiding his sexuality, some of his family did not take well to learning the truth, though in time, they came to know him more fully. For him, that meant tapping into grace for himself, his own need to hide, and his family’s need to grow.

Living through this growth has helped him to focus on creating stories that would not have been available to him as a child and going beyond plays like *Angels in America* or *The Normal Heart*, and their focus on white people overcoming the challenges of queerness. Anthony says that he has been inspired by the now iconic documentary on ballroom culture, *Paris Is Burning*, and its Black and Brown queer subjects to ask, “what is possible?”

During a recent workshop of *Champs* at The 5th Avenue Theatre in Seattle, Anthony immersed himself further in possibility by listening to a community of Black queer elders about the play. The elders addressed a queer elder character in the musical and encouraged Anthony to go deeper—they explained that during the ’80s and ’90s, when the musical is set, there was already a thriving community of Black queer folks living in Kentucky. Anthony realized that he didn’t know this because their stories had not been preserved. Learning about them has given him the spark to honor them, if not in *Champs*, then in a future project.

Far from feeling overwhelmed by the prospect of writing another musical that digs into the not-as-well-known history of Black queer men in Kentucky, Anthony says that he is inspired to do so. One reason is to avert the tragedy of loneliness that hurt one of his dearest friends, Darius Smith, the musical director of the first musical he ever wrote.

In 2019, Smith died from AIDS-related complications after he rejected treatment because he believed that “AIDS is God’s punishment for my being gay.” Smith’s death inspired numerous aspects of Michael R. Jackson’s Pulitzer Prize- and Tony Award-winning Broadway musical *A Strange Loop*, as well as its stigma-busting song, “AIDS is God’s Punishment.”

Smith’s death was difficult for many people to process, especially after they learned about the shame that he was dealing with. Rather than give into that stigma, Anthony says that he writes if only to “remind myself that I’m here choosing life and to understand how scary it was at different times to live with HIV. Even two years ago for Darius, who thought he should let the disease ravage him because he had so much shame. When I think about him and others, I’m motivated to get back to the work and get back to healing.”

Part of that work has included addressing his self-stigma and serophobia. He says that “it wasn’t until I received my diagnosis that I realized how much stigma I had.” After receiving his diagnosis, he said his first thought was, “Oh, how could that be? I don’t sleep around.”

That helped him to confront the judgment that he’d been carrying about what others who were living with HIV must have done to acquire it.

Through writing, he has learned to break through those judgments and embrace the same grace for himself that he tries to give others.

For both Love and Anthony, a central question in the origin stories of their work as writers living with HIV could be, “who is worthy of grace?” This question inspired each to write their thoughts down, creating characters and worlds where the audience is led to confront the question in themselves, just as it has led Love and Anthony to a world of healing for themselves that they could not have previously imagined.

That process of self-discovery, healing, and self-love is something they want for all people living with HIV—not only to help the world to see all the greatness that lives throughout the community, but for the community itself to recognize that even if their stories do not become award-winning plays, they are still beautiful and deserving of love.

JUAN MICHAEL PORTER II (*he, him*) is a Black queer man living with HIV. He has written for TheBody.com, PBS American Masters, the *San Francisco Chronicle*, the *Christian Science Monitor*, *Playbill*, and the *New York Observer*. He is a National Critics Institute and Poynter Power of Diverse Voices Fellow.

Layers of Latinx identity

Family, culture and current events—the complexities of being Latinx and living with HIV

BY **ALEJANDRO ACOSTA**

ISTOCK

Right now, I am going through a depression. Like many people, the daily stresses of life can be tough to navigate. In an average year, things would be okay for me, but these past two and a half years have been anything but average. The uncertainty of the global pandemic, the clear indications of climate change across the world, the never-ending political instability in the U.S., inflation affecting prices everywhere, racial divisions permeating our everyday lives—the list can go on. But no matter how long this list is for you, at the end of my list you can add: I am partially employed without benefits, I'm the caretaker of my disabled older brother—and finally the cherry on top—I am a mixed-race Latinx middle-aged gay Puerto Rican openly living with HIV. Even with all these added stressors and with my ongoing functional depression, I consider myself lucky and privileged because I see every day what life is like for some of my Latinx brothers and sisters living with HIV.

My overbearing Mami, who was smart without formal education, practiced stoicism and taught us that there are always other people who have more difficult situations than we do. She instilled in us that we should always help others when we can. When it comes to HIV and the Latinx community, there are many issues that aggravate an already intrinsically difficult situation. HIV is still treated in the Caribbean and all over Latin America the same way it was treated back in the '80s and '90s, where stigma, misinformation and discrimination still permeate. Many factors contribute to this: poverty, lack of sexual health education, religion, patriarchal society, and LGBTQ discrimination. HIV is still a taboo subject treated like a poor telenovela subplot. I spoke to different Latinx friends living with HIV, to mental health professionals, and did my own research in preparation for this story. With their permission I will discuss some of the wisdom they provided during our conversations. These are real-life examples of some of the difficulties we experience regarding HIV and mental health within our Latinx identities. In order to safeguard their privacy I will use general descriptions.

HIV stigma impacts healthcare access

Understanding the Latinx community takes a lot of work because it's hard to generalize about our communities when we come from so many different backgrounds and traditions. One thing that is universal among all of us is HIV stigma. When someone is newly diagnosed with HIV, they need loved ones and people who can provide emotional support. This means disclosing their HIV status to their family and friends, which can be one of the most difficult decisions Latinx people living with HIV will face. It took me six years to disclose to my family. Once I did, they begged me not to share it with anyone else. Consequently, it took me 15 years to publicly come out of the HIV closet. I was tired of living lies and stressing over people "finding out" about my status and outing me at my job. As a school teacher, I was constantly on edge trying to hide my status from everyone, in fear of reactions from uneducated parents or co-workers. Once away from the school system, I felt comfortable enough to "come out," in part because I became an advocate and needed to live authentically. This is not the case for many Latinx people.

> **I was tired of living lies and stressing over people 'finding out' about my status and outing me at my job.**

One of my Puerto Rican friends did not get tested for HIV for four years. Although he is openly gay, his primary care doctor would not bring up his sexual life during his visits. Nor did my friend, since he doesn't really "trust" the healthcare system. It worked for both of them to avoid the issue. When his results came back, he was diagnosed with AIDS because his T cell count was just below 200. That's hard news for anyone to hear, but he was convinced he could not disclose to his family, as they are devoted religious people and he fears their reaction will damage their relationship forever, especially among his younger family members. He has literally no one else he feels comfortable talking to about his HIV status, except for me. His doctor suggested he go on antidepressants and begged him to "read and get educated about the current science of HIV." After five years, he still has no one he really speaks to about his status, not even a therapist.

According to the U.S. Surgeon General, approximately 1 in 10 Hispanics with a mental disorder receives mental health services from a general health care provider, while only 1 in 20 receive such services from a trained mental health specialist. My friend suffers from anxiety, depression, guilt, shame, and self-doubt. A successful man with access to the best healthcare corporate America can buy gets no real support from his doctors, his family, or close circle of friends. Now, imagine people who do not have access to healthcare due to their immigration status, or are transgender, nonbinary, or gender nonconforming, or are of other groups whose social, political and economic marginalization also keeps them without health care coverage or with few culturally competent providers.

