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28 June 2016, Oakland, California



Addressing Health Disparities for Persons with HIV: Academics Collaborating with Communities to Achieve Equity in HIV Prevention, Care, and Treatment

The homeless young man is the most unlikely of HIV educators. He lives out of his backpack, smokes weed, and sleeps on Venice Beach—far from a conflict-ridden and chaotic home in the Central Valley that he left.

But on his first morning as a "peer leader" in an innovative new HIV prevention program, he arrived 45 minutes early, a fresh cup of hot coffee in his hand.

"He came ready to work," distributing zippered bags packed with condoms, HIV information, and a fruit snack to other homeless youth, said Eric Rice of the University of Southern California's School of Social Work, who is leading the initiative to teach and protect high-risk homeless youth.

The project is part of a major new effort funded by the California HIV/AIDS Research Program (CHRP) to curb the HIV epidemic in California by creating unique interventions tailored to hard-to-reach populations - reducing disparities in HIV prevention, testing and treatment.

Diversity is one of California's greatest assets. But social, economic and cultural differences haunt the HIV prevention and treatment landscape. While services may be easily accessed in affluent white communities, they can be far from reach for the poor, people of color, sexual minorities, homeless youth, and women suffering from domestic violence, substance abuse or mental health issues.

As a result, there has been a shift in the profile of the HIV epidemic. In white, educated and affluent communities, fewer people are contracting the virus. But it is taking a devastating toll on young people, women, and black and Latino men. Their health would improve if treated with medication that suppresses the virus - and new infection rates would fall, due to reduced risk of passing on the virus.

Geographically dispersed, three new CHRP grants – totaling \$9 million over four years - are supporting innovative projects at UC Centers for AIDS Research in Los Angeles, San Francisco and San Diego. The Centers will collaborate with community groups to find, test and treat hidden and high-risk populations. If successful, their novel strategies could be more broadly implemented across California.

"This gives us an amazing ability to start serious investment in this question," said Dr. Paul Volberding, director of the AIDS Research Institute at UCSF. "The support jumpstarts a statewide effort to close HIV care disparities."

Homeless youth may not have a roof over their heads, yet they still find ways to routinely connect to the Internet and reach out to the people who matter to them. Researchers at UCLA and USC recognized this as a route to reach the estimated 4,000 homeless youth ages 13 to 24 who spend the night on the streets, beaches, basketball courts, public parks and in abandoned buildings - but who may seek services from Los Angeles County's physicians and an agency for the homeless called My Friend's Place.

About two-thirds of these youth are members of racial or ethnic minorities; more than one-third are lesbian, gay, bisexual, or transgender. They tend to distrust adults; many have been abused or cast out by their families. "They are a hidden population, trying to blend in. They're not like homeless adults pushing shopping carts on the street," said Norweeta Milburn of UCLA's Department of Psychiatry and Behavioral Sciences, who is overseeing the grant at UCLA. "But they seek out services in LA County's strong network of providers for homeless youth."

Sleeping on friends' couches and in strangers' beds, they are very vulnerable. Drug and alcohol use further boosts risk, by reducing inhibitions and clouding judgment. Transient, they don't carry a reliable supply of condoms. Food, shelter and cash are their top priorities as they navigate a treacherous path into adulthood.

"They participate in a lot of risky behavior to make it through the day," said Rice. Using conventional AIDS education strategies, these at-risk youth can be very hard to reach. With spotty records at school, many have missed the classroom-based sex education programs. "There are big gaps in their knowledge," said Rice. "They are very much lost children." And those at risk for HIV are very unlikely to get tested.

"They ask us questions like, 'Can I get HIV if I am sharing a joint with someone on the beach?' " said Rice. "It is shocking how little understanding there is about sexual health - and how eager they are to learn it and share it with their peers."

These young "peer leaders" are invited to intensive trainings about HIV and other sexually transmitted diseases, as well as lessons in effective communication. They put their new knowledge and skills to work as they travel between cliques at beaches, skate parks, basketball courts, and other spots where homeless youth spend their days, where they discuss HIV risk and how to get tested. It takes a long time to earn the trust and attention of young people who have experienced abuse, Rice said. But they're fiercely committed to each other, and can be powerful messengers about HIV risk reduction.

