Vote of Confidence

Supporting youth leaders to address HIV among Latinos

April 2, 2018 By Daryl Hannah

Giuliani Alvarenga remembers precisely the day their HIV test came back positive. It was a sunny Monday in October. The 29-year-old, who prefers the gender-neutral pronoun “they,” was working in Los Angeles when a nervous case manager called.

“The voice on the other end sounded shaky, like he felt sorry for having to tell me something so important over the phone,” Alvarenga recalls. When the case manager finally delivered the news, Alvarenga immediately thought, How could this happen?

Two days later, Alvarenga was at Zuckerberg San Francisco General Hospital and Trauma Center attempting to sign up for the Positive Health Program, a medical study for people with early-stage HIV. Uninsured and lacking the financial means to pay for treatment out of pocket, Alvarenga figured that participating in the study was the only way to secure free treatment immediately.

However, while sitting alone in the lobby of San Francisco General, Alvarenga was consumed by anger—not directed inwardly but at the cultural and systemic barriers that had long failed them.

Alvarenga came out as gay at age 17. Unfortunately, their mother, a deeply religious Jehovah’s Witness, didn’t take the news well and threw Alvarenga out of the house. Still a senior in high school, Alvarenga was forced to work two jobs while taking advanced placement classes, studying for the SATs and completing college applications.

Thankfully, Alvarenga found refuge with a friend’s family, graduated high school with honors and was accepted to the University of California, Riverside.

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In many respects, Alvarenga’s story resembles the broader lived experiences of many young Latino men who have sex with men (MSM) trying to reconcile their sexual identities with the larger cultural and systemic barriers that often reinforce stigma and shame.

Machismo and family rejection can render young Latino MSM homeless or without stable housing, while a dearth of Spanish-speaking medical providers or culturally relevant networks can prompt feelings of isolation. Furthermore, one-sided conversations about sex can leave many individuals

undereducated about HIV. The conflation of these factors can be seen in the numbers.

According to the Centers for Disease Control and Prevention (CDC), in 2015, Latinos represented 17 percent of the U.S. population but accounted for 24 percent of all new HIV diagnoses. Of those, Latino youth ages 15 to 19 accounted for 7 percent of new HIV cases among Latinos, and those ages 20 to 24 accounted for 33.8 percent of new cases among Latinos.

“Machismo and religion are very strong in the Latino community. Conversations within families about sex are almost always around heteronormative sex, and often parents aren’t talking about sex from a health perspective,” says Xander Pacach, a former health educator in the Division of Adolescent and Young Adult Medicine at the Children’s Hospital Los Angeles, where he drew from his own experience to help young people.

Pacach came out as gay to his mother when he was 17. She didn’t take the news well and kicked him out. Pacach then spent the next several months couch surfing and was forced to drop out of high school. Eventually, he turned to sex work to support himself. Fortunately for him, he was able to find community and even a job at Bienestar (“well-being” in Spanish), a grassroots nonprofit service agency for the Latino community in Southern California.

“I’m thankful to a former mentor at Bienestar. He took a chance on a 19-year-old high school dropout who didn’t know anything about the field but who wanted to help people. Not a lot of young people get that lucky break,” says Pacach.

After much hard work, Pacach saved up enough money to rent his own apartment—his first stable home since he’d been kicked out—and graduated from college.

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Agencies like Bienestar are critically important for Latino youth. They provide a safe place for young people to express themselves, develop leadership and forge new chosen families to replace the ones they’ve lost.

Unfortunately, these centers are also few and far between. More often than not, the leadership of service nonprofits and health agencies are white cisgender men. And when it comes to reaching LGBT Latinos, these organizations tend to run only temporary initiatives or campaigns.

Very few take a 360-degree approach, focusing on the cultural, health and personal needs of LGBT Latinos, let alone the unique needs of LGBT Latino youth. And that, according to Pacach, is a significant blind spot in the LGBT nonprofit landscape.

“My last grant at the Children’s Hospital defined youth as 18 to 29 because one of the biggest issues we realized is that there isn’t a lot of transitional support for young people,” says Pacach. “A lot of agencies define youth as 14 to 24, but then there’s no road map or guidance given to young people to be able to continue. What happens if you need support at 25?”

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As it happens, Alvarenga was around that age when they realized they really needed support.

When Alvarenga first began taking pre-exposure prophylaxis (PrEP) in 2015, they mostly got it from those in the “bottle business” (the selling of medications on the black market). When those connections dried up, Alvarenga faced hurdle after hurdle trying to obtain a prescription.

First, Alvarenga tried getting PrEP through Medi-Cal, but because of a clerical error, the government-issued insurance took several months to kick in. In an attempt to be proactive, Alvarenga then turned to the Los Angeles LGBT Center for help but was denied a prescription because they lacked health insurance.

“I felt as if my access to this potentially lifesaving medicine was being stalled by bureaucratic hoops and not even the largest LGBT center in the world could help me if I didn’t have health insurance,” says Alvarenga.

Willing to do virtually anything to get back on PrEP, Alvarenga began telling white lies to the workers at the center who determine PrEP eligibility.

“I knew if I told them I’d been exposed to HIV that they would give me a 30-day treatment consisting of Truvada and a smaller pill called Tivicay. The people at the center told me that they would do this for me only once and that I should try to get insurance as soon as possible, which is exactly what I was trying to do.”

Alvarenga also had to check in with a counselor at the center as part of the agreement for getting the treatment, but when Alvarenga shared their sexual experience with the counselor, they were called “reckless.”