Using substances to cope with an HIV diagnosis

In college and away from his family, this 25-year-old man newly diagnosed with HIV is an attractive Latinx guy living in South Florida, where many drugs, including methamphetamine (crystal meth), are readily available. He started using meth as an escape from the new HIV reality he was facing alone. Although he disclosed to his family and friends, he felt unsupported by them and hopeless about his future. By his 28th birthday, he had dropped out of college, was using meth regularly, couch surfing for weeks while on meth-benders and forced into sex work to keep up with his addiction. He decided to stop using drugs after he was drugged and raped by multiple men during a sex party. He woke up naked on a park bench near Miami with no possessions, no phone, no shoes, nothing. He is still grateful that he was not a victim of something worse. Yes, he is grateful for something most people would consider an unthinkably damaging experience. Ultimately, he moved back to his country of origin where he says he has found connection to community and friends. These human connections have helped him regain a sense of normalcy. His recovery is ongoing. Although he stopped using hard drugs, alcohol is his new escape, and it's easily accessible. He still struggles, and he says being around loved ones is more important to him than the HIV-related health care he received from the Ryan White program when he lived in the U.S.

The Substance Abuse and Mental Health Services Administration (SAMHSA) reports that in 2019, there were 8.9 million Latinx people with mental illness and/or substance use disorder (SUD) in the U.S., an increase of 3.7% from the previous year. At least 63% of those experiencing either SUD or mental illness go without treatment. These numbers are likely much higher after the COVID-19 pandemic, which exacerbated mental illness and SUD in the general population with added stress and trauma. For some people, racism and the targeting of Latinx communities may add to these stressors that can increase the likelihood of contracting HIV. And if a person receives an HIV diagnosis, more mental health challenges may be piled on.

When sexual intimacy can mean prison time

Once you are diagnosed with HIV one of the immediate new considerations is to remember that sex and relationships are changed forever. I was in a relationship when I was diagnosed, and it didn't survive. There was mistrust, lack of communication,

ALEJANDRO ACOSTA is a Puerto Rican LGBTQ and HIV advocate with over 20 years of experience in education, advocacy, and public policy. He is a writer, makeup artist, and behavioral researcher.

and constant blame, which made it impossible to continue coexisting. Once single, I did not think I would be able to date normally again. I felt toxic for months before I could have sex with anyone. The last Latinx guy I thought I could date told me flat-out he could never date someone like me. I thought maybe I was too old, too femme, too fat, but no. He nonchalantly clarified it was because I was "too open about my HIV status. I just could never." He was also living with HIV but could not imagine anyone finding out he was dating someone living with HIV except for a select group of people. He was from a law enforcement background and had what he described as "conservative values." Other than that, he was a great prospect. This is a frustrating experience to have in the era of U=U (undetectable = untransmittable) and PrEP, which should have resulted in more compassion and less ignorance.

But it's not only ignorance, shame, and stigma; criminal law makes things worse. HIV is still criminalized in some form in 32 states and U.S. territories. In these jurisdictions it is still a crime to not disclose one's HIV status to sexual partners, and/or to "expose" someone to HIV, no matter whether you're undetectable and can't transmit HIV, or through an act that has no risk of transmission such as spitting or oral sex. You can still be subject to prosecution and serve prison time, and be labeled a "sex offender." Florida is one of these states. One of my advocate friends was accused by a sexual partner of non-disclosure and reported to their university leadership and police. He was treated like a criminal despite his undetectable status and the fact they had only had oral sex. The anguish and shame brought on by this accusation has had a detrimental effect on his dating, sex life, and overall mental health. He is young and will probably recover from it well, but right now he is single, demi-sexual, and looking for a deeper connection with someone where sex is not the main focus.

Latinx people need to be in more leadership roles in HIV organizations

This past summer John Leguizamo was publicly calling out Hollywood for the lack of representation of Latinx people in movies and TV shows. The Latinx population is the fastest growing ethnic group in the U.S., at 62.1 million, and the population is projected to double to 123 million by 2060. There is a huge need for Latinx representation in many fields, including HIV care and services.

Although Latinx people make up 25% of new HIV transmissions, national HIV and LGBTQ-focused organizations do not have the diverse composition to reflect these numbers. As a public policy and HIV advocate, I have sat at decision-making tables where I am often the only Latinx person. They say "nothing about us, without us," but this is not the reality these organizations demonstrate with their staff, executive teams, and boards of directors. When we are missing from these organizations there's no one to vouch for the interests of the communities we come from and the people we represent.

Take Puerto Rico for example. San Juan is one of the cities receiving EHE (Ending the HIV Epidemic) federal funding since there are many people there who are newly diagnosed. But our island is much more than just the metropolitan capital of San Juan. Services across the island can be quite difficult to find, if they're available at all. I was consulted by a big pharmaceutical company when they wanted to conduct listening circles with the community. Their community liaison for Puerto Rico wanted to hold one listening circle in the morning in the west coast, and another one in the afternoon in San Juan. I said this would be almost impossible to do with the same staff. They were surprised because they "thought the island was so small this could be done easily." Then they said we could hold it in San Juan and have the people from the island travel to join us. Doing this without travel, accommodations, and a financial incentive would be futile. The lack of basic knowledge about the island was not surprising. They were not Latinx, they had never been to the island, they didn't speak Spanish, and they had no understanding of the idiosyncrasies of our people. Is this the best way to serve our people? How can funds get to the right communities when we don't see ourselves within the institutions that are supposed to serve us? For now, we are barely visible.

Not everything is lost. For the past four years I have been volunteering for Latinx Plus, a network of Latinx advocates living with HIV. We aim to change the current status quo to elevate the voices of Latinx people living with HIV in the necessary spaces to ensure that we are part of the conversations that impact our lives.

This is about Latinx people, but it's also about all people living with HIV—it's about *all people*. Anyone can suffer from mental health issues. You can be surrounded by people and still feel alone because loneliness is not about how many people you have around you. It's about how many people with whom you share deep connections and bonds.

One thing is clear—when we feel like we belong, we thrive. PA

Take time for yourself

How people living with HIV maintain optimum mental health wellness in these tumultuous times

BY **CANDACE Y.A. MONTAGUE**

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It is impossible to not notice the turbulence in our world these days. Politics, public health threats, injustice, gender- and racial-based violence, climate change, and other issues of global concern are on a 24-7 cycle in our news and social media outlets. The stress of our everyday lives is making it hard to even breathe, figuratively and literally.

There have been scores and scores of studies done that show stress as a direct adversary of wellness. Stress is a killer. If you're living with a chronic health condition, stress can exacerbate the symptoms.

When it comes to living with HIV, the effects of stress are deeper. The stress of living with HIV can put people at a higher risk for mental health issues such as depression or mood disorders. And it won't go away by just getting to undetectable. For some, it means dealing with suppressed trauma and healing from past adverse events so that their physical health can be maintained.

Self-care, the act of taking care of one's own needs first in order to be more productive, is a term that has been used for decades by therapists, mental health advocates, and counselors. It was popularized in the early months of COVID as people were looking for ways to grapple with the world being shut down. Self-care has several biophysical benefits in addition to boosting our immune system and lowering the risk for heart disease and high blood pressure.

