The Fight Against HIV Is a Fight for Human Rights: A Personal Reflection

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Abstract: The fight against HIV started and continues to be a fight for human rights. AIDS was observed first in the United States in marginalized and stigmatized populations such as men who have sex with men, injection drug users, and commercial sex workers. Next were the observations of generalized epidemics in sub-Saharan Africa, a continent crippled by the legacy of colonialism. AIDS appeared in post-World War II, which witnessed independence of the former European colonies and the creation of the United Nations. There was remarkable advocacy that led to important advances in the rights of ethnic and racial minorities, sexual minorities, and women. This foundation of activism laid the groundwork to ensure that AIDS, and those infected with HIV, were addressed using the best of human rights frameworks. Social and behavioral sciences contributed important data to the human rights advances in the second half of the 20th century, and to the tools and resources needed for a human rights-based response to HIV. Remarkable investment in science have brought us new tools to treat and prevent HIV. Vigorous social and behavioral science research continues to be needed to ensure that the continued response to the HIV epidemic remains evidence-based, recognizing human rights, and ensuring that the scientific advances are available to everyone who needs them. Generations of scientists and activists need to continue as we are far from finished in the fight against HIV and for human rights.

Key Words: HIV, human rights, social and behavioral science, prevention

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The 38-year fight against HIV started and continues to be a fight for human rights. HIV still challenges society, science, and medicine with equal fury. The social challenges got in the way immediately. The disease initially was called "GRID" for "Gay-related Immune Deficiency Syndrome" because the first cases were described among homosexual men in Los Angeles, San Francisco, and New York. President Reagan did not say the word "AIDS" until 1987, 6 years into the epidemic with over 20,000 Americans dead. This established the narrative that somehow the socially proscribed sexual practices of gay men, which some thought immoral, were responsible for the emergence and spread of the disease. AIDS among injection drug users and commercial sex workers only strengthened the narrative, as did the generalized epidemics in sub-Saharan Africa, a continent hobbled by colonialism.

I experienced this stigma first-hand in a conversation with my father, an otherwise compassionate human being with liberal political leanings. He revealed to me that he had been listening to a radio program in which the commentator laid out the opinion that public resources should not be devoted to people with AIDS because "…they brought it on themselves." I could not resist pointing out to my father that his heart disease was a result of his smoking.

I had the privilege recently to attend a screening of the movie "5B," a 2019 documentary about the efforts of nurses and physicians who opened the world's first AIDS ward at San Francisco General Hospital (SFGH) in 1983. AIDS patients at SFGH were being neglected. Nurses and other hospital workers did not want to get near them, take care of them, change their bedding, or deliver their meals. The courageous nurses and physicians set out to change the way that patients with AIDS were regarded, treated, and cared for early in the HIV epidemic. The challenge was not easy, and the opposing forces were many. One observation in the movie was that the neglect and disregard was much less about the disease and much more about the lifestyle of the people who were suffering from it.

It is hard to imagine today the discriminatory challenges that people with AIDS faced. But consider the fact that I was a felon in the State of California, diagnosable as a person with a mental illness by the American Psychiatric Association, and a sinner by my religion when I first realized that I am gay and began having sexual relations with other men. Most difficult was the fact that my sexual orientation was a deep dark secret that I was afraid to reveal. Friends considering options for the Vietnam war draft were warned not to reveal officially that they were gay for fear of being excluded from acquiring any professional license due to "moral turpitude." The American Psychiatric Association declared in 1973, based on research that demonstrated that homosexuality was not a mental illness. Some of the most

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influential work was conducted by my social and behavioral science predecessors at UCLA and was supported by the National Institute of Mental Health. California legislation decriminalized homosexual relations in 1976, but the Supreme Court upheld the constitutionality of sodomy laws in 1986 Bowers v. Hardwick. It was not until 2003 that the US Supreme Court reversed past decisions in Lawrence v. Texas and invalidated sodomy laws in the United States.

None of these advances occurred in a vacuum. The United States enshrined racial discrimination in its original Constitution. The 13th amendment abolished slavery, but did not grant citizenship to the former slaves. The 14th amendment granted citizenship to former slaves and laid down the rules for the census but noted that Indians were not to be included in the census. The argument for reparations to Black Americans revolves around slavery but also its long-term consequences still suffered today.

