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POSITIVELY AWARE

HIV TREATMENT, PREVENTION AND HEALTH FROM TPAN
SPRING 2021

'My goal in life is to shine a light on individuals like myself to teach them that there's a different way to make it.'

—NADINE RUFF

AGING ON THE FRONTLINES

TRYING MY BEST AT 50 (AND BEYOND)

A 20-plus-year
HIV survivor shares
his six-point plan

WEATHERING MANY STORMS

Examining the physical
effects of discrimination
and other traumas

STAYING WELL BEHIND WALLS

Two pandemics meet
within the broken
prison health system

DAINGEROUS CROSSROADS

The intersections of
addiction, isolation,
COVID-19, and
aging with HIV

FINDING BLACK PLEASURE

One young Black
queer long-term
survivor's journey

SPRING 2021

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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 EDITORS
OLIVIA G. FORD AND GIULI ALVARENGA

Surviving two pandemics

“This pandemic takes me back to when I was diagnosed with HIV. What I went through trying to stay alive—and now all of a sudden COVID-19 comes.”

—**Nadine Ruff**, A 34-YEAR SURVIVOR OF HIV, IN THIS ISSUE

AS WE MOVE further into 2021, we catalogue the innumerable losses of this past year. As these words were being written, the U.S. surpassed 500,000 deaths from COVID-19—another new disease caused by another previously unknown virus, causing another pandemic that starkly reveals this society’s oldest ingrained disparities.

There has rightly been some recent focus in mainstream media on lessons embedded in the HIV response that can now inform a world upended by COVID-19. Particularly for those who witnessed the HIV epidemic unfold— including young long-term survivors who acquired HIV in infancy and have never known life without it—these are lessons wrought by trauma: Taking care of one another when the government abandons your community. Navigating intimacy, identity, and stigma. Learning everything about medications and prevention methods to potentially save your own life. Taking these actions amid a fog of unremitting loss and grief.

In the COVID-19 landscape there are numerous frontlines—spaces where the high impact of the disease and profound disregard for those affected often intersect. These spaces are hidden from popular view not just by the forced isolation of COVID-19, but by systemic bias and neglect by society at large. For example, COVID-19 has rampaged through incarcerated populations. Some social-distancing approaches have rendered people of trans experience more vulnerable to violence. Substance misuse has

skyrocketed in self-isolation. The weathering effects of systemic racism and discrimination pave the way for health conditions like hypertension and other high-risk underlying conditions when paired with COVID-19. And our health care and social service systems still have yet to come up with innovative, creative, widely accessible programs to holistically support people aging with HIV.

In all these spaces we find long-term HIV survivors and older adults with HIV, enduring trauma and bringing hard-won resilience to bear in response to this new threat. While research shows that treated HIV by itself does not appear to equal heightened COVID-19 vulnerability, it is rare to find a person aging with HIV who is not also managing co-existing conditions, social determinants of health, systemic bias, or a combination of these. Part of our charge in the following pages is to bring some of those frontlines into clearer view.

This special issue is an offering from two aspiring allies/accomplices to long-term survivors and older adults living with HIV—a Black queer woman whose adult life has been shaped in connection with people surviving HIV over the long term, and a young person living with HIV who credits our community’s elders with having the privilege to think 20 years down the line to his 50th birthday. We are thankful to the visionary editors, writers, visual storytellers, and truth-tellers whose skills and insights made this project possible. We hope this collection contributes to ongoing conversations around how our people survive, thrive, and fight.

Yours with gratitude,

Giuli Alvarenga (*he or they*) is an award-winning writer who spends much of his time at the border in Tijuana working with asylum-seekers. This fall they are starting a graduate program in anthropology while finalizing their legal studies.

Olivia G. Ford (*she or they*) has worked in HIV-related media since 2007. She is a freelance editor/writer and editorial director for The Well Project, an online information and support resource serving a global audience of cis and trans women living with and affected by HIV.

In the COVID-19 landscape there are numerous frontlines—spaces where the high impact of the disease and profound disregard for those affected often intersect.



Support for the journey

Three women's unique perspectives on long-term HIV survival

BY DAVID EVANS

WASHINGTON, D.C.

Planning home-grown solutions for long-term care

Vanessa Johnson, 63

“DO YOU KNOW how different my life would be if they hadn't told me I'd [die young]?” Vanessa Johnson said, speaking of her and countless others' lack of a plan or resources for eldercare.

Johnson's adolescent fantasies for a life of adventure and a comfortable older age were shattered in 1990 when she learned she had acquired HIV. Though relieved that she hadn't passed on the virus to her son, then a toddler, she was traumatized by the news she'd be lucky to survive more than a few years.

Fortunately, effective combination antiretroviral therapy arrived in time to give her decades of life she'd assumed were forgone. Now 63, Johnson is once again contemplating infirmity and death. But this time, it's not HIV-related sickness that fuels her anxiety. Instead, she worries about a future like that of her mother who, at 84, is disabled by garden-variety age-related health complaints—and Johnson wonders who will take care of her.

“When you're coming into your life, somebody's got to take care of you,” she said, “and then when you're leaving, somebody's got to take care of you, too.” Johnson says the need for care doesn't frighten her. What does is being dependent on people who don't do it properly, which she believes

demands patience and kindness. She points to the reverence for the elderly found in some traditional Asian cultures as a model.

She intends to take her son, now 36, to therapy to work out how they'd both feel about her care needs and whether he's up to the challenge, and she strongly encourages others with HIV to do likewise. She's clear that it'll be okay if he doesn't think he can do it, but she wants him to work with her on a backup plan.

That plan could very well be a home-grown commune of sorts: a large house where she and a group of other Black women with HIV with whom she shares a special bond could live with and care for one another. Alongside the shared experience of HIV, she feels the supportive sisterhood between Black women—who often take on the exhausting role of protector in their communities—to be incredibly precious.

“We fuss, and we fight,” she said, “but we get energy from each other, and when you're around your own people, you don't have to explain anything.”

Making this dream a reality is not without challenges, however. Johnson, who holds a law degree and is a co-founder of Ribbon Consulting Group, is intimately familiar with the brand of bureaucracy that can stifle innovative non-traditional projects before they begin.

“It gets to a point,” she said,

“where you've got to say, *We don't need another study to tell me what I already know I need.*”

Johnson is particularly uneasy about projects that funnel resources toward medical and social services at the expense of existing social networks. For example, how helpful will it be to provide safe housing for someone if it's located so far away from friends, family, and community that it leaves them socially isolated?

She worries particularly for African Americans, whose communities and families have been forced to endure nearly continuous disruptions—beginning centuries ago with the forced passage from Africa to the Americas, to slavery, Jim Crow, and racist social and legal policies that still limit Black lives.

“When I was growing up, if Big Momma decided she was going to tell your momma about you acting up, you knew you had a problem,” said Johnson. For her, that's love—a sign that a community is so tightly bound that its members feel responsible for each other's wellbeing. She admits she does the same now with kids on her own block, and when her son gets embarrassed and tells her, “Mom, you can't do that,” she just smiles, knowing she's contributing to a culture devoted to survival.

Focusing on living—and nurturing a new generation

Lynnea Lawson, 35

LIKE MANY WHO acquired HIV at birth, Lynnea Lawson belongs to a group who contracted the virus in the 1980s and 1990s yet survived into adulthood. These young people, now in their 20s and 30s, share many of the physical, mental, and emotional challenges we see in other long-term survivors who are now in their 50s, 60s, and 70s. That's requiring our community to rethink what it means to "age" with HIV.

For Lawson, it's the psychological and emotional scars she carries, more than the physical consequences of having the virus, that have demanded the most attention. Still, she's also learned that healing can come from the

cool, letting him fall asleep before opening his phone and seeing a message from another woman.

Lawson looks back on the momentous decision to call the woman—whose name is Marneta, and whom she now counts as her best friend—as a radical turning point in life. "The last thing she told me before we got off the phone was to delete her number from his phone and add it to mine," Lawson remarked.

The next day, openly weeping while walking down the street, something inside compelled her to give the woman another call and tell her she'd taken her advice and dumped the boyfriend. Lawson recalls that Marneta—still practically a stranger at the time—dropped everything to come and comfort her.

The experience, said Lawson, taught her that "families, by blood or by choice, come into our lives by accident"—and that you've got to be ready to take the risk of opening yourself up to receive the grace they can bring.

At the outset of their friendship, Lawson, who has struggled with post-traumatic stress disorder (PTSD), depression, and

anxiety since childhood, said her spirit remained buried beneath stigma and fear over her HIV status, questioning her future, and certain she'd never have a child, which she'd always wanted.

"It's that stigma that we put on ourselves that's way worse than the stigma we get from out in the world," she said. "If you're already telling yourself how awful you are, you only need to hear a little bit more from outside yourself for it to be too much."

