The Supplement to HIV-AIDS Surveillance Project: An Approach for Monitoring HIV Risk Behaviors

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SYNOPSIS

A VARIETY OF SURVEILLANCE METHODS are used to characterize the epidemic of HIV infection and AIDS. Such surveillance includes AIDS case reporting, reporting of diagnosed HIV infections, and HIV seroprevalence surveys among targeted sentinel populations. The need for additional surveillance systems to monitor HIV-related risk behaviors has been increasingly evident. One approach to behavioral surveillance, the CDC's Supplement to HIV-AIDS Surveillance project, uses the infrastructure of HIV infection and AIDS case reporting to collect additional information on risk behaviors among HIV-infected persons, who by definition represent those at highest risk.

Public health programs for preventing HIV infection and its complications depend on a variety of surveillance methods to characterize populations at risk for HIV infection. Local, state, and national reporting of AIDS cases has been the mainstay of these surveillance efforts. In addition, health departments increasingly use HIV seroprevalence surveys among targeted sentinel populations to supplement AIDS surveillance and reporting of diagnosed HIV infections *(1)*. Because HIV prevention programs seek to change behaviors, there is also a role for surveillance systems to monitor trends in HIV-related risk behaviors. In a recent review of the Centers for Disease Control and Prevention's (CDC's) HIV prevention strategies, an external review committee listed strengthening of behavioral surveillance as a priority *(2)*.

One of the challenges of conducting surveillance for HIV-related risk behaviors is defining and reaching high-risk groups who should be targeted for such monitoring. Among the many possible behavioral surveillance methods, one approach is to monitor behaviors among persons infected with HIV, who by definition represent those at highest risk. Interviewing persons infected with HIV can identify trends in the behaviors that have led to current HIV infections and that may contribute to future HIV infections. The CDC's Supplement to HIV-AIDS Surveillance (SHAS) project uses the infrastructure of HIV and AIDS case reporting to collect additional information on risk behaviors among HIV-infected persons. This paper will explore the methods of the SHAS project and its role in monitoring HIV-related behaviors.

The key features of the project are that:

- It is conducted by local or state health departments;
- It is linked to procedures for HIV and AIDS reporting;
- Sampling methods are flexible to accommodate local circumstances and data needs;
- It collects information on an ongoing basis from interviews of persons diagnosed and newly reported with HIV infection or AIDS; and
- It includes measures of socioeconomic status, sexual behaviors, drug and alcohol use, use of health services, reproductive health (for women), and disabilities, employing a relatively limited number of survey questions in each of these areas.

The Supplement to HIV-AIDS Surveillance Project

The SHAS project was designed as an extension of AIDS case reporting, which is conducted in all states, and HIV infection reporting, which is conducted in approximately half of the states. The standard case report forms for HIV infection and AIDS provide limited demographic (for example, age, sex, race/ethnicity) and behavioral information (such as information sufficient to identify the most likely mode of HIV exposure). In nearly all instances, HIV infection and AIDS case report forms are completed using available medical records. The SHAS project uses personal interviews to supplement the basic information routinely collected on the case report forms. SHAS data are managed as an extension of the software and routine procedures for both local and national HIV infection and AIDS reporting. As with all other HIV-AIDS case reports, personal identification is retained locally but not forwarded to CDC.

Participating sites in the SHAS project include health departments in Arizona, Colorado, Connecticut, Delaware, Florida, Georgia, Los Angeles County, New Jersey (the newest site), New Mexico, Michigan, South Carolina, and Washington State. These sites represent, first, those areas where health departments expressed interest in the project and, second, those health departments that competed successfully for funding from CDC.

From a national perspective, persons with AIDS from participating sites have a demographic profile that approximates the national profile of persons reported with AIDS. However, because none of the initial sites were Northeastern and several were Western, among Hispanic respondents there was an overrepresentation of persons of Mexican ancestry and an underrepresentation of persons of Puerto Rican ancestry in the project *(3)*. With the recent addition of New Jersey to the project, this imbalance is being corrected.