Mindfulness-Based Stress Reduction is another strategy being embraced more by people from all walks of life. It's more than closing one's eyes and counting to 10 or simply visualizing a happy place. MBSR is a practice that embraces yoga and meditation techniques to provide relief from stress and anxiety. It's being used more and more every day in popular society.

Three people who work in public health while living with HIV discussed their concerns regarding mental health wellness, and how they cope.

George Kerr is a public health advocate, and the founder and CEO of G III Associates, a nonprofit consultation and advocacy organization in Washington, D.C.

Masonia Traylor is an Atlanta-based HIV/AIDS activist and founder of Lady BurgAndy, a nonprofit organization that aims to create spaces and opportunities for women and youth impacted by HIV/AIDS.

Kellie (last name withheld) is a care coordinator for government programs in the state of Illinois.

What concerns you the most when it comes to mental health for people living with HIV?

GEORGE KERR There are not enough resources to get people into therapy who need it. And for those who do seek it, there's a long waiting period. I had a client call me earlier this year. He is HIV-positive. He was doing great, with work and everything. When COVID hit, he lost his job. He fell into a huge depression and was suicidal. When he reached out for help, they told him that there was a two-month wait to get into therapy. If you have someone who is suicidal, two months is not acceptable. We need someone, like yesterday.

KELLIE I think a lot of people are not aware of the resources that are available. I've been HIV-positive for nearly 30 years, so this is nothing new to me. A lot of people are afraid when they are first diagnosed. They don't know where to turn. There are many community-based organizations who can coordinate care. Also, medications are extremely expensive. For people on Medicaid, that's generally not a problem. But for people with HIV who take medications daily and rely on commercial insurance, we have huge co-pays and deductibles that we have to meet before that coverage kicks in. So that can be scary as well. *Editor's note:* A case manager can help people with private insurance access financial assistance for medication, such as that available through Ryan White programs or pharmaceutical companies.

MASONIA TRAYLOR Stigma. Historically, HIV has been weaponized. And because it's weaponized and highly stigmatized it's never seen as a positive thing. It's very morbid. And because we all have perpetuated that stigma in some form or fashion, most people struggle with an HIV diagnosis. People have to be convinced that it's okay. They have to be assured that they're fine.

What are some of your coping strategies?

KERR I have therapy every two weeks. And that's what saved me, my therapist being there for me throughout all of this. Having those 15-minute conversations every other week has really been a lifesaver for me. I do a lot of walking. I enjoy walking by the water. That's been very instrumental. My pastor has been my spiritual guide. I have a Bible study that's been instrumental. We have small group discussions and we talk about our concerns.

KELLIE I have monthly therapy sessions to discuss my fears or stressors. And I learn techniques to deal with stress. I do a lot of mindfulness and meditations. The one that I do that helps me with my own mental health issue is a mindfulness activity. It's really simple. I just take some time out to look for something that I can touch. So if I'm sitting at my desk and I'm feeling a little afraid I will close my eyes and reach out and touch a pencil. Then I open my eyes and focus on something red. Then I will look for three things that I can smell. I will focus on three things that I can hear. It's kinda methodical, having that procedure in place. It brings you to a very peaceful place.

TRAYLOR My peer network, other people living with HIV, helps me. And being in mental health therapy is another tool in my toolbox. I talk on social media a lot. I structured my social media platforms around my diagnosis to create awareness and to bring some normalcy around HIV. Most of the people I see on my social media platforms are people I know in real life. Many of them I went to school with or I have worked with, so they are connected with me in some form or fashion. And even if I don't know them in real life, the honest conversations I have with people about HIV and the responses I get back are a part of my support system. I don't complain on social media. I express myself. And people can relate to me.

We are all moving through volatile times between political unrest, racial and gender oppression, multiple public health threats, and so on. What is your best advice for people who are living with HIV and are trying to keep their heads above water?

TRAYLOR You can get through hard times. Listen to other people's stories that are parallel to yours so you don't feel isolated. This will get you closer to healing. Don't allow someone else's rejection to deter you or tear down your worthiness.

KERR Take time for yourself. It can be a mental health log, meditation, group support, or meeting with a therapist. If you don't take care of yourself, no one else is going to do it for you. Take your meds. You get burned out taking these drugs, and so you say 'I'm not going to take them tonight,' and then the next thing you know it's a month later. That leads to another problem you don't want to have.

KELLIE Go to all of your medical appointments. Make sure that you have a good network of friends and family to turn to. Take your medications exactly as directed. That's going to keep you healthy. Skipping doses happens a lot when you're in stressful situations where you have a lot going on. Keep yourself educated so you won't be afraid. PA

> **Take time for yourself. It can be a mental health log, meditation, group support, for meeting with a therapist.**

CANDACE Y.A. MONTAGUE is an award-winning independent journalist based in Washington, D.C. She has been covering HIV/AIDS along with other health topics for over a decade.

Overcoming the distance

Larry, Kookie Dekay and what love and support look like for long-term survivors

BY **STEPHEN HICKS**

Maggie Anderson and her sister are Larry's primary caretakers. Their dad, Larry, is an LGBTQ elder with a small support network consisting of four people. He doesn't have roommates, but he lives with COPD, asthma, diabetes, chronic depression, and a host of memories—good and bad. He isn't immersed in a queer-affirming, sex-positive, progressive buzzword utopian enclave. He lives in Nebraska. Despite his location, he is one of the many LGBTQ seniors throughout the U.S. living isolated, making do with a patchwork of social supports.

Subsequently, mental health and care-taking are impacted.

"The network that we're able to rely on has gotten smaller and smaller with time," Maggie said. "A lot of folks have either died or are really sick themselves. At the same time, my dad's mental health, because of the trauma of the AIDS crisis, of losing my mom who he was married to even though he was gay, losing my biological dad who the three of them shared a household with. He went from one of three parents to a single parent very unexpectedly. And experiencing trauma over decades, that takes a real toll on your mental health. He can be tough to be around sometimes. As he has aged, more and more people have pulled away, and so our circle has gotten smaller and smaller. It's tough."

Larry, 76, was once a beloved drag queen. The stage was his—better yet, the stage *belonged* to Kookie DeKay, Larry's drag persona. In quick succession, life changed for him as his co-parents died of AIDS complications. The children he raised are now grown, and he spends his days combing Netflix and his extensive DVD stacks.

"Our elders who are living with HIV face their own unique trauma and isolation, and that is an incredibly important experience. The cultural memory and

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the cultural experience of HIV, while it's not the same as living with HIV, is still really important," Maggie said. "My dad is HIV-negative, but I look at him and see how profoundly HIV has shaped his entire life. Not only from the loss of his co-parents, he hasn't had sex with another person since 1989. It scared him so much that he's been celibate. HIV is something we all live with, particularly our elders, but we live with it in different ways depending on who we are and if we have HIV in our body or not."

Geography poses difficulty for in-person connections. Maggie lives in St. Louis, Missouri. Her sister is in Omaha, Nebraska. Dad is about an hour's drive from sis, in Lincoln. Maggie and her sister had to jump into creative mode when Larry's health issues arose. They needed someone to clean the house every few weeks, which would include taking out the trash, lifting heavy grocery bags, and keeping his space—a tad bigger than a garage—livable. Luckily, Maggie's sister's friends, dating back to her middle school days, fill in the gap.