The intervention that Rice works with involves artificial intelligence – a software program that tells the intervention team which homeless kids to enroll in the program. What's particularly valuable about the artificial intelligence system is that it doesn't identify the so-called "good kids" that adults find easy to work with. Rather it finds those who may be less conspicuous, but have the greatest social reach and influence.

"We can invest resources in a small number of people, and work with them - and they are in a better position to impact their whole community," Rice said. "The last thing these kids want to hear is an adult telling them what to do," he said. "Peers can deliver a much more genuine and important message." And this system tells the researchers which peers will potentially have the greatest impact, and lead to more homeless youth getting tested for HIV.

The other CHRP-funded projects target very different populations but share similar strategies, linking street-savvy educators with high-tech tools. For instance:

*** A UCLA project will work with young, black men who have sex with men, especially those who have just been diagnosed with HIV, to design a smartphone app together.** The app will help connect them to social workers and legal assistance. Men in this community may face multiple levels of oppression – racism, poverty,

stigma and judgment about their sexual orientation. These barriers can prevent them from getting the care – and antiretroviral therapy – that they very much need.

Some have 'aged out' of foster care but have nowhere to go. Others feel rejected by their families or conservative communities, where sex between men remains strongly stigmatized. The mobile app will be sensitive to these needs, providing services that can 'meet the patients where they are' and be accessible at their fingertips. Through the app, the UCLA team will help with employment, housing, and legal needs, and these men may be more able to start antiretroviral therapy and stay on it.

Through the app, "young HIV-positive people are assigned to one central staff person who is always there - keeping in contact with them, and checking up on them," said Terry L. Smith of AIDS Project Los Angeles, a community-based group working with the UCLA team. Using the app, "we call, we text, and eventually they show back up," Smith said. "We keep encouraging them, and checking in. When they're ready to go to a doctor, we go with them, to support them."

"By being able to address those outstanding needs, we can impact their overall capacity to address their HIV," said attorney Ayako Miyashita of UCLA, who is designing the project. Even people who can't afford their other bills will always find a way to keep a phone, she said. The low start-up cost, text messaging capabilities, and flexible payment plans make cell phones an ideal tool for interventions - especially if combined with compassionate relationships, she said.

"There are many unmet legal needs for people living with HIV," said Miyashita. This app would provide legal advice and other resources at their fingertips. Issues range widely. Perhaps their landlord is suddenly raising their rent. Maybe their doctor won't provide a referral. They may be denied reasonable accommodation for an HIV-related disability at work. Once these needs are addressed, does their health improve – will they take their medication and keep their viral load suppressed? That's what the project hopes to discover.

*** Empowering HIV-positive women who face problems of discrimination, poverty, substance use, incarceration, mental illness and domestic violence – syndemics – to help one another.** Using a concept called "enhanced peer navigation intervention," known as EmPower Women, it relies on the wisdom and advice of other HIV-positive women who have successfully overcome similar struggles. "We find out what their barriers to care are. Maybe it's transportation or childcare. Or immigration status. Or income," said Jay Blount, a 48-year-old African-American grandmother living with HIV who now counsels dozens of other women.

"They may be afraid to receive care for fear someone might find out." In addition to cell phone conversations and texts, "peer navigators" like Blount accompany clients to appointments, arrange transportation, help with childcare and remind them to take their medicine. "We come up with a treatment plan," said Blount. "I ran the streets and did drugs - so my expertise is my 20 years of being diagnosed HIV positive and my work within the HIV community, working with women. We set goals together. It's all about empowering women."

Added UCSD's Stockman: "We can't just focus on HIV. We have to focus on other underlying issues. In dealing with these underlying issues, women will be more likely to get and retain care related to HIV." The intervention strategy was developed jointly by UCSD and Christie's Place, the only AIDS service agency for women in San Diego County.