Within participating sites, methods for interview sampling reflect local capabilities and local information needs. This has led to the use of two strategies: population- and facility-based sampling. In four areas employing population-based sampling (Arizona, Delaware, South Carolina, and New Mexico), all persons reported with HIV infection or AIDS are eligible for interview. In two other areas using population-based sampling (Los Angeles and Washington State), 30 percent of men with a history of male-to-male sexual contact and 100 percent of all other persons are eligible for interview. For example, in Los Angeles County, the large majority of reported AIDS cases are among men with a history of male-to-male sexual contact, but cases of AIDS among persons with other modes of HIV exposure are increasing as a percentage of reported cases. Thus, there is a local need for a sample that is more diverse than the overall pattern of reported AIDS cases. This enables the county to characterize the largest mode-of-exposure group as well as groups of emerging importance to the local epidemic.

In those areas that employ facility-based sampling (Denver, Connecticut, Florida, Atlanta, New Jersey, and Detroit), local health departments have identified facilities where large numbers of HIV-infected persons receive care, where staff are supportive of the project and facilitate access to patients, and where a mix of patient groups can be interviewed. This method provides a more convenient approach to conducting the supplemental interviews. Because participating sites in these areas are typically publicly funded medical centers, respondents from these areas overrepresent those who use public as opposed to private HIV care services.

This mix of sampling methods, while responsive to local concerns, means that data from the project cannot, in aggregate, be used to calculate AIDS incidence rates stratified by measures of socioeconomic status (SES), such as educational attainment or income. However, differences in the SES profile, with appropriate consideration for the limitations of the methods, can provide insight into the contribution of SES to disparities in AIDS incidence. For example, data from the project document that respondents from racial and ethnic minority groups with higher AIDS rates are more likely to have lower income or educational attainment. When considered in light of other studies of SES' effect on health, the findings strongly implicate lower SES as a contributor to higher AIDS rates *(3)*.

The survey instrument includes the following sections that are relevant to HIV risk behaviors:

Demographic information and socioeconomic status. Routine HIV-AIDS surveillance classifies race and ethnicity into five categories, which, as indicators of HIV-AIDS risk, may reflect in part disparities in SES (*4*). The survey form collects more detailed information on ancestry for persons who identify as Hispanic or Latino or as Asian or Pacific Islander. Measures of SES include educational attainment (for example, number of years of school completed), employment history and status (such as change in job situation since becoming infected with HIV, or primary occupation among all jobs held), income and receipt of public support (for example, main source of income, household income, receipt of public assistance or welfare), and living arrangements (for example, living in household or other setting, characteristics of household, change in living situation since HIV diagnosis). While these indicators do not measure HIV risk behaviors, they are more descriptive than the five race and ethnicity categories alone in describing the socioeconomic context of behaviors. In addition, the interviews provide a mechanism for comparing self-reported race and ethnicity with such information obtained from routine HIV infection and AIDS surveillance *(5)*.

Drug use. Questions cover alcohol use, noninjected-drug use, injected-drug use and needle sharing, and access to and use of drug treatment services. Questions also address the circumstances of drug use (for example, crack cocaine use in a crack house) as well as differences in drug use during different time intervals (for example, 5 years, 1 year, 6 months preceding the interview) which can be compared with the date of HIV diagnosis.

Sexual behaviors and sexually transmitted disease history. Questions address numbers of male and female partners, vaginal and anal sex, condom use, history of sexually transmitted diseases, and exchanges of sex for drugs or money. Again, these behavioral questions relate to specific time intervals in the past.

Other sections of the questionnaire address the use of medical and social services *(6)*, reproductive history (for women) *(7)*, and disability status.

Overall, the interview typically takes 30 to 45 minutes to complete. In three areas, the health departments provide a nominal financial reimbursement to participants. In another, the SHAS interview form is used as part of the initial processing of newly diagnosed clients entering the health department's HIV clinic. In some areas, community advocates have been actively involved in promoting the survey and proposing supplemental questionnaire modules. In one area, community advocates initially discouraged (but later supported) participation, reflecting dissatisfaction with the state's HIV policies.

The questionnaires are administered by health department staff whose training in interview techniques is primarily done locally. The interviewers have diverse backgrounds, and include HIV service providers, HIV-AIDS surveillance officers (many with experience in follow-up of persons with AIDS initially reported with no identified risk), persons with HIV infection, former injected-drug users, and social scientists. Because the interviews may identify medical or social service needs, the interviewers are prepared to make referrals to service providers. They do not, however, attempt to provide such services. Given the sensitive and emotional nature of many of the issues raised by the survey, the interviewers must be prepared to handle the emotional responses that may arise among the persons being interviewed. This capacity is strengthened by biennial national meetings that bring together interviewers from participating sites.