These friends, in their forties now, first met Larry as children before his health started to decline. They understand who he is, and they understand that he's not the same as he used to be, and so they step in when needed because they can see that contrast and know that he needs the support.

"Between me, my sister, and these two friends of hers, childhood friends, we keep it rolling," Maggie said. "We also have a couple folks that we can call on regularly to help with rides to the doctor. He [Larry] stopped driving in 2020, so we do have folks that we can call on to get him to doctor's appointments as needed."

Beyond a quick visit, Larry spends a lot of time alone watching movies and TV. Maggie and crew meet his material needs but know the struggle of meeting his emotional needs. And like many longtime survivors, Larry lives in social isolation with various health issues. Many elders navigate lack of social support and stigma; food and housing insecurity can be present in combination with cardiovascular disease, respiratory issues, dementia, and mobility problems—typical signs of aging.

It took time adjusting to the healthcare system. Maggie said she learned to be happy with simply being misunderstood by her dad's medical team. There have been times where older adults

GEOGRAPHY POSES CHALLENGES FOR IN-PERSON CONNECTIONS. MAGGIE LIVES IN ST. LOUIS, MISSOURI. HER SISTER IS IN OMAHA, NEBRASKA. DAD IS ABOUT AN HOUR'S DRIVE FROM SIS, IN LINCOLN.

have been singled out by staff of various aging care providers because of their sexual orientation, gender identity, or HIV status. Still, Larry hasn't experienced any specific targeting or abuse in his care, she said.

Maggie is thankful but watchful: “As elders' needs become more complex, I think that there can be a knee-jerk reaction to say, ‘Oh well, the family will deal with that.’ It's just the three of us.”

Nearly half of all people living and diagnosed with HIV in the U.S. are at least 50 years old, according to the U.S. Centers for Disease Control and Prevention (CDC). Nationwide, long-term HIV survivors and LGBTQ elders remain isolated even in the country's most progressive gayborhoods.

The burden remains heavy, said George Kerr, III, a community advocate in Washington, D.C. (see page 10). Several of his friends have been isolating at home for at least two years due to COVID-19 risk.

“In June for Gay Pride, we started coming out,” said Kerr. “We finally started seeing our friends again and everything. Then monkeypox happened.”

To Kerr, advocacy is a must along with building social ties. He serves as a board member of the LGBTQ Task Force for the D.C. Department of Aging and Community Living.

“Particularly with the LGBTQ community, our seniors have been activists for so many years that they're tired. How do we get our seniors and our younger people to have these community conversations so that the young people have the history and know-how to bring up these needs? We need to pair them together,” he said.

Food insecurity, mental health crises and overdoses don't get enough attention, and Kerr is adamant about sounding the alarm.

“Queer elders are truly invisible in so many ways, not just within the culture at large, but within the queer community itself,” Maggie said. “The queer community's obsession with youth, I think, is a real problem.”

ACCORDING TO SAGE, a national advocacy and service group for LGBTQ elders, about 40 percent of queer older adults do not disclose their sexual orientation to their primary care providers. This leaves thousands of people without appropriate care.

Larry, Maggie describes, is of a generation where he fought really hard to come out, and now that he's out, he's not going anywhere. “He intentionally agitates and pushes, going out of his way to come out as soon as he can. When he meets his nurse, almost immediately he says, *Oh, I love your hair color. My favorite wig was that color when I still did drag*."

The nurse's response determines everything. If it doesn't go well, Larry and Maggie don't waste time making further plans.

“Not every queer elder is going to be like that, so I think he's really unique in his fearlessness. That's something I love about him. And in a way, that's really relieving to me,” Maggie said. “My dad is kind of an outlier in that he goes out of his way to come out as soon as he can without apology, but that is not an option for a lot of people depending on a lot of factors, depending on where they live, depending on their level of family support, all kinds of things.”

There have been lots of hospital visits over the last 10 years. After a lengthy hospital stay in 2019, Larry began several weeks of home healthcare. Maggie thought of her dad's home: framed photos of him and others in drag on the wall, books and movies related to queer history on the shelves. Any outsider, namely a home healthcare aide, could use his queerness against him and not provide the best care.

“I was observing really closely to make sure that the care felt genuine and that it felt thorough. Of course, I couldn't be there for every single meeting, but I had regular check-ins with him to make sure that he felt safe and that he felt that he was receiving good care, that he got along with the physical therapists and nurses who came in and out for weeks on end,” Maggie said. “Microaggressions or the refusal to do certain things compound over time.”

Laws are sweeping through state legislatures backpedaling on anti-LGBTQ discrimination. This along with social isolation mean that thousands of Larrys can fall through the cracks—a tragic irony for people who lived long enough to see progress and old age when neither was promised. For now, Larry and his small network continue to make do. PA

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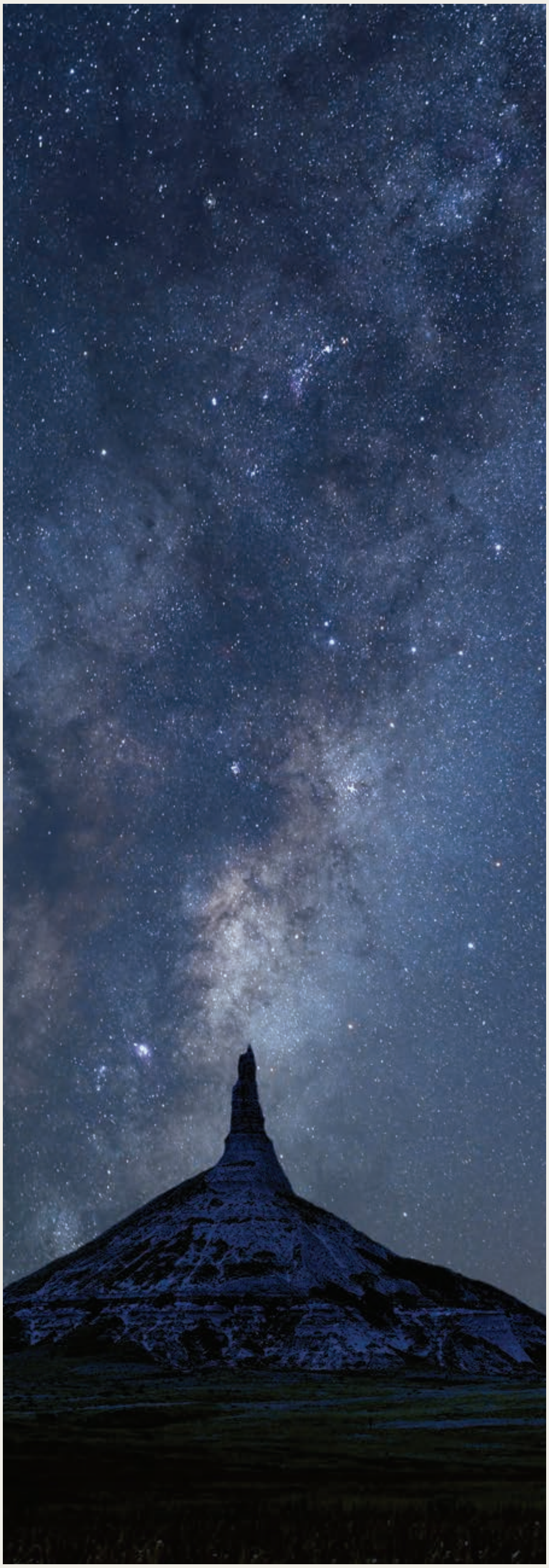
STEPHEN HICKS (*he, him*) is a writer and has been a public health advocate for more than 10 years, focusing on sexual health and harm reduction. He is the Narrative Justice Fellow at CNP (formerly The Counter Narrative Project).