When Marneta became pregnant, she asked Lawson what her own plans around motherhood

were. Lawson said she told her, "I don't think I can ever have a child because I'm HIV positive." Her friend didn't hesitate to reply, "You can have mine. We'll share him." She asked Lawson to be her son's godmother.

"I thought, if I'm going to be someone's godmom, I've got to lead by example," said Lawson. "I've got to stop focusing on dying and instead focus on living, because I've got this little boy coming who I'm going to be partially responsible for."

Within a couple of years, Lawson decided to have a child of her own, knowing that HIV medications for mother and child can reduce the risk of HIV transmission during birth to less than one percent. Her daughter, Nae'lyn, was born without HIV in 2014 (see "Born Free", POSITIVELY AWARE January+February 2020).

Despite decades of survival, having a beautiful daughter, being a loving mother and best friend, and making progress toward a college degree in psychology, Lawson continues to be haunted by depression, anxiety, and PTSD. The dearth of effective and affordable mental health care has left her lacking some of the support she'd like to have.

Nevertheless, she says, her life is so much bigger and better than she imagined when she kept her HIV status a secret. She now thinks nothing of telling work colleagues, and doesn't hesitate to bring up her status when dating.

"I just met some guy on Facebook Dating, and I was like, *Oh yeah, I'm HIV positive, and if you have a problem with that, let me know now so we can get past it,*" she said. The guy told her it was no big deal, that he was definitely interested.

She laughs when recounting the chat. "Just being open and accepting people into your life, whoever they are and wherever they are," she said, "that's medicine. It's better than any pill."

'It's that stigma that we put on ourselves that's way worse than the stigma we get from out in the world.'

—LYNNEA LAWSON



most unlikely people and places.

Like many long-term HIV survivors, regardless of age, Lawson had carried the belief that you've got to settle for whatever you can get because anything good (including life itself) can be taken away at a moment's notice. A late-night call she placed roughly nine years ago to "the other woman" of her then-boyfriend was her unanticipated catalyst for healing. She had come home after a long day at work to find the boyfriend on the couch, pointedly ignoring his phone which was buzzing nonstop with text messages. She played it

Finding intimacy, trust, and community

Billie Collins, 53

BILLIE COLLINS IS GRATEFUL this past year to have been surrounded by the diverse community of people living with HIV who make up the neighbors in her supportive housing complex. Although restrictions due to the coronavirus nixed all large gatherings, she and her neighbors got the better of social isolation by spending time outdoors, binge-watching movies over popcorn only with close friends, and checking in on each other more often.

Collins says her current life—and the fact that she enjoys it—is a surprising departure from the future she'd imagined before her fiancé's HIV diagnosis led her to be tested in 1996 at age 24. At the time, she said, she essentially shut down. "I cleaned up after myself and kept to myself, but I was scared and afraid," she recalled.

Despite the desire for companionship, and the significant stigma around HIV, her fiancé had shattered her trust about men living with the virus, and she went on to fall in love with and marry a man who was not living with HIV.

"He did genuinely love me," she mused, "but he could never get over the hurdle of everything to do with my status."

Her husband's concerns about transmission led them to lead a "non-intimate life." When Collins ultimately began volunteering at HIV organizations and being more open about her status, things grew worse.

She'd met a bright, young, and passionate health educator who taught and encouraged her to be more proactive about her health and the rest of her life.

"I was volunteering for a lot of different agencies, and I was

becoming more and more public, and I lost my marriage in the process," she said.

Collins came to know and befriend other cisgender women living with HIV, as well as gay men and transgender women. Without realizing it, her beliefs about what might constitute an emotionally safe romantic partner had grown to include men living with HIV.

Although she says she shares the longing that many of her neighbors in the housing complex have for romantic companionship, she's alert to the tendency she sees in herself and others to compromise too much for partnership.

"Sometimes we settle for a little less than perfect not to be alone, or we get up in age, and the medical issues start to happen," she said. "You don't want to be there alone and having to brave your way through it by yourself."

Over the past two years, Collins has been confronted with her biggest health challenge since testing positive. She said if you'd asked her back in 2018, she'd have told you she never even got a cold or a headache. Then she was diagnosed with pancreatic cancer. She said she tries not to let it get her down, reflecting that "everybody has to take their turn," but it has affected how she sees the future.

On the plus side, she's currently dating a man who has also been living with HIV for decades. There's an emotional intimacy that comes with that, she said—and she might not have opened



'Sometimes we settle for a little less than perfect not to be alone, or we get up in age, and the medical issues start to happen.'

—BILLIE COLLINS

herself up to the friends she's gained had she not been ill.

Her brush with a type of cancer that is so highly fatal has left her all too aware that nothing is forever. She's glad to have someone with whom she can disclose more—someone who, she said, "can walk down that path with me." **PA**



DAVID EVANS is a longtime HIV science advocate and educator. His written work for the HIV community has appeared in POSITIVELY AWARE, AIDSmeds, POZ, and TheBody.com. His scientific work on HIV cure has appeared in top medical journals.

Layers of resilience

Two transgender activists of color share how they support their communities—and themselves

BY ALEXANDRA RODRÍGUEZ DE RUÍZ



NADINE RUFF TAKES A BREAK AT HOME FROM HER ADVOCACY WORK.

'My goal in life is to shine a light on individuals like myself to teach them that there's a different way to make it.'

—NADINE RUFF

In the early 1980s, I was living in Los Angeles when I began to hear rumors within LGBT communities about an illness. The media and the health care system were calling it an unknown “gay cancer” that was afflicting mostly white males. We didn’t know much about it in the transgender Latinx immigrant community. As a transgender teen, I didn’t see this as relevant to me.

A few years later, some of my transgender friends started to become ill and quickly died from the new virus, just recently christened as HIV. I began to pay attention. It didn’t matter if they were sex workers or substance abusers or not—this virus was spreading regardless of gender identity, race, social status, or sexual orientation.

Thanks in part to the fictional

television series *Pose*, younger generations can now get a sense of what our communities went through during the HIV pandemic at the moment it all began. Things haven’t changed much in almost 40 years. Transgender people are still at high risk of acquiring HIV; systemic violence, discrimination, substance abuse, homelessness, and incarceration make us even

more vulnerable. Now, the same is happening with the coronavirus pandemic. Many people are dying of COVID-19 and, once again, transgender communities are severely affected as we continue to fight for our place in a cis-heteronormative society.

In Mexico City, where I have lived for the past nine years, this new pandemic has given visibility to the great inequality that trans-identified individuals face in a society and a system that see us as disposable. For example, as COVID-19 began, the hotels where trans sex workers work and reside were closed down, leaving this group, which includes trans migrants and trans mature women, in the streets with nowhere to stay. Thanks to local

and international organizations along with local activists, we were able to support our sisters who were suddenly put in an extremely precarious situation through no fault of their own.

Like me, there are other trans women who lived through the early HIV pandemic and now are fighting to stay alive during COVID-19. I recently spoke with two longtime trans activists living and aging with HIV who model that struggle to protect and uplift their own lives while advocating for human rights, justice, and wellbeing in their communities. Their testimonies bring to light the realities of living and aging with HIV that we may not see in any television series.

KENYA CUEVAS is an award-winning human rights advocate from Mexico City. She founded several programs and organizations helping transgender women in vulnerable situations—including Casa Hogar Paola Buenrostro, a shelter for trans women experiencing homelessness. The shelter is named for one of Cuevas' friends, a young trans woman whose murder she witnessed.

NADINE RUFF coordinates the Aging Positively program at A Place to Nourish Your Health (formerly AIDS Project New Haven) and is a mother and grandmother based in New Haven, Connecticut.

What can you share with us about yourself?

KENYA CUEVAS I like to share that I am a survivor, a tenacious woman, a very brave woman with many values. Even through the pain that I had to go through as I witnessed one of my trans sisters being murdered, I learned how to transform this pain into something positive to help benefit other trans women and other people with my story.

NADINE RUFF I'm a Black woman with a transgender experience;

I'm HIV positive—I've been living with this virus for over 33 years—and I'm an LGBT activist since 2004. I'm a founder of a transgender support group and I'm also a community organizer and a student. I graduated with a bachelor's degree in social work, and continued my education to get my master's degree. I work as a program coordinator for an organization that works with people living with HIV who are 50 years old and over.

You are a trans woman, an activist, living and aging with HIV. What does this intersectionality look like in your daily life?

KC I'm also a woman who spent time in prison and dealt with substance abuse for 20 years. I'm aware that not everyone can come out of these situations of vulnerability. Truly, these situations are what made me a humble person with a different vision in life: to protect and care for others.

My life experiences helped me to have a different perspective regarding institutions, and educate them to better serve my communities. I believe that my pain and my vulnerability kept me focused to be able to help other trans women and to give them hope. >>



KENYA CUEVAS IN ACTION ADVOCATING AND PROTESTING IN MEXICO CITY FOR HUMAN RIGHTS.

