Silence = Defunding, New Infections, Social Injustice, and Death

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Key words: advocacy, health policy, HIV, nursing

Thirty-six years ago, on June 5, 1981, the Centers for Disease Control and Prevention described a rare lung infection in five previously healthy gay men in Los Angeles (AIDS.gov, 2016). The report in the Mortality and Morbidity Weekly Report was America’s introduction to what would become known as HIV infection and AIDS. Since those early years, significant scientific advances–isolation of HIV in 1984; introduction of the first screening test, enzyme-linked immunosorbent assay (ELISA), in 1985; approval of the first antiretroviral agent, zidovudine, in 1987; and the introduction of protease inhibitors and highly active antiretroviral therapy in 1995 – have transformed HIV into a chronic, manageable disease. To achieve these milestones, investment in biomedical research was essential.

However, throughout the epidemic, HIV has been politically charged. Persons living with HIV (PLWH) have been fired from jobs, denied housing, and barred from attending schools. Federal legislation mandated that HIV prevention programs focus on abstinence, prohibited HIV education materials that “promote” homosexuality or drug use in the Helms Amendment in 1987, and limited or banned funding for needle and syringe exchange programs (AIDS.gov, 2016). Constructively, federal legislation and subsequent funding established the Ryan White Care Act, the AIDS Drug Assistance Program, the Office of AIDS Research at the National Institutes of Health, and the Housing Opportunities for People with AIDS program (AIDS.gov, 2016).

Despite all of the progress that has been made, nearly 40,000 new people became infected with HIV in 2015 (Centers for Disease Control & Prevention, 2016). In the same year, more than 18,000 people were diagnosed with AIDS and nearly 7,000 deaths were attributed to HIV—a totally unnecessary outcome if a PLWH was diagnosed, engaged in care, offered antiretroviral therapy, and virologically suppressed. Gay and bisexual men, especially men of color, continue to bear the burden of the epidemic. PLWH feel shame, guilt, fear, and stigma, and they experience discrimination.

My goal in this editorial is not to provide an HIV history lesson. Instead, I ask you to recommit to raising your voice so that we can ensure that PLWH, domestically and around the world, and those at risk of infection, continue to have access to prevention, care, and treatment that is affordable, of high quality, culturally relevant, and state of the science.

In 1987, six gay men in New York City established the Silence = Death project as a mechanism to raise awareness and to encourage people to vote, to boycott, and to become politically active (http://www.actupny.org/reports/silencedeath.html). Earlier this year, in an interview with the Advocate, Kelsey Louie, the current CEO of Gay Men’s Health Crisis in New York City stated, “... silence equals death, and in order to make change, we often need to have our voices heard” (Reynolds, 2017, ¶ 8). If we do not raise our voices, silence could result in defunding...
federal agencies supporting HIV research, HIV prevention and treatment programs, and the nursing workforce. Reductions in funding will translate into new infections, exacerbate health inequities, and widen the gap caused by social injustice. Consequently, without access to health care, HIV care, and treatment services, including medications, the burden of disease will increase and avoidable deaths will skyrocket.

In the first few months of Donald Trump’s presidency, we have seen anti-LGBTQ appointments in the executive and judiciary branches. The White House Office of National AIDS Policy website has been taken down. The administration has requested a nearly 20% cut in the National Institutes of Health budget. Similarly, in the 115th Congress, legislation was introduced to repeal the Affordable Care Act.

Since the beginning of the HIV epidemic, nurses have stepped forward to care and to advocate for rational policy. In 1987, the Association of Nurses in AIDS Care (ANAC) was founded to equip nurses to provide care, engage in research, and influence public policy. ANAC’s core ideology recognizes that “public policy must be grounded in patient advocacy, human rights, compassion and social justice” (https://www.nursesinaidscare.org/i4a/pages/index.cfm?pageid=3293). Today, more than ever, it is essential that the nursing voice be heard. We need to monitor local, state, and national legislation to ensure that scientific funding for HIV research is maintained. We need to ensure that all people have access to affordable, culturally relevant health care. We need to ensure that legislation is based on evidence and not political ideology or fear. We need to ensure that health and health care are viewed as essential human rights and not as a privilege only for those with resources.

To stay informed, you might consider subscribing to the Henry J. Kaiser Family Foundation (www.kff.org), the Center for HIV Law & Policy (https://www.hivlawandpolicy.org/), or Lambda Legal (http://www.lambdalegal.org/issues/hiv) for policy updates related to HIV, health care, and health policy. Similarly, you might join regional advocacy and policy groups such as the Southern AIDS Coalition (https://southernaidscoa lition.org/) or Southern Poverty Law Center (https://www.splcenter.org/). When legislation is introduced, please consider sending an e-mail, writing a letter, or calling your local, state, or federal representative to have your voice heard. To contact your national Congressperson or Senator, call the U.S. Capital switchboard at (202) 224-3121 and follow the prompts to connect to your elected official.

In closing, I do not consider myself to be an alarmist. But now, more than ever, it is critical that nurses recommit to raising their voices and ensuring that their voices are heard so that morally defensible health policy prevails. After all, nursing is the largest sector of the health care workforce and has a long legacy of being the most trusted profession. Together, we can make a difference.

Disclosures

The author reports no real or perceived vested interests that relate to this article that could be construed as a conflict of interest.

References