I-80: ABILOLA KOSOKO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A daughter's view on aging and chosen families

"In queer communities, we love to tout the power of chosen family, and for very good reason. Historically and today, people are kicked out of their homes, disowned by their family of origin, or if not entirely cut off, may be experiencing a feeling of discomfort or little moments of exclusion that aren't super drastic; not total disownment, but not feeling safe or good either. We have this robust history in queer communities of cultivating chosen families, but at the same time, we know that LGBTQ older adults are much more likely to experience social isolation.

"So something isn't adding up there. There's a disconnect. And I think that ageism within the LGBTQ community is a big problem, just like in the country at large. We build these chosen families, we find each other, we do potlucks, and we show up for each other on birthdays, and through divorces, and all kinds of things. However, when you are all relatively of the same age, the same generation, and because of your identity, because of heterosexism and cissexism, you are more likely to experience health disparities. Add onto that other identities, like race and experiencing racism, or poverty, all these things that make you more likely to experience health disparities, and you're all rocking your chosen family over time.

"Well, over time, a lot of your peers are either going to die or are going to become really, really sick and won't be able to show up the way that they used to anymore. So I think it's really important that we are critical of how we talk about *chosen family*—what do we really mean by that, and think about ways to make our chosen families intergenerational. Because I look at my dad, and I look at photos from when I was a little kid. Oh my god. Everybody was always over at the house. We had big Christmas Eves and all kinds of things.

"I look at those photos, and I can point out, okay, they've died, they've died, they died—some of them of AIDS, but some of them of suicide, of alcoholism, of cancer—disparities that are more likely to impact queer folks, particularly as they age. Even if they're not dead, chances are that their health is very, very precarious. So when you're struggling to keep yourself alive, how are you going to keep showing up for your chosen family with the same energy that you always did before? I think the question of social isolation for queer elders, whether they're living with HIV or not, is a really important thing to really think about and prompt us as younger folks to change how we interact with one another, and expand our social circles to be inclusive of multiple generations."

—**MAGGIE**

What comes first?

Gender-affirming care is primary care

BY **FINN SCHUBERT, MPH**

Trans people living with HIV experience numerous barriers to receiving appropriate and culturally competent healthcare. One study found that 82% of Black and Latina transgender women living with HIV had experienced at least one barrier to healthcare access. While high-quality data on HIV outcomes in transgender individuals living with HIV can be hard to come by, existing studies suggest that there are significant disparities between transgender and cisgender people living with HIV at various points of the HIV care continuum, including linkage to care, retention in care, and viral load suppression. It should be noted that existing studies tend to include data on people who were identified as transgender women and transgender men, and that there is a lack of data on HIV prevalence and outcomes for nonbinary individuals. Despite these limitations, it is clear that HIV care delivery systems have not yet been successful in fully meeting the needs of trans people living with HIV.

For many trans individuals (though certainly not all), gender-affirming hormone therapy is an important aspect of overall primary care, and many studies have shown that access to gender-affirming hormone care for trans individuals who seek it can substantially improve mental health outcomes. A 2019 systematic review found several studies that demonstrated an improved quality of life after initiation of hormone therapy—one before-and-after study showed that life satisfaction scores nearly doubled among transgender men on testosterone over the course of five years, while a different study found a 16% improvement in quality of life scores among trans women over the course of one year of hormone therapy. Similarly, numerous prospective studies have shown a decrease in depression symptoms while on hormone therapy—one study found that symptoms of depression decreased from 42% to 22% over one year of hormone care. Although some studies in the literature on this topic show a null result (no difference in the mental health outcome related to hormone therapy), not a single study identified in the systematic review found that hormone therapy worsened quality of life, depression, or anxiety.

Gender-affirming healthcare is often seen by providers as secondary to other healthcare needs.

Gender-affirming care improves HIV outcomes for transgender women

Among trans people living with HIV in particular, research is more limited but supports the idea that access to hormone therapy improves health outcomes. A survey of Black and Latina trans women found that having an unmet need for hormone care was significantly associated with having also experienced an interruption in HIV treatment. Another study found that excellent adherence to hormone therapy was associated with adherence to ART in trans women living with HIV. Similarly, a retrospective chart review study conducted at a Ryan White service provider found that transgender women living with HIV were more likely to be virally suppressed over time if they were receiving gender-affirming hormone therapy than if they were not. It should be noted that all of these studies were specific to transgender women, and there is a need for more research exploring the relationship between gender-affirming hormone therapy and health outcomes for trans men and for nonbinary individuals who desire it.

Despite the limitations, the data clearly show a relationship between hormone therapy and improved outcomes for trans people living with HIV (PLWH). Unfortunately, however, gender-affirming healthcare is often seen by providers as secondary to other healthcare needs, even though prioritizing access to gender-affirming healthcare has the potential to improve both mental health and HIV care outcomes for trans PLWH.

Health systems should integrate HIV and gender-affirming care approaches

Given the importance of gender-affirming hormone therapy in improving mental health outcomes, it's essential for HIV care providers to prioritize gender-affirming hormone therapy as a key part of primary care for trans individuals living with HIV. While entry to HIV care has been highly streamlined in recent years—with interventions like quick start antiretroviral therapy (ART) and seamless clinical, case management, and pharmacy workflows that get patients on medications as soon as possible, resulting in better outcomes—initiation of gender-affirming hormone care often remains highly cumbersome. In some cases, individuals are sent to a separate provider, resulting in the need to coordinate a second set of medical visits and blood draws. This can be particularly challenging for individuals for whom access to care is already a struggle, which can magnify existing inequities in healthcare access.

Further, although many clinical providers have moved to an informed consent model for hormone initiation, some still require mental health referrals or multiple visits to start on hormone care. Unnecessary barriers to initiation of hormone care can lead to mistrust of providers or clinic sites regarding engagement with HIV care.

A community needs assessment of trans people living with

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‘I would caution HIV providers from gatekeeping gender-affirming hormone care or using, say, viral load suppression as a condition of getting hormones. Trans people living with HIV deserve gender-affirming hormone care, full stop.’

HIV found that many trans PLWH consider access to gender-affirming hormone therapy a higher priority than access to antiretroviral therapy. Despite the numerous systems-level factors that influence health disparities for trans individuals (such as discrimination in employment, housing, and healthcare, economic marginalization, and violence, among others), some providers highlight their trans patients’ focus on hormone therapy as a significant barrier to HIV care engagement for this population. This is likely reflective of stigma and other outdated attitudes in which hormone care is seen as being cosmetic or unimportant for mental health and well-being.

Erin Kathleen Swepston, DNP, AAHIVS, a New York City-based provider with extensive experience providing HIV care and trans care, sees it differently. “As a primary care provider and a specialist, I feel lucky when I get to work with a patient who has very clear goals and priorities regarding their health,” she said. “If we can partner with our patients to approach their health goals—in the order of importance set by them—we are better positioned to help patients better manage their health overall.”