Many people in the period from the end of World War II until the 1970's worked under challenging and difficult circumstances, often incurring serious injury and even death, as in the case of the Rev. Martin Luther King Jr, to advance human and civil rights on many fronts. President Truman desegregated the military in 1948. Brown v The Board of Education of Topeka Kansas established the principle that segregated education was not equal education. Before the unanimous 1954 9-0 Supreme Court ruling, racially segregated education in the United States was mandatory in 16 and optional in another 3 states. Seven states had no legislation on the issue and racially segregated education was against the law in the remaining 22 states. Even though the battle for equality is far from over, these movements prepared the way for a vigorous response to the AIDS epidemic.

Women's rights, including sexual and reproductive rights, also advanced markedly during my lifetime. The Civil Rights Act of 1964 prohibited sex discrimination in employment and the Supreme Court, in 1965, established the right of married couples to use contraception. The nation's first "no fault" divorce law was passed in California in 1969, and the landmark Roe v. Wade, making abortion legal, was given in 1973. Women were not allowed, until 1974, to open a bank account without a male relative's permission. Women were denied the privilege to plead a client's case as a lawyer until 1971. Only in 1975 did the Supreme Court rule that states do not have the right to exclude women from juries. Women were first admitted to Harvard in 1977 and were excluded from running the Boston marathon until 1972. The first woman Senator was elected from Florida in 1980. Sandra Day O'Connor was the first woman appointed to the Supreme Court in 1981. The list of accomplishments in the women's movement could go on. Clearly the battles continue to the present day. The courageous people leading the charge for the equality of women before the law and for sexual and reproductive health rights also provided vital energy for the fight against AIDS.

It is rare that a scientist such as me gets to witness first-hand the emergence of a completely new disease and then is presented with the unique opportunity to focus his work against that disease. It is even more rare, because I have had the privilege of working against a disease that I have. I had the good fortune to be hired into my dream job in the University of California, San Francisco, School of Medicine in 1982. I was tasked with establishing the Behavioral Medicine Unit within the primary care practices of the Division of General Internal Medicine, teaching residents about psychosocial issues in medical practice, and continuing my research. I established a line of research in the prevention of cardiovascular disease among adolescents and adults, which I had begun in my graduate studies with the Stanford Heart Disease Prevention Program. The interns and residents soon began to see many AIDS patients in their practices and the entire city was overwhelmed with the tragedy of an epidemic that no one knew how to treat. I knew that I had to redirect my academic career to AIDS, and HIV and AIDS prevention became my passion.

The gay liberation movement of the 1970s lead to the 1977 election of Harvey Milk as the first openly gay elected official in the United States. His murder in 1978 was shocking and distressing, but only fueled forward action. The emergence of AIDS in San Francisco in 1981, and in New York and Los Angeles, was devastating because it meant that leaders were dying, the community was faced with horrible suffering, and opponents used the disease as an opportunity to attack "the gay lifestyle."

The Reagan administration was slow to fund AIDS research, prevention, and care. But activists played an essential and important role in ensuring a vigorous, well-funded, and targeted response to HIV. The activists demanded, and got, increases in funding. They fought for, and achieved, the affected communities having a say in how funds were allocated, and they held scientists accountable for advancing clinically important research. Funding, at first, was devoted to the biomedical and clinical sciences, and US scientists saw the incredible opportunities for advancing knowledge and clinical care. I am alive today because of the scientific work that taught us how to interfere with HIV's reproductive cycle.

It took a while before the social and behavioral sciences were recognized, not only as useful but vital, to the HIV/AIDS response. The Reagan administration began defunding social and behavioral science research, including work on sexual behavior, and this delayed a vigorous response from the social and behavioral science research community. Many social and behavioral scientists worked courageously to advocate and generate the research response necessary.

Social and behavioral science on HIV has gone through several phases. The first phase was descriptive and contextual. Accurately measuring sexual behavior and documenting the multiple effects of AIDS on affected communities laid the necessary foundation for policies and programs and investigations of their efficacy. These data were crucial in the struggles to advocate for additional resources for prevention, mental health care, drug abuse treatment, and decent care for people with AIDS.