'I believe that my pain and my vulnerability kept me focused to be able to help other trans women and to give them hope.'
—KENYA CUEVAS

To have lived through these experiences has given me a resilience to generate seeds of hope without making me feel I'm better than others. My intersectionality has helped me to have tenacity, to build humility around me, and also to be strategic on how to better serve these disadvantaged communities.

NR I've done sex work, I've been in prison, I've been homeless. All these experiences I lived through are what motivate me to try to save another individual from going through what I went through.

I try to break these identities down little by little. If I was to think about all the things I have to face every day in society, I'd probably give up. I have come to terms with the fact that I do not live with HIV; HIV lives with *me*. I'm more than HIV—I'm a sister, I'm a parent, I'm a student.

I don't look at the things that I go through in society; I look up at how these experiences are going to help me to save the next transgender person coming behind me.

As a long-term HIV survivor, what are your thoughts on living and aging with HIV?

KC It's not the same, to be a young person diagnosed with HIV, and now being an older person living with this virus. I have been living with HIV for 34 years and I'm one of the survivors from my generation. I'm glad I can talk about it, and tell you that I'm undetectable.

I can remember that, ever since I've been living with HIV, I have never felt like I was living with something different or strange. I have seen more than two hundred people die from this virus—so, I feel very privileged and blessed to be a mature woman that lives with HIV.

NR As I'm aging I try to center myself on some positive aspects. I try to take care of myself and take my medications. I look at other people who live with other chronic illnesses, not necessarily HIV, and I try not to let that deter me or make me feel negative about what I'm doing. HIV is a part of who I am. As I'm aging and living with HIV, I know I have to stay tuned in with my doctors and my medications, because I know my body better than anybody else.

As we know, now we are going through the COVID-19 pandemic. How do you envision the future for transgender women who are living and aging with HIV?

KC We still have a lot to fight for—our human rights, for example, to be accepted in this heteronormative society. The future for us trans people living and aging with HIV is desolate. I see the government's posture of total abandonment—and not only for us trans people, but for communities in vulnerable situations. We trans people have no recognition, nor the same rights, and we're still being limited in society because of our gender expression.

I see this new pandemic being used as a political and economic strategy by governments to control us. Unfortunately, we transgender people living and aging with HIV are the most vulnerable and forgotten community. We must continue fighting and not let our guard down.

NR I have to admit that right now is a scary time for those of us who are aging—especially for us transgender people living with HIV. We are dealing with loss because of COVID-19; we've seen friends and family die this past year.

This pandemic takes me back to when I was diagnosed with HIV. What I went through trying to stay alive—and now all of a sudden COVID-19 comes. I just hope we can survive this new pandemic.

Now they are telling us there's a vaccine for COVID-19—and we have had HIV for almost 40 years and there's no [effective] vaccine? That doesn't sound right. They might be just testing with us to see if it works. It's like when AZT came out: I took it and it made me very sick; I had to stop taking it. It killed many who were trying to survive AIDS. It might be the same thing with COVID-19; our lives are at risk once again. **[EDITOR'S NOTE: Vaccine skepticism and medical mistrust have valid, understandable origins, as**

Ms. Ruff's comment makes clear. Still, it is important to note that studies, some of which included people living with HIV, have shown COVID-19 vaccines to be safe and effective in over 40,000 people studied. Further, while HIV and the new coronavirus are very different viruses, some researchers are hopeful that new processes that led to a COVID-19 vaccine in record time will have a beneficial impact on HIV vaccine development as well.]

What message would you like to send out to new generations—to our transgender youth?

KC To love each other. Love transforms and changes people. With love there can be empathy and solutions. There can be harmony.

We know that within our trans communities, violence is rampant. Therefore, with love, forgiveness, understanding, and solidarity, the new trans generations will be better. We must educate them and show them how to believe in these values. Our greatest justice [in the face of violent systems] will be for us transgender people to be happy.

NR I understand that people don't see us as a significant part of society. In other words, we have to do the work that no one else wants to do, for example, we have to rely on sex work to survive.

My goal in life is to shine a light on individuals like myself to teach them that there's a different way to make it. I'm not putting sex work down, but there are other opportunities we must consider—and take them. Sex work is not going to give us security. That's one of the reasons I put myself through school—I wanted to do things differently.

I want the new generations to know that education is the way to go—education opens doors for you. There are more opportunities for you as an individual, and for you to do something positive for your community. **PA**



ALEXANDRA RODRÍGUEZ DE RUÍZ is an author, activist, scholar, and co-founder of the support organization El/La Para TransLatinas in San Francisco.



Weathering many storms

A clinical psychologist examines the physical effects of discrimination and other traumas

BY SANNISHA K. DALE, PHD

Systemic oppression and mental health struggles faced by people living with HIV throughout the course of their lives may accelerate the aging process and continue to have a negative impact on their physical health and wellbeing as they age. In the context of COVID-19, these issues are further exacerbated by the loss of loved ones, financial resources, housing stability, and access to in-person social support systems. Nonetheless, out of the sheer need to survive and in the absence of vital structural changes, people living with HIV continue to lean into resilience resources at the individual, interpersonal, and community levels.



oppression:
prolonged
cruel or unjust
treatment
or control

SOURCE:
OXFORD
LANGUAGES

Discrimination, mental health, and engagement in care

THE VAST MAJORITY of individuals living with HIV in the U.S. are Black, Latino, and LGBTQ. For example, among 1.2 million people living with HIV in the U.S., 40% are Black, 22.8% are Latino, and 61.7% are gay and bisexual men. Further, 14% of transgender women in the U.S. are estimated to be living with HIV, the vast majority of them Black or Latina. The primary driver for this disproportionate effect of HIV on marginalized communities

is oppression. These communities face racism, homophobia, transphobia, poverty, and significant barriers to culturally competent, humanizing, and linguistically accessible medical care.

For instance, my research team found that among Black women living with HIV in the U.S., 51% experienced racial discrimination, 36% experienced HIV-related discrimination, and 94% experienced gendered racial microaggressions. These intersecting forms of oppression place individuals at risk both for contracting HIV and for negative mental and physical outcomes while living with HIV. Once diagnosed with HIV, many are then subjected to HIV-related discrimination and stigma.

People living with HIV experience higher rates of mental health struggles compared with individuals without HIV. For instance, up to 42% of people with HIV have struggled with depression compared to 7.1% of people without HIV. Researchers have also found that 30% of women living with HIV had recent post-traumatic stress disorder (PTSD), which is over five times the rate of PTSD in a national sample of women. These higher rates of mental health struggles may in part be due to the trauma of initially being diagnosed with HIV and the stress of adjusting to managing a chronic health condition (for example, taking medication and attending appointments). However, similar levels of mental health symptoms and trauma exposure in a cohort of women living with HIV and women without HIV (matched on variables such as substance use, unstable housing, and transactional sex) suggest that mental health symptoms are also driven by structural and systemic issues.

Oppression experienced by people living with HIV at the nexus of intersecting identities may cause or further exacerbate mental health symptoms. Researchers have found that explicit or “macro” acts of discrimination (for example, being denied housing or a job, refused services, or called a stigmatizing word) based on race, HIV status, or sexual orientation are linked to symptoms of depression and PTSD among Black women and Black gay and bisexual men living with HIV. Further, daily microaggressions based on race and gender, despite their subtle nature, impact depression and

PTSD symptoms beyond the effect of macro discrimination experiences. Similarly, discrimination based on transgender or nonbinary identities has been associated with depression and anxiety symptoms.

Both oppressive experiences and mental symptoms may negatively impact appointment attendance (engagement in care), adherence to HIV medication, HIV viral load, and immune function (for example, CD4 count). For instance, among Black women living with HIV, my team found that microaggressions (based on gender and race) and discrimination (based on HIV status, race, and gender) are related to barriers to engagement in HIV care and HIV medication adherence. Similarly, colleagues have found among Black and Latino gay and bisexual men living with HIV that discrimination based on race, HIV status, or sexual orientation are related to lower medication adherence and engagement in care. Other work by colleagues found that among Black women living with HIV, experiences of race and gender discrimination were associated with lower CD4 count and higher HIV viral load moderated by coping (for example, critical consciousness/awareness of systemic discrimination). Likewise, studies among Black gay and bisexual men have noted that discrimination based on race, HIV status, and sexual orientation are associated with higher viral load.

Oppression, physical health, and aging

THE PATH BY WHICH oppression affects the immune function and viral load of people living with HIV is likely both behavioral and biological. Being subjected to negative comments, behaviors, and policies simply for being themselves (for example, living with HIV; LGBTQ; Black, indigenous, people of color—BIPOC) naturally may result in behaviors that may not be optimal for one’s health. For instance, one might avoid a follow-up medical appointment with a provider who made a stigmatizing comment at the last visit. Similarly, if one experiences an act of discrimination that throws off their mood for the day, they may forget to take their medication. At times looking at one’s pill bottle

may be a reminder of HIV stigma, and thereby affect adherence. Further, experiencing an episode of depression, PTSD following a recent trauma, or another mental health diagnosis may decrease one’s ability to engage in self-care activities such as taking medication or going to appointments.

