

Healthful initiatives vitalize

Abstract

In this brief communication, I review basic concepts of HIV and AIDS surveillance, as performed within the United States. The intent is more descriptive than analytic, more historic than prognostic, more procedural than clinical, and more reflection than state-of-the-art discussion.

Keywords: HIV/aids, surveillance, united states, centers for disease control and prevention, hiv testing and diagnosis, aids determination, HIV/aids reporting

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Abbreviations: HIV, human immunodeficiency syndrome; ELISA, enzyme-linked immunosorbent assays; IFA, indirect fluorescent antibody; PCP, pneumocystis carinii pneumonia; PJP, pneumocystis jirovecii pneumonia; KS, kaposi's sarcoma; SMSA, standard metropolitan statistical area; IDEP, interstate duplication evaluation project; CDC, centers for disease control and prevention

Discussion

As a society, and as a global planet, we have benefited from healthful initiatives. These initiatives may take the form of improved therapies and more effective medications, innovative ideas on the place and the process of recovery (e.g., home care versus institutionalization, and dietary avoidances and inclusions), and strategies to avoid relapse and/or re-infection. Anthropologists and community researchers remind us that the application and outcomes of these initiatives vary. Structural vulnerabilities often hinder comprehensive receipt of initiatives within a given society. Not everyone will have beneficial initiatives locally available. Even when available within a reasonable distance, not everyone will be provided equal access or helpful assistance with services.¹⁻⁵ In the field of public health, professionals devote time and energy to remove barriers, re-align resources, and, thereby, decrease health disparities. For this brief communication, I provide a short review of HIV and AIDS surveillance within the United States. Since the beginning years of 1981 through 2015, the cumulative number of AIDS cases surpassed 1.2million in the United States. Nathan Wolfe⁵ in *The Viral Storm* observes that HIV/AIDS has become a pandemic beyond the United States, having "spread to individuals on all continents" (p. 99). My review will focus on ways that HIV and AIDS are reported within the United States, however, rather than provide a numerical-statistical synopsis or summarize the situation outside North America. These ideas stem from ethnographic fieldwork with individuals, families and communities affected by HIV and AIDS, and time working with or for community organizations and health departments on HIV education and prevention.

Opportunistic Infections initially were used to diagnose AIDS within otherwise healthy individuals, who had passed the stage of asymptomatic HIV infection. Within two years of these first cases, the "causative agent" was identified as HIV (Human Immunodeficiency Syndrome).⁶ Testing for HIV has grown in sophistication and effectiveness. Recent tests are identified as fourth generation in consideration of improvements that shorten the window period in which HIV can be detected.⁷ Widely used tests are those that detect

antibodies that the body begins to produce after HIV has entered the body. The earlier tests were effective at detecting antibodies to HIV present six to 12weeks after infection. The newer generation tests can detect antibodies three to four weeks after infection.⁸ Frequently used tests include ELISA (Enzyme-Linked Immunosorbent Assays) and rapid saliva-based HIV assays (e.g., Ora-Quick Advance), the confirmatory Western Blot and indirect fluorescent antibody (IFA) assay, among others. Confirmatory tests verify that a test has not yielded a false-positive. Testing initially has a fine-tuned sensitivity but lacks sufficient specificity, which requires further testing for assured "confirmation."

Official dissemination of HIV/AIDS data within the United States is through HIV Surveillance Reports,⁹ published annually and then semi-annually by the Centers for Disease Control and Prevention (Atlanta, GA). Among Opportunistic Infections, those utilized diagnostically in HIV Surveillance Reports⁹ from 1986-1987 included KS (Kaposi's sarcoma), PCP (Pneumocystis carinii pneumonia and later re-named PJP (*Pneumocystis jirovecii pneumonia*). For these four years, Opportunistic Infections appear in initial tables, before being relegated to the penultimate table from 1986 through 1987. It is important to recognize that the first reports from 1982-1985 comprised two to three pages, before being expanded to five pages from 1986-1987. As attention to HIV/AIDS increased in the United States, including funding to various community groups, HIV Surveillance Reports⁹ grew to fourteen pages in 1988 and included a table of contents, maps, and final page of technical notes. This becomes more or less a customary format. Technical notes were expanded in later volumes. A list of web addresses for state/local health departments began appearing as the final page in 2003 and continued into 2015. The first maps appeared on two initial pages in 1988 and the first charts co-appeared with three maps in 1989. Maps and/or charts were moved from interior pages to the cover in 1993, occasionally appearing on a few initial pages. The most recent map appeared in 2011; listed references appeared in 2002, with additional resources and suggested readings were listed in 2005. Starting in 1988, covers for HIV Surveillance Report⁹ included a large title, "HIV/AIDS Surveillance," beneath "Centers for Disease Control." Agency name at the top was moved to the bottom of the title page in 1989. Descriptions ranged from simple to complex within the organizational hierarchy (newer names consistently included "center" and "division"). U.S. Department of Health and Human Services, and Public Health Service, were always included (this was moved to the top of the second page in 2008). The 1992 cover revealed a

name change to “Centers for Disease Control and Prevention.” The acronym “CDC” remained. Covers included colors from 2007 through 2015 as background to the title (white on red at the top) and blue logo for the Centers for Disease Control and Prevention, which included organizational identification of responsible branches, National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention, atop Division of HIV/AIDS Prevention (shaded blue bars at the bottom of the page).