Some issues were considered for inclusion in the survey but were excluded because local investigators and interviewers considered the topics too sensitive to be effectively handled by the interviewers. For example, while better understanding of child and sexual abuse may contribute to improved services for HIV-infected persons, project staff concluded that the interview staff was not equipped to discuss these issues.

Uses of SHAS Data

The initial analyses of data from the SHAS project have been cross-sectional and have not provided information on trends. As data collection began in June 1990, it will soon be possible to describe trends in behaviors among persons with recently reported HIV infection or AIDS. The project has yielded information on:

- Risk behaviors among persons with heterosexually acquired HIV infection. Noninjected-drug use, alcoholism, a history of prior sexually transmitted diseases, and a history of purchase of sex by men are common among many persons with heterosexually acquired HIV infection, while condom use prior to HIV infection is infrequent. However, a particularly notable finding was that, of women who acquired HIV through heterosexual contact, approximately one-third had had only one sex partner in the preceding 5 years. This finding has important implications for prevention recommendations, for example, recommending reductions in the number of sex partners would not be an effective prevention strategy for women who have only one partner *(8)*.
- The types of drugs used by persons exposed to HIV through drug injection. Polysubstance abuse, including injected- and noninjected-drug use, is important among HIV-infected drug injectors, and there are striking regional differences in the predominant drugs injected. For example, amphetamines, cocaine, heroin, and a combination of heroin and cocaine were the most commonly injected drugs among persons reported from different geographic areas *(9)*.
- Sexual behaviors among crack cocaine users. Crack cocaine users continue to engage in high-risk sexual behaviors, most notably exchange of sex for crack, despite their awareness of being HIV-infected *(10)*.
- The living situation of women with AIDS. Dependence on public support and poverty compromise the ability of many women to use HIV care and preventive services *(11)*.
- Behaviors of bisexual men. Men whose HIV infection is attributed to male homosexual contact but who also engage in sex with women differ in their demographic profile from infected men who report sexual contact exclusively with men. For example, many bisexual men with AIDS are married, suggesting that their sexual behaviors may put their

male and female sex partners at risk for HIV infection. In addition, bisexual men are more likely than homosexual men to have a history of illicit drug use *(12)*.

- Women who have sex with women. In nearly all instances, homosexually active women with HIV infection were exposed to HIV through sexual contact with men or through injected-drug use, reflecting a pattern of high-risk heterosexual and drug-use behaviors *(13)*.

Each of the above analyses provides guidance to HIV prevention programs. A common theme from these reports is the importance of integrating or coordinating HIV prevention and substance abuse interventions. The data also demonstrate differences in HIV risk behaviors among population groups that must be taken into account in prevention programs. For example, efforts to prevent male-to-male sexual transmission of HIV should take into account the greater potential role of illicit drug use in contributing to unsafe sexual practices among bisexual men than among exclusively homosexual men. Bisexual men, particularly those who are married, may not be reached by prevention messages targeted to gay communities. Efforts to integrate HIV prevention and drug treatment services must consider important regional differences in the types of drugs that are injected. Efforts to prevent heterosexual transmission of HIV to women should consider that some lesbian women may be at risk for HIV infection as the result of unsafe sexual contacts with men.

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Local use of the data mirror national use. Many areas publish results in local newsletters, data have been used in interviews with local media, and most sites use the SHAS data in planning for HIV care activities funded under the Ryan White Comprehensive AIDS Resources Emergency Act. In addition, several health departments have added supplemental questions to address topics of local concern. For example, the Arizona health department developed questions about the use of dental care services, an important part of overall HIV care; these questions were subsequently adopted by other areas. The Florida health department added questions about pet ownership, reflecting concerns about the risk of certain opportunistic infections that may arise from handling pets.

Recently, CDC has initiated a new procedure for funding HIV prevention grants to state and large-city health departments. This procedure requires that health departments develop a formal mechanism for community-based prevention planning. An initial step in the development of such a plan is the preparation of an epidemiologic profile and a service needs assessment. Based on discussions with SHAS project coordinators, CDC has developed a supplement to the project's data management software that produces a set of tabulations to support prevention planning.