Beyond the impact of oppression on behaviors, oppression directly impacts the bodies of people living with HIV. Chronic stressful experiences such as discrimination and stigma can result in elevated levels of negative hormones (for example, cortisol and norepinephrine) and inflammation, which in turn places individuals at risk for developing various health issues. For instance, research has shown that discrimination can lead to hypertension, heart disease, and early mortality. Further, the inflammation caused by oppression can place one at risk for mental health diagnoses discussed above, and mental health diagnoses place one at risk for chronic illnesses such as heart disease.

Researchers have also specifically linked experiences of discrimination to markers of aging. For instance, a study by psychology professor Sierra Carter, PhD, and colleagues found that among African Americans, experiences of racial discrimination between ages 10 and 15 was related to depression at ages 20–29, and the depression was related to accelerated aging at the cellular level. Past and ongoing oppression causes wear and tear on the body and, by doing so, may accelerate the aging process for people living with HIV who experience discrimination based on multiple marginalized identities.

The COVID-19 crisis has further compounded the level of stressors, trauma, and mental health struggles people living with HIV may experience. To date, over 500,000 individuals in the U.S. have died from COVID-19, with a disproportionate burden on BIPOC communities (much like with HIV) and people age 55 and older. COVID-19 has also increased the unemployment rate and resulted in many people struggling to afford food or stable housing. In addition, social distancing measures to reduce the spread of COVID-19 have increased isolation and limited physical contact with friends and



micro-aggression:
a statement, action, or incident regarded as indirect, subtle, or unintentional discrimination against a member of a marginalized group
SOURCE:
OXFORD
LANGUAGES

loved ones. These cumulative losses of people, resources, and support place further strain on the mental and physical well-being of people living with HIV, whose pre-COVID reality was already impacted by oppression and mental health struggles that weathered their bodies.



Individual coping and systemic solutions

SOLUTIONS TO AMELIORATE the oppression, mental health issues, and physical weathering faced by people living with HIV must be led by rigorous policy and structural changes that center those most affected by stigma, discrimination, and other forms of trauma. Historically, people living with HIV have created and accessed resilience resources within themselves, their social support systems, and the greater community to manage these conditions. People living with HIV may utilize coping strategies including, but not limited to:

- listening to music
- watching movies

weathering: describes the biological effects of repeated experience with often unseen factors, such as racial and gender oppression or material hardship, which result in earlier health deterioration

SOURCES:
JOURNAL OF
PUBLIC HEALTH;
EVERYDAY
HEALTH

- preparing a favorite meal
- going for a walk
- reading
- doing arts/crafts (for example, coloring, drawing, knitting)
- getting adequate rest/sleep
- helping others
- leaning into their spiritual practices and/or praying to a higher power
- setting boundaries with others to limit negativity
- engaging in activism to bring about change

Each person may prefer different coping strategies, and that is normal. The important thing is to do positive things that bring comfort and peace of mind. People living with HIV may also seek helpful support from peers,

friends, or family members in the form of phone or video calls, text messages, and limited in-person contact (with COVID-19 prevention measures such as mask wearing). Numerous organizations also exist whose mission is to provide essential services, resources, and support—some to people living with HIV in general, others specifically for Black, Latino, and LGBTQ communities. Lastly, support may also be beneficial from mental health providers, case managers, and medical providers who prioritize the healing of their clients, and do so with a compassionate and non-judgmental approach informed by an awareness of the complex challenges faced by people living with HIV. **PA**



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BY 2030, UP TO 70% OF PEOPLE LIVING WITH HIV WILL BE OVER AGE 50.

Gilead's HIV Age Positively Initiative

Anyone who experienced the early days of the HIV/AIDS epidemic remembers the generation we lost, and the enduring impact it has had on our community.

Since then, we've made tremendous progress. This is the first time in American history that more than 50% of people living with HIV are over the age of 50, according to the CDC. Their stories are an inspiring and powerful reminder of the heroic efforts that have made this possible.

It's expected that by 2030, 70% of people living with HIV will be over the age of 50.

More critical work remains to be done. Aging with HIV presents new, different challenges for people affected by this epidemic and for the healthcare system as a whole. By 2030, more than 80 percent of people living with HIV will have at least one age-related medical condition, such as cancer or heart disease—an underexamined,

underappreciated and underfunded public health issue demanding urgent attention.

This led Gilead to invest in action. **Gilead's HIV Age Positively initiative aims to support programs focused on improving the quality of life and health for people growing older with HIV.** Read more about what Gilead learned: bit.ly/gilead-what-we-learned.

In November 2018 Gilead awarded more than \$17.6 million in grants to support 30 organizations—from healthcare organizations to advocacy groups working to address the interrelated challenges within the healthcare system and the general HIV community—addressing stigma, loneliness and better coordination of care. Grantee organizations are working to improve care coordination, increase resources for a greater wellbeing, expand education and inform policy. **Learn more about the work of Gilead's 30 grantee organizations:** bit.ly/gilead-30-grantee-organizations.

Dangerous crossroads

A therapist and long-term survivor surveys the intersections of addiction, isolation, COVID-19, and aging with HIV

BY DAVID FAWCETT, PHD, LCSW



Since the onset of the COVID-19 pandemic, some people aging with HIV have encountered challenging, harsh, and even dangerous medical, social, and emotional challenges. Especially among individuals who also misuse substances, the toll has been overwhelming, with rates of drug use, overdoses, and fatalities reaching new heights.

Drug and alcohol users find themselves at increased medical risk for the novel coronavirus. For example, those who vape or smoke tobacco or marijuana heighten their vulnerability to the effects of COVID-19. Those with opioid or methamphetamine use disorder are overrepresented among aging persons living with HIV, and are at heightened risk for respiratory and pulmonary complications because of their drug use. Methamphetamine, in particular, constricts blood vessels, causing pulmonary damage and (potentially) pulmonary hypertension, which can impact the severity of COVID-19.

At a practical level, the very real and warranted fear of going out has disrupted ongoing and essential treatment and care. A person

aging with HIV may defer medical appointments due to concern about exposure at the doctor's office. This, in turn, may lead to an interruption in care or medication refills. Efforts to increase the application of telemedicine have been impressive, but many aging persons, especially those with limited incomes, may lack the comfort or proficiency to easily maneuver such technology, even despite having a computer or smartphone and broadband service.

The social impact of this confluence of HIV, addiction, and aging in the midst of COVID-19 is equally consequential. Risk for homelessness and incarceration increase, and there may be decreased access to health care for several reasons. As hospitals fill to capacity, persons needing care for an addictive disorder, already stigmatized and

underserved, may find even more barriers to care. Longstanding patterns of inequitable access to health care and housing have spiraled into a crisis. As the economy continues to falter, conditions worsen for those already marginalized who experience greater food insecurity, unstable housing, and inadequate funds to cover expenses. They are the first to fall through the tattered social safety net.

While there has long been a growing epidemic of loneliness, perhaps the most deleterious impact of life during COVID-19 is the catastrophic increase in isolation which has especially impacted persons living with HIV, including those who are aging or suffering addiction. The mandate for social isolation has exacerbated an unfortunate situation and resulted in worsening conditions that have negatively impacted everything from income to food and medical supply access.

When substance use is added to this complex scenario it becomes even more dire. Since the first lockdowns began, alcohol sales have nearly doubled and the reported use of other drugs has increased as well. The pandemic, along with restrictions of social movement, has

disrupted illicit drug supply chains. Unable to get their drug of choice, many users take anything to numb themselves from emotional pain. Scrambling to obtain drugs from any source has raised the risk of exposure to adulteration (mixing or cutting) with fentanyl and increased overdose deaths. Sadly, among treatment professionals it is commonly assumed that a significant number of overdose deaths are in fact suicides.

Supports for recovery such as 12-step meetings have rapidly moved online and have been vital in saving lives. Social connection is a widely recognized element of addiction recovery, yet these online meetings can't match the benefits of real-time gatherings. Some individuals may struggle with the technology and, even for those who are able to attend without issue, simply getting a hug, having an informal chat with someone, or enjoying the fellowship following a meeting is sorely lacking. One upside of the online meetings is the new ability to regularly attend recovery groups around the world. While global online recovery acquaintances are appealing, they can't provide the level of real-time interaction and support required when someone is struggling or near a relapse.

Isolation has been recognized as a potential *source* of mental health concerns such as depression and anxiety, as well as a *consequence* of them. Aging persons living with HIV are at higher risk for such mental health problems, which have been even further aggravated by months of social isolation. Support networks and the protective power of robust social connections have begun to fray. Month after month of living apart has resulted in further withdrawal from society, medical care, and vital support.

