# Review of Death Certificates To Assess Completeness of AIDS Case Reporting

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## Synopsis

*To assess the level of reporting of acquired immunodeficiency syndrome (AIDS) cases, the authors reviewed death certificates for periods of 3 months during July through December 1985 in each of four cities: Washington, DC, New York City, Boston, and Chicago. Since reporting began in 1981, these cities have reported 38 percent of all AIDS cases in the United States. Death certificates were selected and matched to the AIDS surveillance registries in each city, and medical records of those not on the AIDS registry were reviewed to determine if AIDS had been diagnosed.*

*The estimated completeness of AIDS case reporting to AIDS surveillance systems was high in all four cities (ranging from 83 percent to 100 percent). The unreported cases were similar to reported cases with respect to sex, race, risk factor, and specific diagnosis. Of the causes of death examined, AIDS,* Pneumocystis carinii *pneumonia, and Kaposi's sarcoma were predictive of AIDS as defined by the CDC case definition. However, 77 of 588 deaths (13 percent) attributed to 1 of these 3 causes occurred in cases that were presumptively AIDS but did not meet the diagnostic requirements to be classified as AIDS for reporting purposes. A review of death certificates provides an easy and rapid means of evaluating surveillance efforts and can be a useful adjunct to other methods of surveillance for AIDS.*

INFORMATION ABOUT CASES of acquired immunodeficiency syndrome (AIDS) reported to the Centers for Disease Control's AIDS surveillance system is useful for understanding the epidemiologic patterns and trends of severe illness resulting from infection with human immunodeficiency virus (HIV). For accurate interpretation of surveillance data, some estimate of the completeness of case reporting is needed. Previous evaluations of AIDS surveillance systems indicated high levels of completeness of reporting (from 77 to 96 percent) but were limited to one type of AIDS-associated opportunistic disease or to one geographic area (R. M. Selik and coworkers, Centers for Disease

Control, unpublished data, June 1986) (*1*). To assess national reporting of AIDS, a collaborative study was undertaken with the health departments of Washington, DC, New York City, Boston, and Chicago to evaluate surveillance effectiveness by comparing death records with AIDS case registries. From 1981, when reporting of AIDS began, until the end of the study period in December 1985, the four participating health departments had reported 38 percent of all AIDS cases in the United States; during the study period, July through December 1985, they reported 33 percent. This paper describes the results of the study.

## Methods

AIDS is reportable by law to the four participating health departments, and all four had conducted active surveillance for AIDS for at least 3 years (*1*). Although the case-finding methods used by these health departments differ somewhat, all are primarily hospital-based. Hospital personnel (often infection control practitioners) are contacted on a regular basis and asked to report AIDS cases. In some instances, health officials visit hospitals, review records, and complete the AIDS case report forms themselves. In addition, cases are sought by contacting private physicians and by reviewing various record systems, such as laboratory reports, tumor registries, and hospital discharge summaries. Officials at three health departments had previously reviewed death records to a limited extent to search for cases. This practice was discontinued during the study.

For this study, health officials in each of the four cities first determined which causes of death to include in the review. All selected AIDS, *Pneumocystis carinii* pneumonia (PCP), and Kaposi's sarcoma (KS). In addition, officials in three of the cities selected unspecified pneumonia and the other opportunistic infections associated with AIDS (*2, 3*); in two of the cities non-Hodgkin's lymphoma was selected; and in one city deaths investigated by the medical examiner were reviewed—suicide, intravenous (IV) drug overdoses, and deaths for which the causes were not apparent initially. To simplify the review process, in three of the cities the study was limited to deaths occurring in age and sex groups most closely approximating those of previously reported AIDS patients: males ages 25 to 45 years in one city, males and females ages 15 to 64 years in another, and males and females ages 20 to 50 years in the other.

Certificates for deaths that occurred among city residents during any consecutive 3-month period from July through December 1985 were reviewed, and those that listed the pertinent causes of death were included in the study. For three of the cities, all of the death certificates were reviewed manually, and those with any of the pertinent causes listed anywhere on the certificate were chosen for the study. For the other city, a computerized search by ICD-9 code (International Classification of Diseases, Ninth Revision, code) was conducted for the underlying cause of death only (*4*). After a 1- to 3-month delay to allow time for cases to be reported through routine surveillance mechanisms, the deaths attributed to the selected causes were matched to confirmed resident cases already reported to the local AIDS registries. Matching was done by local AIDS surveillance personnel and involved comparing the names of patients on the AIDS registry with names on the death certificates. Demographic variables such as age, race, sex, and address were also used. If there was still doubt after these variables were compared, the physician who signed the death certificate was contacted. For deaths that could not be matched, medical records were reviewed to determine whether AIDS as defined by the CDC surveillance case definition (*2, 3*) had been diagnosed. Unreported AIDS cases identified in this manner were characterized by the patient's sex, race, risk group, and opportunistic disease and the reasons for not being reported.