The second social and behavioral science phase was the attempt to develop social and behavioral interventions to reduce HIV acquisition. There was nothing else available. The social and behavioral science strategies worked, but not enough to stop the epidemic. Nonetheless, important data were collected to shape important strategies such as the best ways to deliver HIV counseling and testing, incorporating stigma reduction and other mental health services into HIV prevention and treatment, and the importance of wrap-around care as set forth in the Ryan White Care Act.

The third phase saw the introduction, in 1996, of highly active antiretroviral treatment (ART) for HIV. This was an important game-changer. Social and behavioral strategies focused, quite successfully, on adherence to ART, HIV-related stigma, prevention for positives, expanded resources for HIV testing, and prevention of mother-to-child transmission. The data showed, quite convincingly, that social and behavioral strategies were essential in ensuring the best impact of ART.

The XIII International AIDS Conference in 2000 Durban, South Africa, was the first to be held south of the equator. This was a game-changer as it highlighted the injustice of disparity. The world's advocates stood up and declared that it was not acceptable that those countries with the highest burden of HIV disease, especially low- and middle-income countries in sub-Saharan Africa, should not have access to life-saving treatments. Not surprising was the fact that discriminatory attitudes toward populations in sub-Saharan Africa, such as the fact that ART would not work, because they are not able to tell time, were not in short supply. Nonetheless, this led to programs such as PEPFAR and the Global Fund.

Three other game-changers occurred in the 21st century. Scientists and clinicians worked hard to improve ART to reduce side effects, simplify regimens, and improve adherence. The findings that ART that leads to suppressed HIV rendered transmission impossible (U = U) demonstrated that the individual and society can benefit from ensuring that all people with HIV have access to care and treatment. Pre-exposure prophylaxis—providing ART to people not infected with HIV—meant that uninfected individuals could avoid infection even if exposed to the virus.

Some social and behavioral scientists get threatened with these scientific and clinical advances. They worry that there is nothing left for social and behavioral scientists or that their biomedical colleagues do not appreciate the potential contribution that the social and behavioral scientists can make. I applaud these scientific and clinical advances. I am alive today because of them.

Scientific findings and clinical advances are important, but not practically important, unless they can be implemented on a broad scale. Clearly, the biomedical and clinical advances are necessary, but not sufficient, to end the HIV epidemic. The advances in the science and clinical practice of HIV blend treatment and prevention. Blending the social, behavioral, biomedical, and clinical sciences is essential to ensure that these advances work in the real world. The NIMH Division of AIDS Research website makes this abundantly clear: "The behavioral science research agenda emphasizes developing and testing behavioral, social, and combination interventions that are effectively integrated with biomedical approaches to significantly affect the HIV/AIDS epidemic. The behavioral science agenda targets prevention of both transmission and acquisition of HIV, adherence to intervention components to reduce the burden of disease, and studies that address the behavioral consequences of HIV/AIDS." The mandate is broad and includes creating maximum benefit through combination prevention and treatment, understanding and addressing the facilitators and impediments of effective prevention and treatment, and continuing to study and engage in effective strategies to ameliorate the consequences of HIV infection.

One of the most consistent and important social and behavioral science findings is that vulnerability is pervasive and predisposes individuals to HIV infection and makes it more difficult to access care. The multiple vulnerabilities affecting HIV include everything from adverse early childhood experiences to current life circumstances such as poverty, mental health, substance use, and limited future opportunities. Now more than ever social and behavioral science research is needed to describe and identify the consequences and injustices that these vulnerabilities confer and strategies to ameliorate their consequences.

This takes us back to the beginning. Continued attention to human rights and freedom from discrimination are essential to continue the fight against AIDS. Vulnerability in the world today is defined along multiple dimensions. We have witnessed advances in the rights of women, racial and ethnic minorities, and sexual minorities. But we know that we have a long way to go to achieve full equality for even these groups. Those who experience the multiple vulnerabilities that help HIV/AIDS thrive and prosper need protection along multiple dimensions. The fight for human rights, essential in the fight against HIV/AIDS, is far from over.

We are the fortunate ones. I am lucky to be alive. Advances in biomedical science have changed the clinical outcome of HIV and I have access to world-class medical care. Those of us pursuing HIV research have the advantage of our education and the opportunity to work on areas of our passion. Not everyone has these advantages. The fight to stop the HIV/AIDS epidemic is ensuring the human rights of everyone, and especially the right to health. We, the fortunate ones, must do everything we can to make that happen.