Isolation has also resulted in expanding the divide between certain population groups and the society at large. For instance, aging persons living with HIV are already marginalized; meanwhile, younger people may perceive themselves to be at lower risk for COVID-19, and many appear to have just moved on with their lives. Facebook and Instagram are filled with images of maskless people celebrating birthdays or gathering at bars. This can cause aging persons and others who need to isolate for survival to feel even more lonely and devalued. The unstated policies that appear to sacrifice the aging population for the dubious goal of "herd immunity,"

at least prior to the release of vaccines, give rise to a disturbing echo of selective discrimination toward a group or groups of people for those of us who survived the early years of HIV in the 1980s and '90s.

Despite the promise of vaccines, we have months ahead of us that will largely resemble the past year. It is up to each of us to do what we can, both for ourselves and for others. Here are some actions we can take:

Prioritize self-care: Our normal lives have been transformed. The disruption of routines such as the closing of hair salons, churches, and gyms has thrown everyone off balance, requiring a recommitment to self-care. Whether protecting our physical health with adequate nutrition, sleep, exercise, and proactive management of any health conditions, our emotional wellbeing by giving or receiving social support and getting professional care when we need it, or spiritual support to help us grieve and find meaning in all that has happened, taking the best possible care of ourselves must remain a top priority.

Embrace technological alternatives: More than once I have heard people marvel that just a few years ago we would have had a much more difficult time functioning remotely to the extent that is common today. Video conferencing has enabled everything from online support groups to teletherapy and even Zoom dinner parties. But the digital divide creates a rift between those with adequate resources and those without, including those whose jobs can be managed from home versus those who need to put themselves at risk by going out to work.

To the greatest extent possible, it is important to prioritize connection in each domain of our lives and apply any tech solutions that are available. We all recognize that sharing screen time is not an ideal solution, but it is far better than no contact at all. Thankfully, today one can turn to YouTube tutorials to learn how to use these new technologies to best stay connected.

Practice kindness: Our world is filled with people on edge. Months of disruptions, fear, sickness, death, and economic and political instability have left us exhausted and short-tempered. Our limited emotional bandwidth along with social distancing has eroded common courtesies, compassion, and social

pleasantries, all of which serve the vital function of preserving social order. Even the all-important mask hides facial expressions that help us read social cues and feel connected. To compensate, we need to consciously practice kindness for ourselves and others. The world sorely needs more compassion and connection to help us remember that our fate is truly in each other's hands.

Invest in social outreach: In the early days of the AIDS epidemic, when there was no governmental or other support structure, people living with HIV took matters into their own hands. Call lists were created for daily telephone outreach. They identified buddies with whom they checked in, assisted with medical appointments, or for whom they simply became a good listener. Today, along with an epidemic of isolation, we have more communication options than ever before. Whether by text, phone, Zoom, or other means, a practice of daily outreach to a few people is incredibly healing for both the caller and the person called. There is an addiction recovery slogan that captures this sentiment: *One call saves two lives.*

Cherish your connections: We are constantly getting new evidence of the lifesaving power of connection. The nature of our early-life attachment (or lack thereof) with caregivers affects how we form relationships for the rest of our lives. Studies show that long-term couples begin to co-regulate heartbeat, respirations, and even pain levels. And copious work has been done proving that connection with others is essential to recovery from addiction. When we are connected we thrive, reminding us that we are loved, supported, and perhaps most of all, that we belong.

The months ahead will continue to challenge our spirits. But, by taking actions that are available to each of us, we can preserve our wellbeing and provide potentially life-saving support for those around us. **PA**



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Fighting to stay well behind walls

Two pandemics meet within the broken U.S. prison health system

BY VICTORIA LAW

Yolanda Camacho turned 56 in January. Like many people across the country, she was unable to celebrate with family and friends. It's not just the coronavirus that is keeping her from spending the day with her loved ones—Camacho is in prison. If she's lucky, she might be able to get to one of the housing unit's three phones and call her son that day. But, with COVID-19 raging through the nation's prisons, including New York's state prison system where she is currently incarcerated, Camacho spent the day in her cell hoping to avoid the new virus.

That won't be easy. Since March 2020 and as of this writing, 5,016 people imprisoned in New York's prisons have tested positive for COVID-19. Of those, 30 incarcerated people and seven staff members have died. At Bedford Hills Correctional Facility, where Camacho has been since 2006, 82 women have tested positive as of January 29; two have died.

Camacho is also living with HIV and terrified of contracting COVID. "My immune system is already destroyed," she said.

Across the U.S., the pandemic has exploded behind bars. In state and federal prisons alone, there were 355,780 confirmed COVID cases and at least 2,228 deaths as of January 19. These numbers only encompass state and federal prisons for adults—not local jails, immigrant detention centers, juvenile jails or prisons, halfway houses, or locked-down psychiatric treatment or drug rehabilitation centers. One in five prisoners has had COVID-19 since the pandemic began.

While the Centers for Disease Control and Prevention (CDC) believes that people who are on effective HIV treatment have the same risk for COVID-19 complications as people without HIV, Camacho worries that being in prison increases her risk of contracting the virus. In prison, it is virtually impossible

to maintain a six-foot distance from other people at all times. While the prison has issued masks, not everyone wears them—or wears them correctly. Furthermore, guards, medical personnel and other staff members enter and leave the prison on a daily basis; each person is a potential vector for the coronavirus to enter. The same holds true for jails, prisons, and immigrant detention centers across the country.

Camacho is currently on her 14th year of a 20-to-life sentence. This means that she will not be eligible to appear before the parole board for another six years; even then, she is not guaranteed release. In August 2020, Camacho applied for medical parole, which would have allowed the parole board to consider granting her parole earlier because of her medical conditions. She was denied. "They said I didn't meet their criteria," she said. "I wasn't sick enough."

Medical care, already inadequate, becomes worse

OUTSIDE OF PRISON, Camacho, at 56, would not be considered particularly old. But incarceration, complete with inadequate health care, bad food, little opportunity to exercise, and non-stop stress, hastens physiological aging and shortens life expectancy.

At least 10% of people in state

prisons are age 55 and older, many of whom have been sentenced to decades, if not life, in prison with few chances of reprieve or early release. Between 1995 and 2010, the number of prisoners age 55 or older nearly quadrupled while the number of all prisoners grew by 42%. It's estimated that, at this rate, one-third of the nation's prison population will be over 50 by 2030.

At the same time, the risk for severe illness from COVID is higher for adults age 50 and over. The combination of age and prison thus heightens the risk of COVID complications for those whose bodies have already been worn down by lengthy incarceration.

Even before COVID reached the United States—and its prisons—medical care behind bars was, at best, inadequate and, at worst, fatal. For the entire month of November 2020, Camacho was not given her medications, causing a decrease in her T cells and a spike in her viral load. Red welts began spreading across her body.

Camacho repeatedly visited the prison's medical clinic—no easy feat in prison, where movement requires prior permission. "You cannot just go to the clinic," she explained. First, she had to fill out a nurse's screening form. "If you're lucky, they will call you down the very next day, two days later." There have been times, she said, that she was never called at all and had to submit another form. "When you finally get called, you then see a nurse, tell her your problem, and she decides the severity of the situation and either puts you down to see the doctor right away or sets up an appointment."

Camacho was finally reissued her medications on December 8 of last year. She worries that, because of the month-long lapse, she may not be safe taking them due to potential drug resistance. The red welts remain on her body and continue to make her itch. She has still been unable to see a doctor to talk about her concerns.

Allyse Wurcel, MD, is the co-founder of the COVID Prison Project, the infectious diseases liaison for the Massachusetts Sheriffs' Association, and an assistant professor of community medicine and public health at Tufts University. Prior to the pandemic, her work focused on HIV and hepatitis C in jails. She emphasized that it is the responsibility of jails and prisons to provide medications to people with chronic health needs, including HIV. If Camacho has started her medications again, Dr. Wurcel said, her viral load can once again be suppressed and her T cell count increased. But, she added, the lengthy lack of access can cause psychological distress. This is particularly true for people who were diagnosed over a decade ago and had been told repeatedly that missing their medications could mean a death sentence.

In Idaho, Kerry Thomas has encountered similar problems getting his medications even before the COVID-19 pandemic hit. When he entered the Idaho State Correctional Center in 2009,

medical staff initially told him that they didn't have his HIV medications and were not sure when they would have them available.

Not willing to wait and allow his health to be jeopardized, Thomas called his doctor in Boise, intending to ask if he would send medication until prison medical staff were able to obtain his prescriptions. Instead, his doctor called the prison asking why Thomas was not receiving his meds. Half an hour later, prison officials summoned Thomas and reprimanded him for calling his doctor rather than waiting. But his unintentional advocacy worked: The prison quickly got his pills.

Still, each month he was left to hope that medical staff had reordered his medications before his existing prescription ran out. If his refill did not arrive, he had to put in a sick call request and wait, usually 48 hours. At that appointment, he was given another appointment, typically one week later, with a provider who then ordered his medications, which would take several days to arrive. This

meant that Thomas—like many others—could have a lapse in medications of up to two weeks, making his HIV vulnerable to becoming resistant to the drugs.