Swepston has also personally seen the impact of hormone therapy on mental health and well-being for patients she has worked with. “In every case where I have been able to provide gender-affirming care, there has been a rollover of improvement in at least one other area of that person’s life.” She noted that often the most immediate effect she observes is an improvement in mental health. “There is a weight lifted when they know they have access to care. It may be as simple as relieving the stress of having to find a hormone specialist or the worry of how they are going to be able to continue hormone therapy—but it is noticeable and the impact continues to grow as the therapy continues.”

She noted that in trans PLWH, she has seen improvements in viral load and CD4 labs after receiving hormone therapy, which she attributes in part to decreasing the burden on patients regarding coordinating multiple providers for care. She has also observed increased confidence and agency in some of her patients, which has helped them to become more assertive in other areas, such as negotiating condom use or leaving dangerous situations.

In recent years, there have been some major shifts in recognizing the importance of offering hormone care in the context of HIV care. Last December, HRSA (Health Resources and Services Administration) released a letter to Ryan White HIV service providers encouraging them to offer integrated hormone care to transgender patients living with HIV. A 2016 report from NASTAD (National Alliance of State and Territorial AIDS Directors) found that 16 state ADAPs (AIDS Drug Assistance Programs) include at least one gender-affirming medication on their formulary. And many HIV providers have chosen to provide gender-affirming hormone care, believing it is essential for them to provide this as part of primary care for their trans patients, rather than sending them to another physician for this important element of their medical care.

But stigmatizing attitudes toward gender-affirming care persist. Although 57% of HIV providers in one survey stated that they provide hormone care to their patients, some HIV providers who offer hormone care to their trans patients see this care as an incentive to keep the patients in HIV care, rather than as an important element of primary care on its own. A survey of trans people living with HIV found that 15% had experienced a provider restricting access to hormone therapy based on compliance with ART, and among individuals surveyed who were not currently virally suppressed, the percentage was even higher, at 28%. This reflects that even among providers who offer hormone therapy, there can be a misunderstanding of the role and importance of hormone therapy in the overall care of trans individuals.

Rebecca Green, LMSW, a former HIV program director in New York City, said, “I would caution HIV providers from gatekeeping gender-affirming hormone care or using, say, viral load suppression as a condition of getting hormones. Trans people living with HIV deserve gender-affirming hormone care, full stop.” Green also notes that the integration of gender-affirming hormone care with HIV care can be a team effort: “Train medical providers, nursing staff, and social service members of the care team (care navigators, social workers, etc.) to understand the importance of access to gender-affirming hormone care and have them be equipped to assist with any case management or care navigation issue that might arise.”

There are significant barriers to provider training regarding hormone care. Only 7% of HIV providers in one survey had received formal training in providing gender-affirming hormone care, though many more provided it. Additionally, even if care navigators or other social services staff have been adequately trained regarding transgender identities and cultural competence, further in-depth training may be required to prepare them to help their patients navigate common issues such as obtaining a legal name change, addressing employment or housing discrimination, and obtaining insurance coverage for gender-affirming care.

While ultimately the barriers to health care among trans individuals exist at a variety of systems levels and intersect with other systems of oppression, understanding the importance of gender-affirming hormone therapy for mental health in those who desire it is a key piece of improving HIV care delivery for trans people. HIV care providers must focus on reducing barriers to accessing gender-affirming care, and health systems must invest in creating environments that are appropriate and welcoming for trans individuals—which can include training staff at all levels of the organization as well as investing in electronic medical record systems that allow accurate reporting of gender identity and provide appropriate preventive care recommendations for people with trans bodies.

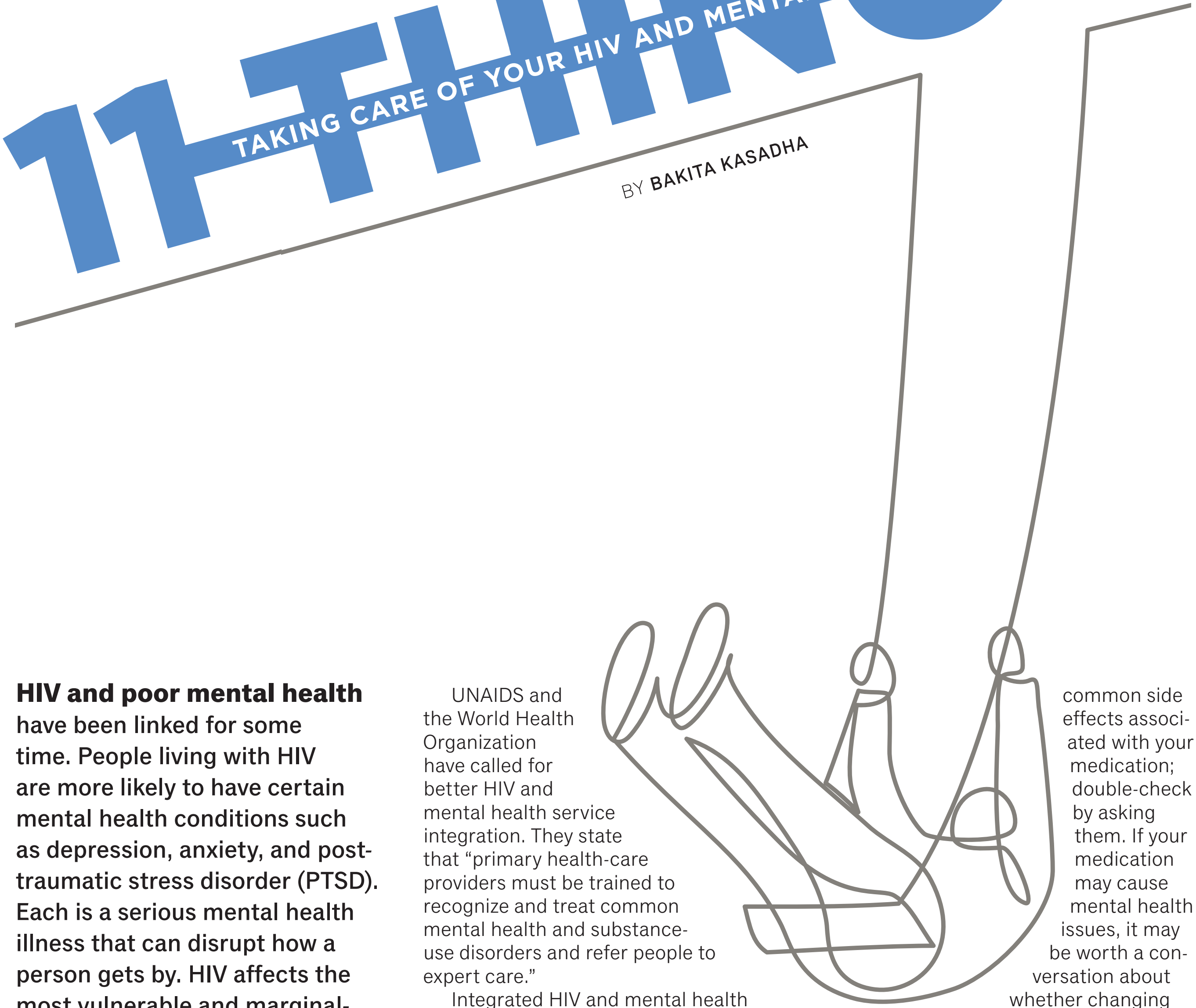
Instead of seeing hormone care as a distraction from HIV care or a tool to coerce patients into HIV care engagement, providers and health systems must recognize the vital role of gender-affirming hormone care for the mental health and well-being of trans individuals, seamlessly integrating this care into HIV care delivery as the important element of primary care that it is.