The HIV/AIDS Surveillance Technical Report⁹ first appeared in 2000 (Vol. 1, No. 1). This report discusses variation in ways that states collect and manage surveillance data. The basis for surveillance is reporting to the designated health department(s) by medical providers (e.g., clinics, hospitals, physicians) and laboratories any instance of someone diagnosed with HIV or AIDS. Generally, anonymous tests are not reported to CDC (even when the data is reported to the state/local health department), owing to insufficient information that included the test result. Coded patient identifiers were a recent innovation that was designed to work around using a name-based identifier, while still ensuring that the test is not anonymous. During the early years, before sixteen Standard Metropolitan Statistical Areas were introduced in 1986 to present AIDS cases, five cities (New York City, San Francisco, Los Angeles, Miami, Newark) were listed individually as hot-spots for infection (“Epi-centers”). The number increased continuously and became a list of 108 Standard Metropolitan Statistical Areas by 2015. Interestingly, once listed separately, the city of Newark was included as one of three divisions for the Standard Metropolitan Statistical Area (SMSA) of New York-Newark-Jersey City NY-NJ-CT-PA (Nassau County, New York, Newark), which cover four states and thirteen counties. Standard Metropolitan Statistical Area for San Francisco-Oakland also has three divisions but only five counties, and that for Los Angeles-Long Beach-Anaheim has two divisions and two counties. Of 108 SMSA jurisdictions listed in the HIV Surveillance Report⁹ for 2015, a total of 22 cover more than one state and eleven are broken down into two to four divisions.

HIV laws vary state by state.¹⁰ By the end of 2001, thirty-three states were implementing confidential name-based surveillance. By 2015, 42 states were following a recommendation by the Centers for Disease Control and Prevention that both CD4 data and viral load be collected and submitted. Each state cleans their data, when sending nameless surveillance data to the Centers for Disease Control and Prevention. The 23 Opportunistic Infections identified during the early years remain as of May 2017¹¹ with minor clinical clarifications and re-naming over the intervening years. One challenge that remained was the potential for duplicated cases appearing from one state or territory to another. Someone may move, recognize a need for services, and seek to be tested in the state to which they relocated. At times, the diagnosis might change from AIDS in one state to HIV in another. Someone diagnosed with AIDS who takes medication that reduces viral load and increases their CD4 count to HIV levels (above 200) might wish to avoid the stigma of once having AIDS. The CDC implemented a broad Interstate Duplication Evaluation Project (IDEP), whose purpose was to identify duplicate cases across states. The first state assigning the diagnosis as HIV or AIDS “counted” the case. De-duplication process continues among health departments. To date (as far as I know) these duplication surveillance data have not been released, which would provide a view of how often people with HIV/AIDS move and which states or regions are more likely to be their destination. Additional surveillance challenges include delays in reporting, which requires updated counts the following year that provide more accurate data. Another challenge is utilization

of the plentiful data sets, which often are embellished by the use of particular data more relevant to a population or community of interest. Formal procedures within the legal system disallow evidence that is “hear-say,” this means that an individual must testify. In the world of data analysis, formal procedures expect that data will be from primary sources. This challenge I call “read-write,” which means that researchers too often re-use data that may not be compatible to their analysis, repeat a particular numerical value without validating how it should be used, miss an opportunity to improve on what has been offered by deeper analysis, and, unfortunately, confound utility of the remaining analysis that is solid. We might transpose the title to this brief communication, to suggest, “Hapless inattention victimizes.” We need more attention to healthful initiatives. These vitalize the work of public health, and, importantly, they serve the people that public health is meant to help.

Surveillance data requires further elaboration to contextualize the situation lived and experienced by people that public health strategies aim at modifying or alleviating. We need to provide social supports when educating and training in practical prevention strategies^{12,13} and we need to consider the full range of risk engagement (intentions and efficacy), which may differ in larger-category populations, depending on current or recent experience in a particular geographic place.¹⁴ It goes without saying that the enumeration of numerical values for common risk behaviors differ from geographic place to place, and within a particular Standard Metropolitan Statistical Area. Finally, we need to be attentive to real-world interference with preventive strategies already in place.¹⁵ I bring closure by quoting a statement offered by Blake Scott² in relation to HIV testing, which reminds us of the people in our data and the human dimension of the work we do: “Testing practices should be sensitive and responsive to people’s needs, concerns and material circumstances... and respect the competing situated knowledge’s of their participants, treating difference as a resource for the development of reciprocally caring, responsive actions rather than as something to fear and guard against... creating more egalitarian forms of power rather than stigmatize, discriminate against, and otherwise oppress people...” (p. 8) After all, testing procedures generate the reported data that appears within the surveillance analyses from which healthful initiatives and effective interventions are generated.

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Conflict of interest

Author declares that there is no conflict of interest.

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