These days, Thomas's medications are classified as keep on person (or KOP), allowing him to skip the two-week process and reorder his medications directly by filling out a health services request and then picking up his refill three to four days later.

Because of his age and HIV status, Thomas, also 56, has been classified as medically vulnerable despite evidence that treated HIV alone does not increase risk of COVID-19 complications. Yet, he noted, he has not seen medical staff in the more than six months since that classification. He has submitted written requests asking to be seen by a nurse to discuss his medical status. He even tried following up with a staff member, who identified himself as

a COVID nurse, when the nurse made his rounds through the housing unit. Neither garnered him any additional medical attention or answers.

Prisoners form support groups to battle stigma; the pandemic shut them down

FOR ANYONE LIVING and aging with HIV behind bars, medical neglect is compounded by widespread stigma and ignorance. In some prisons, fear and ignorance have led to physical attacks against people believed to be living with HIV.

At the same time, incarcerated people have organized to overcome stigma and build support for those living with HIV. In the 1980s, women at Bedford Hills Correctional Facility, the New York prison where Camacho is currently incarcerated, began organizing to combat this stigma. As with everything in prison, it wasn't easy. First, they had to request permission from the prison's superintendent to start a peer support group; without such permission, members would be unable to reach out to others in the prison and could even get into trouble for congregating without permission. In 1988, after years of watching women around them die, the prison's superintendent granted them permission and the AIDS Counseling and Education (ACE) program was born.

"ACE changed the culture in the prison," co-founder Kathy Boudin recalled. "It changed the culture because it was about people coming together—some were HIV-positive, some were not. But we all were saying, 'We have to do something about the crisis where there's a lot of fear. If we don't do it, no one else will do it.'"

Through ACE's efforts, women learned how HIV could—and could not—be spread. They learned that they would not contract HIV from breathing the same air or from taking care of someone with AIDS. They helped women understand medical terminology and, at times, get needed medical care.

Still, stigma and violence persist. Brittney Austin, who entered Bedford in 2015, has had people post signs disclosing her status on the housing unit bulletin board. Once, she was assaulted. Her assailant wore gloves which, she explained before attacking Austin, were to prevent her from contracting HIV.

"Prison is generally not a place where HIV/AIDS is socially accepted. It's taboo," Austin explained. In 2017, Austin saw a flier for ACE and signed up to become a peer educator. "I realized that the only way to defeat stigma is to educate others," she said. She remembers the first time she facilitated a session on U=U (Undetectable = Untransmittable). Many



YOLANDA CAMACHO
AT HER HIGH SCHOOL
GRADUATION IN
PRISON IN 2018.

of the women attending had no idea that a person with an undetectable viral load cannot sexually transmit HIV to another person. “I literally saw a chain of stigma shatter before my eyes.”

While stigma persists, support has also become more available. By the time Camacho arrived in the early 2000s, Bedford had a weekly Friday group where women supported each other through their concerns and fears. They also helped each other understand the effects of various medications and taught one another how to self-advocate. Once, Camacho recalled, a medication she had been prescribed for hepatitis C seemed to be interfering with her HIV drugs. “I was scared that I would get really sick,” she said, “but the women talked me through it and told me the questions to ask [medical staff].” She also was able to have one-on-one sessions with an HIV counselor.

On the other side of the country, the Central California Women’s Facility

(CCWF) has had a peer mentoring program since the 1990s, when women began banding together to educate and support one another as they attempted to navigate the prison’s health care system.

By the mid-2000s, the peer health program was run by Centerforce, an Oakland-based reentry non-profit. In 2013, three years after arriving in prison, Shawndra Boode decided to take the 80-hour training required to become a peer health mentor. The training focused on women’s health, including HIV/AIDS, hepatitis, and other sexually transmitted infections (STIs or STDs)—as well as the Prison Rape Elimination Act (PREA), a federal law passed in 2003 aimed at eliminating sexual abuse behind bars. Under PREA, prisons that receive federal funding must adopt a zero-tolerance policy towards sexual assault behind bars.

For Boode, then in her 30s, the decision wasn’t based on her own health concerns. (Boode does not have HIV.) Instead, she said, “I love helping my peers and being able to empower them with facts to make better choices.” Once she completed the trainings, she was able to teach classes on all these topics. She also became part of a cohort who could be called upon to support an incarcerated person when they were told they were positive for a sexually transmitted infection, or to visit the prison’s skilled nursing unit, which houses women whose advanced age and medical needs make them unable to live in the prison’s other housing units.

Not all prisons have similar programs. When Thomas first entered prison, there were no such support groups. At intake, new arrivals were given a flier and, in a group setting, asked if they had any questions. Thomas and others worked to change this and in 2016, the prison administration agreed to a peer mentor program. The program begins with Coffee Time, an orientation session for newly arriving prisoners. There, Thomas shares his personal story of living with HIV—and of being criminalized and incarcerated for HIV non-disclosure. (Idaho is one of 28 states with HIV-specific laws punishing activities like non-disclosure before sex, sex work, exposure to bodily fluids, needle sharing, and donations of blood, organs, or semen.)

“This has provided me the opportunity to mentor men with STDs where transmission risks are discussed ... sexual, drug use, tattoos,” Thomas explained. “Being a mentor has given me a sense of purpose. Specifically with the HIV population, an opportunity to share my experiences, give support, and hopefully make a difference.” Since the program began

in 2016, Thomas has mentored approximately 60 people one-on-one.

The COVID-19 pandemic put all such programs on pause.

The same is true in California, where the peer mentoring office has been shut down. Even before the pandemic, institutional support for the program had chipped away. When Boode began working as a peer mentor, she was paid 32 cents per hour. Five years later, pay for the peer mentors was slashed to 18 cents per hour. Boode, who relies on the wages from her prison job to buy food and hygiene products, took a prison construction job instead, where she earns \$1 an hour, though she continued to volunteer as a peer mentor in her spare time.

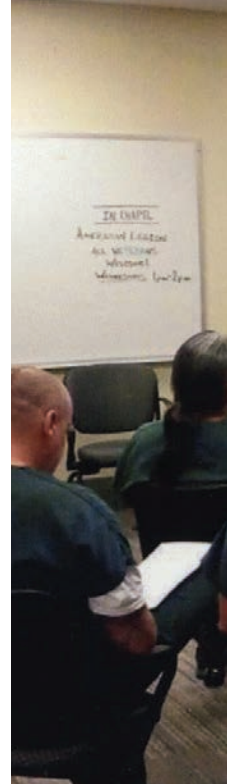
Boode is saddened and frustrated that the prison is not allowing mentors to educate their peers about COVID and transmission prevention. “It is always better coming from us, their peers, than from staff, even medical, because there is no trust there,” Boode explained. “We are their peers and in the same boat, so to speak, so our work means more.” As of January 7, CCWF has 601 confirmed COVID cases (or 30% of the 1,994 prisoners); 460 occurred within the previous 14 days.

Still, though the program is technically closed, women who are known peer mentors continue to be approached by those needing support and information.

Shortly before New Year’s, prison medical staff passed out fliers about the COVID-19 vaccine to the 2,011 prisoners. “Normally, we would have passed them out and been able to encourage our peers or give them the pros and cons of the vaccine,” Boode explained. “Most of the time when we do [give out fliers about] the flu shots, we are asked, ‘Well, do you get it?’” When Boode or another peer mentor answers in the affirmative, the incarcerated person is more likely to agree to be vaccinated as well.

Punished for being medically vulnerable

IN DECEMBER 2020, in an attempt to isolate older men at risk for COVID, Idaho prison officials moved Thomas and 255 other men into a newly created unit for those considered high risk for COVID



Send them home

AS COVID RAVAGES the country—including its prisons—advocates, including formerly incarcerated people and those with loved ones in prison, are pushing for decarceration, or mass releases, to stem the spread.

In many states, including California, Indiana, and New York, advocates demanded that people whose age or preexisting medical conditions made them vulnerable to COVID complications be released—either temporarily or permanently. These calls have had varying degrees of success: California reduced its prison population by 22,148 since March 2020, largely by expediting the release of those already slated to leave prison within months. New York allowed 3,145 early releases, decreasing its state prison population by 8.8%.

But these decreases have failed to protect those left behind, who still are unable to socially distance, wash their hands, or take precautionary measures against exposure. In California, nearly 50% of its prison population has had COVID, with 45,486 confirmed cases and 175 deaths as of this writing. In New York, the COVID rate behind bars is 13%, with 4,502 confirmed cases and 30 deaths, nearly double that of the rest of the state (6.8%). Other states—including Idaho, where people must serve 100% of their sentence—did not sizably decrease their prison populations.