*** Leveraging strong social networks in the Oakland-based "House Ball Community," a UCSF project is reaching deep into the underground world of close-knit African American and Latino men who unite together as informal families and compete in glamorous fashion shows.** "It is like a fraternity - a group of African men and transgender folks who become a family of choice, who support each other," said UCSF's Lightfoot. "By collaborating," she said, "we can develop an intervention that will engage the population to help overcome

stigma and deal with barriers to care." House members themselves are already doing HIV-related prevention, education and treatment "inventions" through the community's rich network of "houses" and "balls," but there is little research about its effectiveness, said Emily Arnold of UCSF, who is leading this research project. "Someone might say: 'We are going to go get tested together.' Then everyone at the next house meeting gets tested," Arnold said.

The structure of the House Ball community's home and family life offers additional possibilities for HIV/AIDS education and treatment, she said. "We're really aiming to promote house-based activities that offer 'protective' social norms - such as getting tested, and then if they're positive, linking them to care," she said.

*** Teleconferences and texting to support substance abuse treatment along with engagement in HIV care.**

A substantial body of research has shown that text messaging programs can help reduce cigarette smoking and improve management of diabetes and pregnancy. The messages work by reminding people about their medications and upcoming appointments. Alternatively, teleconferences, or "virtual hospitals", where patients meet doctors or counselors by video chat, may be more effective than texting.

The team at UCSF will use both strategies to help youth in San Francisco, ages 18 to 25, who are living with HIV but do not regularly take antiretroviral medication because of their substance use issues. This may be methamphetamine, heroin, cocaine, or any other illicit drug.

The group will use a technique called Motivational Interviewing -- a collaborative conversation between the counselor and the patient, to focus on the person's own internal motivation and commitment to change. This will be paired with either text messages or teleconferences, to increase engagement in HIV related health care and decrease substance abuse.

"We want to help young people maintain their appointments, manage their treatments and remain in care," said Marguerita Lightfoot, Director of the Center for AIDS Prevention Studies and UCSF Prevention Research Center. UCSF is collaborating with Larkin Street Youth Services, a clinic for young people that provides HIV testing and treatment.

*** A two-way text messaging intervention to boost HIV treatment among people of color living in San Diego.**

The app is called "iTAB", or Individualized Texting for Adherence Building. "A reminder text message helps them adhere to antiretroviral therapy. It reminds them: 'Take care of yourself. Don't forget your meds,'" said UCSD's Jamila Stockman, an infectious disease epidemiologist whose research focuses on HIV prevention among low-income and vulnerable women, and who is leading the UCSD effort.

"We will monitor improvement, over time, with this intervention," she said. The project will work with African-Americans, who represent only five percent of San Diego County's total population but 13 percent of those diagnosed with HIV. UCSD is collaborating with Family Health Centers of San Diego, the county's largest provider of comprehensive HIV services, to provide HIV care.

In the 33 years since virologists identified HIV as the cause of AIDS, research laboratories have made great strides in defeating a complex and wily culprit that once seemed unbeatable. Still, the economic and social determinants of health have proven harder to conquer.

But social scientists are catching up. These CHRP-funded projects recognize that closing the gap on disparities in the HIV epidemic means confronting the underlying factors that fuel viral transmission in these struggling populations - and tackling them head-on, with the urgency they deserve.

Part of the solution is ready and waiting on street corners, in homeless shelters and at flamboyant balls - little noticed, yet in plain sight. As he helps his friends, the young man from Venice Beach is beginning to heal himself, said USC's Eric Rice. He understands HIV risks. He's reduced his drug and alcohol use. He is beginning to look into stable housing. "He just needed the opportunity to do something positive out there," said Rice. "It is amazing how much more people care about themselves when they engage in work around their community."

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The California HIV/AIDS Research Program (CHRP) fosters outstanding and innovative research that responds to the needs of all people of California, especially those who are often underserved, by accelerating progress in prevention, education, care, treatment, and a cure for HIV/AIDS. CHRP was founded by the California state legislature in 1983 to respond to the HIV/AIDS crisis in the state. Since the program began, CHRP has funded more than 2,000 research projects and distributed and monitored more than \$275 million in state funds for HIV/AIDS research.



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