“The word felt like an admonishment when all I was trying to do was protect myself,” says Alvarenga. “This wasn’t the first time I’d been stigmatized by a medical provider.”

One month later, Alvarenga tested positive for HIV.

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Young uninsured and undocumented immigrant MSM are perhaps the most at risk of contracting HIV, yet navigating the health care and immigration systems simultaneously is a challenge for them. The racist, anti-immigrant sentiments originating in Washington, DC, can discourage some young people from getting tested, even if they may have been exposed to HIV.

Alex Aldana knows firsthand how difficult it can be to find one’s way through the red tape of immigration and health care. Born in Mexico, he was raised there for 16 years before he, his mother and his sister joined his father in Los Angeles. In December 2013, he self-deported back to Mexico to take care of his grandmother, who was gravely ill.

When Aldana tried to reenter the United States, he was stopped at the border and held in a detention center for four months. It was only after he posted a $10,000 bond that he was released and allowed to reenter the United States and work legally. However, when he returned to California, he found it nearly impossible to regain access to PrEP, which he had previously been taking for five years.

“I happened to be without a work permit for three months. This meant I had no insurance through work,” says Aldana. “I could have applied for assistance programs or gone for additional help, but my priority was getting extra income while I had to deal with the United States Citizenship and Immigration Services. It was during those three months of uncertainty that I seroconverted.”

Today, Aldana uses his story, skills and network to help others get through similar situations.

“Working with the Healthy Young Men’s (HYM) Study, in our research we’re noticing that other undocumented youth of color have a huge fear of going to a doctor and misconceptions about how one can get PrEP or post-exposure prophylaxis (PEP) or, when they’re HIV positive, access to health care,” says Aldana, now a research assistant at Children’s Hospital Los Angeles.

The HYM Study is a research initiative funded by the National Institutes of Health focused on preventing HIV and improving the health and wellness of Black, Latino and multiracial young MSM in Los Angeles.

“Anger has transformed and redirected my mission to fight local organizations that are incompetent, state legislatures that criminalize our youth and the current federal government,” says Aldana.

“I believe government at all levels needs to be accountable, and I believe the Trump administration will be a terrible era for young men of color and the fight against HIV, just like the Reagan administration took away so many of our elders.”

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So what can be done right now to prevent more young Latino MSM from contracting HIV? A first step is to begin having honest conversations about sex and sexual identity at home. In short, parents have to be willing to “go there.”

“We need to normalize conversations about sex at a young age and talk explicitly about our body parts,” says Pacach. “We give our genitals different nicknames because in a lot of households, parents are uncomfortable talking about sex. We need to get over that.”

Pacach says these discussions also need to evolve beyond conversations solely about procreation to “open conversations about condoms and testing,” but they needn’t be a one-way street. While parents should certainly educate themselves about HIV, both for their own health and that of their children, young MSM should also be more empathetic about where their parents are coming from.

“My mother passed away a decade ago, and we never reconnected or brought closure to this issue,” says Pacach, referring to his sexual orientation. “When I came out, I wanted to be accepted immediately, and it took me a long time to come to terms with why she was so apprehensive. Then I had to remember that it took me 17 years to come to terms with my sexual orientation and I shouldn’t expect her to get over it overnight.”

Beyond education and more dialogue, advocates say medical providers also need to be more relevant, inclusive and culturally sensitive. Those changes ought to include extending their hours of operation to accommodate people who work 9 a.m. to 5 p.m., Monday to Friday, and providing spaces for LGBT-adjacent people to confront difficult issues.

“There’s a strong cultural component in Entre Hermanos, the LGBTQ Latino center in Seattle,” says Edric Figueroa, a former outreach worker in Atlanta who has since moved to Washington state. “It’s a place for Latinos to talk with other Latinos about how they’ve navigated multiple cycles of coming out. Sometimes it’s our tías, tíos and abuelos [aunts, uncles and grandparents] advocating for us or praying for us. There need to be more spaces for them to have those hard conversations as well,” he says.

Figueroa says expanding HIV intervention efforts to online dating apps is also essential in order to reach younger MSM who may not identify as LGBT. This approach, he recognizes, is different from when he first started going to gay clubs in Atlanta and is a result, in large part, of geographical barriers. However, these dating apps themselves are not without fault.

“Today, it’s a lot easier to seek out sex online anonymously,” says Figueroa. “And while apps can be friendlier to queer people of color, they do reinforce the conditioning of gay men of color to see white men as more desirable.”

There are plenty of young MSM who want to be involved.

Perhaps the biggest move we can make to slow or stop the spread of HIV among younger Latino MSM is to support youth leadership, particularly youth from marginalized aspects of the community.

“Leadership positions for young people are incredibly lacking today,” says Moisés Agosto-Rosario, an activist who became involved in the HIV/AIDS movement in the early 1990s. Agosto-Rosario was featured on the cover of POZ magazine in May 1997. Today, he is the director of treatment for the National Minority AIDS Council (NMAC).

“When I go to meetings, I don’t see young activists at the table. Some leaders need to understand that there is a time when you need to move to the side,” says Agosto-Rosario. “It’s not that young

people don’t want to lead. There are plenty of young MSM who want to be involved—they just need my generation to help them do that by moving aside.”

If not for a combination of cultural pride, support and early leadership opportunities, Alvarenga might have strayed from their path. As it is, today Alvarenga is in the second year of a two-year law clerkship and waiting for the law school acceptance letters to pour in.

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