KERRY THOMAS PRESENTING TO PARTICIPANTS OF THE PEER MENTORING PROGRAM HE CO-FOUNDED.

seen by medical staff who prescribed TabTussin for his stuffy nose, but did not test him for COVID. His cough lingered another week. Later, he spoke to correctional officers who had contracted and recovered from COVID. They described the same symptoms, making him wonder whether he had had COVID.

Over the summer, Thomas's current roommate experienced a fever, sore throat, dry cough, chest congestions, body aches, and fatigue. He requested a COVID test, but was not given one. The following week, he was moved to a different housing unit. Neither man was ever tested.

On December 29, 2020, the prison tested every man on Thomas's housing unit for COVID, placing the entire unit on lockdown pending the results. Thomas was only allowed out of his shared eight-by-10 cell for 20 minutes each day. Thomas was, understandably, frustrated. "I am locked down because of who I am," he said. He knows that precautions need to be taken to prevent spread, particularly in a congregate environment, but, he questioned, "Where does punitive lockdown come into play?"

That's what Wurcel says too. "Jails and prisons have isolation policies meant to be punitive," she noted. These come into play when someone breaks jail or prison rules or is deemed a threat to others. "It's wrong to restrict some people [simply] because of their age or other conditions."

In November 2020, Thomas received some good news: His sentence was commuted (or reduced), making him eligible for parole in September 2023 rather than waiting until 2029.

For the next three years, however, he remains behind bars, struggling not to lose hope in an environment that, in the name of protecting him from COVID, has instead further restricted and punished him for his age and status.

Thomas was told that, if he tests positive, someone would tell him. If he did not test positive, he would hear nothing. "That is another unnecessary layer added to an already stressful situation and environment," he said. "So now I'm sitting around, tripping every time the door opens or I hear keys, wondering if my results have come in." **PA**

complications: men age 55 and older who have underlying medical conditions. For Thomas, this meant moving from an open dormitory to an eight-by-10 two-person cell. Depending on the day, he's allowed out of his cell for either five hours or seven hours. During that time, he can take a shower, make phone calls from the shared phones in the common area, order items from the commissary (prison store), or socialize with the men from other cells. Otherwise, he and his roommate are locked together in their cell.

For Thomas, the move has impeded his ability to work, participate in prison programming, and be part of the mentoring program he co-founded. Before the move, he had worked as a clerk in the prison's education office, earning 40 cents per hour or roughly \$80 a month. That amount allowed him to buy his own necessities. More important, it provided him with a sense of value and purpose, even behind bars.

"There are a few areas that I define myself as a man," he said. "Being courageous, having integrity. Financial independence is on the same line." Now, he must rely on his son, friends, and advocates at the Sero Project—an organization that fights HIV criminalization laws, where Thomas is on the board of directors—for help with buying soap and other necessities.

Isolating those who are deemed medically vulnerable is a bad idea, said Wurcel. Including people with HIV in that cohort also discloses their status to the rest of the prison population. In addition, she said, "putting the most vulnerable

people in one spot goes against the idea that everyone needs to be safe and protected." In some instances, this may mean those in other units are not treated with the same precautions—such as requiring everyone to wear masks properly. Plus, if a person contracts COVID, all of the most vulnerable people are in the same unit, thus putting them all at risk.

Despite his efforts over the years, the stigma of HIV remains strong and, compounded with fears and ignorance about COVID, has rendered Thomas, who is open about his status, a pariah to many. "Comments are made daily that I must have AIDS or why else would I be on the high-risk unit," Thomas said. "Therefore, if I sneeze or cough, men scatter, not to mention I eat alone and [am] generally viewed as a walking danger."

Furthermore, these precautionary measures may have come too late to prevent his exposure to COVID. In November of last year, Thomas began suffering what he at first thought was a sinus infection with nasal drip, a dry cough, headache, and loss of taste. "I didn't think much about it because I didn't have a fever," he recalled. He was



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Finding Black pleasure

‘Growing up poz’ is just one aspect of this young Black queer long-term survivor’s journey

BY TIFFANY MARRERO-STRINGER



Prior to experiencing the genius of Black and queer folks in the HIV community who intentionally held space for my growth, I had no idea I was Black.

I was born and raised with HIV in a family where exploring my Blackness wasn't a priority. I realized that non-Black people would always find beauty in my proximity to all things white. But, when I found other dark-skinned melanated folks who could see in me the Black girl who did not know she had Black tears, the result was *relief*. Relief in finding safety and understanding from people

who do not just look like me but who provided a physical space where I could ask Black cultural questions as I worked on my own self-awareness. People whose presence somehow let my nervous system feel safe—and let me be able to feel *pleasure* in Blackness.

“Relief and pleasure” is a meditative mantra that I will be boppin’ all year long. I want more Black pleasure for

us all in 2021. The yearning to share space with and be elevated by other Black activists and Black artists continues to grow as I continue to age alongside HIV. And while I am *not* throwing in the towel for an HIV cure, what I *am* doing in the meantime is going back to that sweet spot of Black pleasure—which means I write, argue, sing, eat, play, *exist* as Black as humanly possible.

I had no real understanding that pleasure, first and foremost, is a human right; and that my Black pleasure is negatively impacted by the consequences of white supremacy. I came to understand that white supremacy is terrifying, and hiding is a perfectly understandable reaction to feeling scared. So I am entirely thankful for the Black birthing process: understanding that my melanin is political and that, regardless of my education level or income, there will *always* be a negative bias against darker-skinned folks. Understanding even a small percentage about intersectionality (as coined by Kimberlé Crenshaw but taught to me via the Black United Leadership Institute at HIV Is Not a Crime) relieved me of feeling shame and staying isolated in my own head.

Black-cultivated spaces provided me with enough love, and poured enough into all my self-discovery, to pull my soul out of a very dark place—a place I feel I had been stuck in for the last 28 years.

Black-cultivated spaces provided me with enough love, and poured enough into all my self-discovery, to pull my soul out of a very dark place—a place I feel I had been stuck in for the last 28 years. “Growing up poz” really is a vibe—but I wouldn't have known that I am a vibe, a whole walking sacred space drizzled in melanin realness, had it not been for random miracles we call mentors, who guide Black young girls through our journeys.

Mine happened to take form as an editor named Kenyon Farrow, who helps me to communicate; as community organizer Venita Ray, who helps me by *showing* me through actions what Black women have done in leadership positions; as the queen Gina Brown, with whom I can have *daily* chats about Blackness because Black mothers pour into the community; and so many more.

If I am Black then my pleasure should affirm my Black life. Rarely seeing my people depicted in pop culture outside of outdated stereotypes (Black mummies, Black Aunties, etc.), I couldn't grow if I wasn't in close proximity to Black humans who provided the catalyst of what I know to be the foundations of Black pleasure. Period. **PA**



TIFFANY MARRERO-STRINGER is a sex-positive advocate using her lived experience as a Black, queer millennial woman living with HIV to work with, and on behalf of, others in her community.

Creating spaces of care

Two programs help gay men of color living with HIV weave new social connections in older age

BY DAVID EVANS

Two innovative programs more than 2,200 miles apart are successfully reweaving the frayed social networks of older gay, bisexual, and same-gender-loving men living with HIV. Both prove that home-grown social support networks could become the backbone for people living with HIV to build a happier and healthier future as they grow older. Their remarkable success and resilience in the face of a world upended by the COVID-19 pandemic stand as a testament to the need for—and the power of—social connection to extend our lives and make them feel worthwhile.

In Los Angeles, saving men's lives with outdoor and virtual connections

APLA HEALTH AND WELLNESS'S program for 50-and-older gay, bisexual, and same-gender-loving men of all ethnicities—dubbed HIVE (HIV-Elders)—was designed to address social isolation. Isolation is strongly associated with poorer health and shorter lives in the general population; multiple needs assessments across the U.S. have found it is highly prevalent among older people living with HIV.

HIVE's program coordinator, Emmanuel Sanchez-Ramos, sees his role as an amalgamation of facilitator, confidant, cheerleader, and event planner to the dozens of men who attend HIVE's events. Sanchez-Ramos says that each event is geared to help members see that they are not alone.

"They know they can show up, and there are no expectations," he says of the members, "but [they will always] feel cared for and respected."

A look at HIVE's January 2021 event calendar

shows the diversity of offerings, ranging from online support groups and one-on-one chats to beach walks, virtual happy hours, and bingo games. It also suggests that older adults with HIV can successfully gain the technical skills needed to maintain social connection despite the stay-at-home orders that haven't meaningfully lifted since COVID first slammed Los Angeles in the spring of 2020.

'They know they can show up, and there are no expectations, but [they will always] feel cared for and respected.'

Frank Largaespada, an active HIVE member for more than a year, names Tuesday Night Bingo as a literal lifesaver during

his COVID-induced isolation. For the 52-year-old Nicaraguan transplant, isolation is especially deadly, having served as fuel for the debilitating depression and years of methamphetamine abuse that accompanied his HIV diagnosis in 2012. A self-described loner who rarely left the comfort of his home and his dog, he was introduced to HIVE by a friend in 2019.