Conclusions

The SHAS project provides a method for health departments to collect information on HIV risk behaviors that is useful both locally and nationally for guiding HIV prevention and care programs. To date, information has not been collected for a sufficient length of time to monitor trends in behaviors among persons reported with HIV/AIDS, although this will be an important use of SHAS data in the future.

The attributes of the SHAS project reflect the following concepts that underlie all public health surveillance systems *(14)*:

- The process and role of surveillance. In general, surveillance is a process of collecting a limited amount of information from a relatively large number of people. Although the SHAS project is more detailed than routine HIV infection and AIDS surveillance, it remains modest in its scope of information collection compared with behavioral research studies which obtain more in-depth information from smaller numbers of people. In contrast to studies which may seek to define the determinants of behaviors or evaluate the effectiveness of specific interventions, surveillance systems seek to monitor HIV risk behaviors within more broadly defined populations over time. Such monitoring can be used to target intervention programs and to assess (if not directly measure) their impact.

- The importance of logistic concerns in designing surveillance systems. While all data collection activities are affected by logistic constraints, logistic considerations are often paramount to state or local public health agencies that are responsible for managing surveillance activities. Surveillance systems are shaped by the balance between information needs and the capacity of health departments to collect and use the information over time. One result is that health departments often attempt to build on existing capacity in developing new surveillance activities. Thus, efforts to strengthen HIV behavioral surveillance have included not only the SHAS project (which builds on HIV infection and AIDS surveillance) but also the use of supplements to the Behavioral Risk Factor Surveillance System (a state-based telephone survey that monitors a variety of health-related behaviors *[15]*).

• The need to focus information collection. Just as the case definition is the cornerstone of surveillance systems that monitor diseases, behaviors must be selected or defined for behavioral monitoring. Surveillance definitions for diseases often do not include the full spectrum of illness, but rather that part that provides a reliable and measurable indicator of impact. Likewise, in establishing a surveillance system for behaviors, it is necessary to identify a limited number of questions that can sufficiently represent the broader and more complex array of behaviors that affect HIV risk.

• The definition of target populations in surveillance. It is also necessary to define who will be asked these questions. Individuals within the population vary greatly in their risk for HIV infection. Surveillance systems that target the population at-large may provide little information about groups at highest risk. Surveillance systems that seek to monitor those at highest risk face the difficulty of identifying and accessing representative groups.

Responding to calls for further improving surveillance of HIV risk behaviors will require a careful assessment of different monitoring strategies: what is the role of nationally versus locally defined samples, what is the appropriate scope of information collection, to what extent should surveys be targeted to the population at-large versus high-risk groups, how should high-risk groups be defined and reached for ongoing behavioral monitoring, and what is the capacity of local health departments and community-based HIV prevention planning groups to collect and use this additional information?

The experience from the SHAS project has been valuable in helping to answer these questions. While the project does not satisfy the need for more in-depth behavioral research or surveys, it does provide an important piece of the puzzle and a practical approach to behavioral surveillance in support of HIV prevention.

Valuable assistance was provided to the authors by the project directors from the participating health departments: Lisa Conti, DVM (Florida Department of Health and Rehabilitative Services); Eve Mokotoff, MPH (Michigan Department of Public Health); Frank Sorvillo, PhD (Los Angeles County Health Department); Patricia J. Checko, MPH (Connecticut State Department of Health Services); Pat Hermann, MD (South Carolina Department of Health and Environmental Control); Cornelis A. Rietmeijer, MD, MSPH (Denver Department of Health and Hospitals); Harrison Stetler, MD (Georgia Department of Human Resources); Samuel Costa, MPH (New Jersey Department of Health); Denise Boyd, MPH (Arizona Department of Health); Mary Herr, MT (Delaware Department of Health and Social Services); Margaret Frederick MA, MPH (Washington Department of Health); and Michael C. Samuel, DrPH (New Mexico Department of Health). In addition, we would like to thank the many interviewers, whose hard work and dedication make this project possible. We also thank Barbara Schable, MPH, for her ongoing efforts and general support of the project, and W. Meade Morgan, PhD, and Roseanne English for software development and software support.

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