FINN SCHUBERT, MPH (*he, him*) is a writer, consultant, and former HIV program director living in New York City.

11 THINGS

TAKING CARE OF YOUR HIV AND MENTAL HEALTH

BY **BAKITA KASADHA**



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HIV and poor mental health have been linked for some time. People living with HIV are more likely to have certain mental health conditions such as depression, anxiety, and post-traumatic stress disorder (PTSD). Each is a serious mental health illness that can disrupt how a person gets by. HIV affects the most vulnerable and marginalized in society; these are groups that are also disproportionately affected by mental health issues. Mental health can also be impacted by biological and environmental factors and life events.

Poorer mental health is linked to poorer sexual health outcomes and can increase the likelihood of acquiring HIV. Moreover, poor mental health can impact medication adherence and engagement in services for people already living with HIV. Mental wellness is a major factor in quality of life and key to the well-being of people living with HIV.

Mental health conditions can be managed and treated with the right support and diagnoses.

UNAIDS and the World Health Organization have called for better HIV and mental health service integration. They state that "primary health-care providers must be trained to recognize and treat common mental health and substance-use disorders and refer people to expert care."

Integrated HIV and mental health services are not available to all. Where you live in the world or what part of the country your clinic is based has a considerable impact on the type of HIV and mental health support you receive. It can also impact how much you may have to self-advocate for the right care and support. Here are some top tips to consider for mental wellness while living with HIV.

1. Check the side effects of your HIV medication

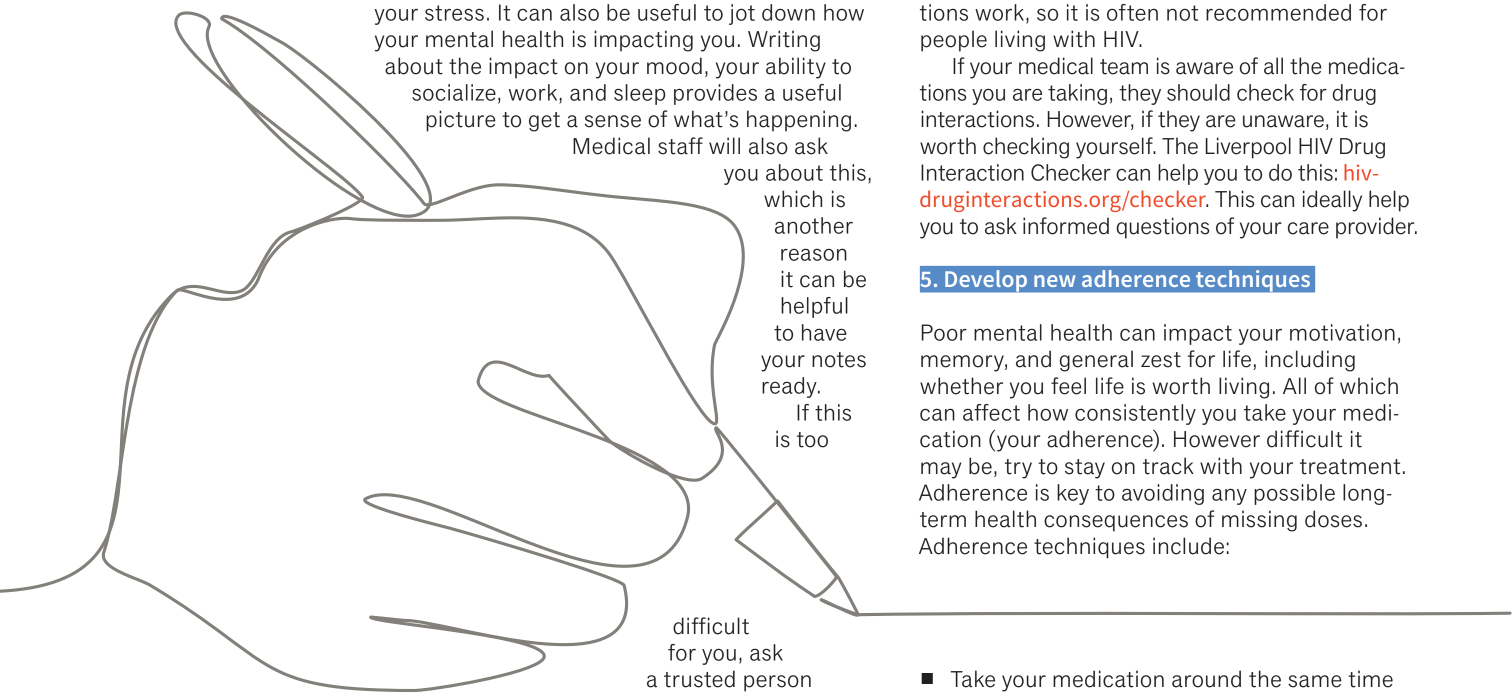
Some antiretroviral therapies (anti-HIV medication) can have side effects affecting mental health, particularly depression. Similarly, some HIV treatments can disrupt sleep and cause fatigue, which can negatively affect mental health.

Before you start treatment, your medical team should tell you about the common side effects associated with your medication; double-check by asking them. If your medication may cause mental health issues, it may be worth a conversation about whether changing them is appropriate.

Editor's note: The most commonly prescribed medications for first-time HIV treatment are associated with rare reports of depression and suicidal ideation, primarily among people with a history of psychiatric illnesses. These are the INSTIs (integrase strand transfer inhibitors) and are found in Biktarvy, Cabenuva, and Dovato, among others. Potential side effects of NNRTIs (non-nucleoside reverse transcriptase inhibitors) include neuropsychiatric events such as depression, sleep disturbances, and dizziness. These medications include Sustiva, found in Atripla, and Pifeltro, found in Delstrigo. See the March + April annual HIV drug guide issue for more information.

2. Note how your mental health affects you

Journaling your feelings can help you manage your stress. It can also be useful to jot down how your mental health is impacting you. Writing about the impact on your mood, your ability to socialize, work, and sleep provides a useful picture to get a sense of what's happening. Medical staff will also ask you about this, which is another reason it can be helpful to have your notes ready. If this is too difficult for you, ask a trusted person to help. They may have noticed changes in you if your mental health has declined and can share their observations of how it's negatively impacting you day to day.



3. Communicate with your medical team

Many mental health conditions can be managed and treated. A core element of your mental health support could be through medical professionals.

Being honest with your HIV team is important. During your appointment, you should be asked about how you are feeling and your general well-being. If you are not asked, bring it up yourself. Having a list of things you wish to talk about can be a simple, helpful way to remember all that you would like to share. By understanding how you're feeling, your care provider may be able to refer you to additional support, such as peer support or more specialized mental health services.