"We go on outings and have events," he remembered his friend telling him. "You'll get to meet people and have fun."

Delicious food, laughter, bowling, and bingo have not only helped cure Largaespada's loneliness, they've also helped him avoid misusing substances and keep his HIV undetectable.

A large percentage of HIVE participants are Latino, though the program serves men of all ethnic backgrounds. The staff and membership have proved an exceptionally safe and welcoming home away from home for Largaespada. As is often the case for immigrant communities, HIV is not spoken of openly in his family. His mother has asked him only obliquely about his HIV.

"Son, are you sick?" Largaespada said she asked him once, to which he simply replied, "Yes, Mother."

He credits the brotherhood he's found at HIVE with giving him a voice and saving his life, despite the crushing stigma that keeps so many silent. In fact, he's almost jubilant about sharing his story in POSITIVELY AWARE, joking, "I'm going to be famous!"

Celebrating life while facing stigma and trauma in Atlanta

ACCORDING TO MALCOLM REID, a co-founder of THRIVE SS's Silver Skills education and support curriculum, the seeds of the program emerged on a gay cruise in 2016. After some false starts, a friend


'I don't do pity parties.'


proposed a simple Facebook Messenger group where, Reid said, "We say good morning to each other, talk shit, and have a good time."

The group organized a photo-shoot, determined to openly portray the beauty and vibrancy of life for Black gay, bi, and same-gender-loving men over 50 living with HIV. Having noted the absence of such men in HIV- and gay-related spaces in Atlanta, Reid knew visibility was critical. So many of his friends had shared an experience he calls "no longer being the cute face at the end of the bar."

Silver Skills sessions take place over the course of a weekend. The program directly addresses HIV and aging, post-traumatic stress disorder (PTSD) and trauma, loss and spirituality, and ends on stigma. "We focus on the intersectionality of being Black, being older, being gay, living with HIV, and the stigma and everything else you have to deal with growing up," Reid said.

Facilitators provide ample space for grieving, processing, and bonding over shared trauma—including the impact of living through the earliest days of the HIV epidemic as Black men. However, Reid also believes the best antidote to stigma is openness and celebration. The program always culminates with the event that started it all: a group photoshoot.

"I don't do pity parties," Reid tells group participants at the end of the program. "Life ain't over. Let's live!" 



Reprocessing trauma with EMDR

A therapeutic technique with potential
to support long-term HIV survivors
BY GIULI ALVARENGA

"I remember all those beautiful masculine faces that grace the walls of my memory ... [C]ountless [gay men] didn't survive the angst of knowing they wouldn't die ... and so they dove deep into the darkness of crystal meth, alcohol, and the like, dancing their way into the arms of death."

—ALAN DOWNS, PhD, PREFACE, *THE VELVET RAGE*

People who lived through the 1980s and '90s witnessed a generation lost to the AIDS epidemic: siblings, lovers, friends, parents, community members, culture bearers. Given the overwhelming grief and injustice embedded in those losses—experienced alongside their own health concerns, stigma and discrimination, survivors' guilt, and other life-altering challenges—it is not surprising that many long-term survivors of HIV show signs of post-traumatic stress disorder (PTSD).

Left untreated, PTSD can lead someone to behaviors such as self-medicating as a way to process—or numb—those difficult experiences. The effects of living in the aftermath of this dire focal point in history are only recently starting to receive serious attention in community and research circles. Meanwhile, long-term HIV survivors may consider innovative ways to heal from their pain and loss. One such technique is known as Eye Movement Desensitization and Reprocessing, or EMDR.

Therapists who use this technique argue that EMDR can diminish the

negative residual effects of traumatic memories. "EMDR is an effective treatment that uses increased bilateral brain stimulation to help resolve traumatic memories," says David Fawcett, PhD, LCSW, a therapist practicing in South Florida. "This simply means that communication between the two halves of the brain is increased through alternating movements."

A therapist may move their fingers back and forth in front of their patient's face and have their patient follow hand motions with their eyes. At the same time, the trained therapist will have patients recall a disturbing event—including the emotions and body sensations that went along with that traumatic experience. The EMDR therapist will evaluate a patient's distress levels, before and after the technique, in order to properly document if the patient has had any successful outcomes. It is crucial for the patient to have secure housing, along with other vital necessities, in order to properly support the evaluation of stress levels. This integrative psychotherapy technique has demonstrated a high success rate with PTSD, and is also

used to treat eating disorders, panic attacks, and other conditions.

While there is still much research to be done on this approach, EMDR has shown positive results in treating people with substance misuse challenges, and the technique is currently being studied in greater depth. "EMDR has only been around for 30 years or so," explains Portia Gordon, LPC, a therapist based in New Orleans. "Therapists need two to three years of study in order to practice EMDR on their patients."

According to Fawcett, there are three levels to EMDR training: level one, level two, and a certified level that requires a certain number of practice hours with supervision. The first two levels simply reflect the number of hours of training.

It is important for patients to consult with their health care providers before moving forward with this approach. It is essential for anyone interested in this practice to do their homework first and regard the technique for what it is: therapy. Not a cure for HIV or the challenges of long-term survival, EMDR may simply provide an opportunity to help people heal that is supported by research. **PA**

TO FIND an EMDR therapist in your area, go to emdria.org/find-a-therapist.

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Trying my best at 50 (and beyond)

A 20-plus-year HIV survivor, **Tim Murphy** shares his **six-point plan** for feeling and living well after 50

Little did I know when I turned 50 in June 2019, after living with HIV for 20 years, that the final months of my 50th year on the planet would be spent mostly in COVID-19 lockdown.

I'd greeted 50 with mixed feelings. On one hand, the fact that my 50th birthday year coincided with the 50th anniversaries of the Stonewall uprising, Woodstock, and the first moonwalk made me feel like a walking museum—absolutely

ancient. On the other hand, I mused, if Obama could be running the free world when he turned 50, then certainly I had no reason for not rising to the occasion.

So I decided that I would be—to drop a dreadfully overused word these days—*intentional* about entering my sixth decade, a plan that COVID both complicated and enhanced. This is the blueprint I've lived by ever since—more or less.

I try to get my heart rate up every day.

I've been a workout freak most of my life, but in recent years, I've become addicted to burpees—those exercises in which you jump in the air, down to the ground, do a push-up, jump up, and repeat. (YouTube it for a demo.) There's no quicker, more efficient way to make my heart pound for 15 to 20 minutes each day, which is perfect for days when I don't have time to go for a run or hit the gym. There are also plenty of examples online of "alternative burpees" for those who may be less mobile, have problems with their joints, be low on core strength—or just plain hate burpees, which many do. I know I hate them while I'm doing them, but afterward I always feel great.

I try to be as vegan as possible.

Let me be clear: I am *not* vegan. I'm not even vegetarian. But in recent years, I've tried to cut beef and pork out of my life almost completely, save the occasional burger or bacon (bacon!), and stick mostly to chicken, fish, beans, whole grains, fruit, and vegetables. It's as much for health purposes as my ever-increasing discomfort with eating the flesh of other living creatures. As with so many things in life, I've learned to take my journey toward veganism one day at a time rather than making a lifetime commitment—always a sure set-up for failure.

I try to cook my own food.

One of the good things to come out of COVID was the necessity of cooking nearly all my own meals, which reintroduced me not only to the pleasure and creativity of it, but also the wonderful feeling of self-reliance. As I told my mother recently, the sheet pan has become my best friend. I just slather it with olive oil, throw on it fish, vegetables, and herbs, shove it in the oven while boiling some rice or farro, and my meal is ready before I'm out of the shower.

I try to be present for those in my life.

Especially during COVID, when so many are isolated, I have revived the lost art of actually picking up the phone and having a proper conversation with someone. Something else I've started doing recently with friends who are stuck inside is watching a movie "with" them: We pick a movie, cue up to the start point, hit "Go!" on our text thread, then "chat" as we watch. It's not exactly togetherness, but it's better than nothing.

I try to live beyond myself.

I was a fairly callow party boy in my youth, but with every passing year, I've found more urgency in striving to be a part of systemic change, whether it's marching for racial justice, working on elections and legislative campaigns, or raising money for groups providing necessary services such as access to food for hungry families during COVID. I've met so many great people outside my own immediate orbit this way that I see it not as a chore but as a source of gratification and pleasure.

MY PERSONAL PLAN FOR LIVING WITH HIV OVER 50

Which brings me to ...

I try to find joy.

I am acutely aware of how lucky I am to live into middle age, as opposed to so many people diagnosed with HIV in the decades before me who did not get that gift. So I try to devote at least a part of each day to pure joy, whether that's taking a very long walk, plunging into the surf in the summer, cooking for and hosting friends (back when we could do that!) ... or even something as simple as staying up into the wee hours bingeing a good book or TV series. **PA**



Brooklyn-based journalist and novelist **TIM MURPHY** has been writing about HIV/AIDS for 25 years.



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