You may choose to seek your own mental health support, independent of your HIV clinic. Depending on where you live, you may or may not be legally required to share your HIV status with others. It can be useful to share all your medical conditions with different medical teams so that they can properly support you. It can help to receive holistic support and avoid drug interactions, for example. If you are receiving mental health support and HIV care in separate places, consider letting your medical teams know and decide if you are comfortable having them communicate with each other.

4. Check for drug interactions

A drug interaction is when one medication affects how another medication works; a drug may not be as effective, or its side effects could be worsened. For example, St John's wort is used by many people as an herbal remedy for depression and anxiety. However, St John's wort can interfere with how well many HIV medications work, so it is often not recommended for people living with HIV.

If your medical team is aware of all the medications you are taking, they should check for drug interactions. However, if they are unaware, it is worth checking yourself. The Liverpool HIV Drug Interaction Checker can help you to do this: hiv-druginteractions.org/checker. This can ideally help you to ask informed questions of your care provider.

5. Develop new adherence techniques

Poor mental health can impact your motivation, memory, and general zest for life, including whether you feel life is worth living. All of which can affect how consistently you take your medication (your adherence). However difficult it may be, try to stay on track with your treatment. Adherence is key to avoiding any possible long-term health consequences of missing doses. Adherence techniques include:

- Take your medication around the same time every day; set a daily alarm.
- Have the medication in a visible place for you to see.
- Ask a trusted person to remind you.
- Carry a medication pill keychain, so that your medication is with you when you're on the go.
- Have a "days of the week" pill container, so you can track whether you've taken your medication that day.
- Take your medication at the same time as a daily activity such as brushing your teeth after a meal.
- Speak to your medical team if you're struggling with adherence.

6. Stay connected

Poor mental health can play tricks with our thoughts, and lead us into taking actions that aren't the best for staying well. Self-isolation is a major detriment to mental health. This may happen for a variety of reasons, including low self-esteem and feeling unmotivated. However, socializing and interacting with other people can be great for improving your mental health.

How you choose to socialize is up to you, but it can include making time to see family and friends, or attending support groups where you can share how you're feeling with people who are going through similar experiences. It may also be helpful to think about connecting with people online or face to face, depending on your preference, comfort level, and what you feel will be best for you.

7. Make a note of any life changes

Different things can impact mental health, including biological factors and life events. For example, menopause is associated with poor mental health, in part due to changes in hormone levels when people enter menopause.

Individuals can experience depression during and after pregnancy (known as prenatal depression and postpartum depression) and anxiety during and after pregnancy (known as prenatal anxiety and postpartum anxiety). Certain contraception can negatively affect your mental health.

An HIV diagnosis can be difficult and even traumatic for some people, triggering or exacerbating mental health conditions. Your transmission route can also impact your mental health. People with a history of substance use and intimate partner violence also have poorer mental health. Also, higher rates of psychotic disorders have been found in young adults who were born with HIV, due to a number of factors, which may include lifelong exposure to the virus and its impact on the neurological system and/or the social stigma of navigating complex issues like disclosure and the onset of sexual desire in adolescence and the fear of disclosing one's status.

If you have been living with HIV for a long time or live where access to HIV treatment is less consistent, then you may have experienced AIDS-related illnesses or loved ones dying. These are all traumas that can gravely impact your mental health.

Trauma-informed care and understanding how different life events might impact your mental health can help manage that. Hopefully, recognizing your experiences will allow you to see yourself as a full human being deserving of support and kindness.

8. Recognize the stressors that are beyond your control

Managing stress is an effective way to improve your mental health. There are different ways to do this.

Recognizing that some stressors are out of your control, however, is also important. Unhealthy and violent relationships, poverty and discrimination all significantly impact a person's mental health, and there are no easy ways to overcome these, but your medical team and local HIV support groups may be able to refer you to additional support.

9. Learn more about HIV

With access to treatment, HIV is a manageable health condition. When a person living with HIV has a viral load that is undetectable as a result of consistent antiretroviral treatment, they are unable to transmit the virus to a sexual partner. This is known as Undetectable equals Untransmittable, or U=U. Being undetectable also means that the possibility of HIV being passed to a baby during pregnancy, childbirth, or breastfeeding is greatly reduced.

However, HIV is still a misunderstood health condition, leading to stigma. HIV stigma is discrimination that impacts people living with HIV (and sometimes their loved ones). It can result in people with HIV being treated badly, and it can also affect how they feel about themselves.

Learning about the realities of HIV and keeping up to date with the latest information can help lessen self-stigma. Joining peer support groups, talking to your HIV medical team, or checking trusted resources (such as aidsmap.com, POSITIVELY AWARE and TheBody.com) can help.

10. Exercise and well-being

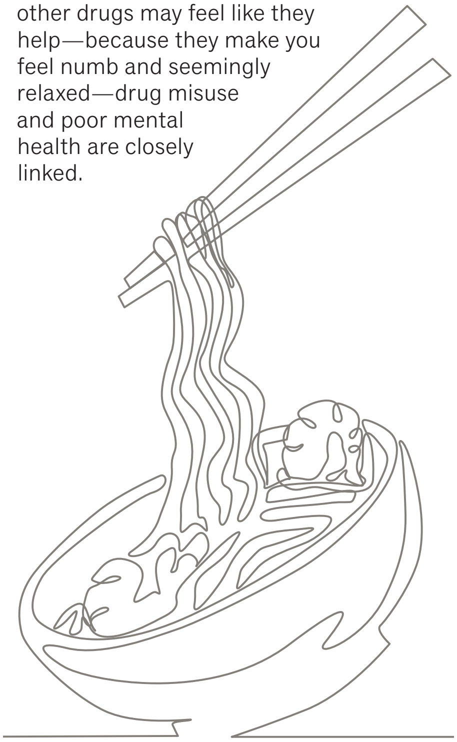
Physical activity is a great way to improve your mental health. If your motivation is low, set bite-sized goals. This may include going for a 10-minute walk each morning or regularly stretching. Having an accountability partner who checks in with you—or better yet, exercises with you (movement and socializing)—is great! Any physical movement positively improves mood.

Editor's note: CJE SeniorLife in Chicago offers a free weekly 30-minute Otago exercise class on Zoom for people who are LBGTQ or living with HIV, as well as their allies. The program started as a collaboration with POSITIVELY AWARE. Join at cje.net/otago or e-mail Andy Rapoport at andy.rapoport@cje.net or call (773) 508-1055.

11. Eat and drink well

Research shows a link between what we eat and how we feel. Missing meals or not drinking enough water can lead to low blood sugar and dehydration—both of which can impact your mood.

Reduce your caffeine intake, especially late in the day (it can affect your sleep quality). Although alcohol and other drugs may feel like they help—because they make you feel numb and seemingly relaxed—drug misuse and poor mental health are closely linked.



Closing thoughts

There are no quick fixes when it comes to taking care of yourself. It's the small consistent acts that have the biggest impact. Mental health "recovery" is complicated. It may be easier to think about what makes you feel "less bad" rather than "better" in the early stages. You may find that some tools are more effective at key points in your life, while others are generally helpful. It's useful to reflect on what works for you and how you feel after doing them.

BAKITA KASADHA is a writer, poet, and health researcher. She's currently a qualitative researcher at the University of Oxford (UK) working on a study exploring infant feeding decisions among new mothers and birthing parents living with HIV.

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