The method of Chandra Sekar and Deming (*5*) was used to estimate the completeness of reporting AIDS cases:

| *Case identified by review of death certificate* | *Case reported to the surveillance system* | | *Total* |
|---|---|---|---|
| | *Yes* | *No* | |
| *Yes* | *a* | *b* | *D* |
| *No* | ... | ... | ... |

The character $a$ = AIDS cases identified in both the death records and the registry; $b$ = AIDS cases identified by review of death certificates only (unreported cases); and $D$ = total AIDS cases identified by review of death certificates. Completeness of reporting AIDS cases to the surveillance system = $a \div D$.

Ninety-five percent confidence intervals (CI) for the estimates of completeness of reporting were calculated with the use of the exact binomial distribution for the proportion of cases reported through the routine surveillance system. For cases

Table 1. Estimates of the completeness of reporting AIDS cases, by city [1]

| City | Deaths matched with case registry a | All cases found in review of death certificates D | Percent completeness of reporting (a ÷ D) × 100 | 95 percent confidence intervals |
|---|---|---|---|---|
| 1 ..... | 34 | 34 | 100 | 92–100 |
| 2 ..... | 39 | 39 | 100 | 93–100 |
| 3 ..... | 394 | 451 | 87 | 84–90 |
| 4 ..... | 20 | 24 | 83 | 63–95 |
| All..... | 487 | 548 | 89 | 86–91 |

[1] Participating cities were (by alphabetical order) Boston, Chicago, New York, and Washington, DC.

identified by the review of the death certificates, chi-square analysis was used to determine the significance of demographic differences between reported and unreported cases.

## Results

**Completeness of reporting.** No unreported cases were found for two cities. It was therefore estimated that completeness of reporting was 100 percent (with lower 95 percent confidence bounds of 92 and 93 percent) (table 1). For the other two cities, it was estimated that 87 percent (95 percent CI, 84 to 90 percent) and 83 percent (95 percent CI, 63 to 95 percent) of AIDS cases were being detected by routine surveillance. Combining results from the four cities yielded an estimate of 89 percent (95 percent CI, 86 to 91 percent) for the overall completeness of reporting.

**Results by specific cause of death.** A high percentage (73 to 80 percent) of death certificates listing AIDS, PCP, KS, and the other AIDS-related opportunistic infections corresponded to previously reported AIDS cases (table 2). Between 0 and 20 percent of these certificates represented unreported AIDS cases, and 0 to 17 percent were not classified as AIDS cases. Eleven death certificates (21 percent) listing unspecified pneumonia corresponded to previously reported AIDS cases; only one case (2 percent) was unreported. No unreported cases were identified from the certificates listing the other opportunistic infections or non-Hodgkin's lymphoma or from the review of the deaths investigated by the medical examiner.

When unreported and reported cases that were identified by the review of death certificates were compared, no significant differences were found by chi-square analysis with respect to race, sex, risk factor, or opportunistic disease. In most instances, cases had not been reported because of a breakdown in an established system (such as the key hospital reporter having been absent when the case was diagnosed) or because they were diagnosed in a hospital where reporting systems were not well established.

**Deaths not meeting the AIDS case definition.** Of 588 patients whose deaths were attributed on death certificates to AIDS, PCP, or KS, 494 (84 percent) had AIDS as defined by CDC's 1985 case definition, 77 (13 percent) were "clinically suspicious" for AIDS because they had an opportunistic disease included in the case definition but not confirmed by the required methods, and 17 (3 percent) either did not have a disease currently considered indicative of AIDS by the CDC definition (such as HIV-associated encephalopathy) or had another reason for underlying immunosuppression. In this study, the possible underascertainment of AIDS cases, assuming all cases identified with the use of less definitive diagnostic methods were in fact AIDS, was approximately 13 percent (77 ÷ 571).

**Predictive value.** We determined the proportion of patients with specific causes of death who had AIDS as defined by the CDC case definition (which we termed "predictive value") by dividing the number of AIDS patients whose death certificates included a particular cause of death by the total number of death certificates containing that cause (table 3). Because one study area selected for underlying cause only and the other three cities selected for any cause, we also determined if the predictive value of a particular cause was dependent on whether it was designated as the underlying cause or as one of any of the causes appearing on the death certificate. For AIDS per se, this was not a concern because, by convention, nosologic review always assigns AIDS as the underlying cause of death. For PCP and KS, we were able to calculate separate predictive values because these causes of death were reviewed by all four cities.

Other than for AIDS, PCP, and KS, we could calculate only a single cause-specific predictive value regardless of where the cause was listed among those recorded on the death certificate (table 3). The predictive value for AIDS, PCP, and KS on death certificates for case-definition AIDS (within the age and sex groups included) was high (more than 80 percent). For PCP and KS,

Table 2. Results of the review of death certificates for cases of AIDS, by cause of death

| Cause of death (ICD–9 code) | Number of cities selecting | Number of death certificates | Matched to registry | | Not matched to registry | | | |
|---|---|---|---|---|---|---|---|---|
| | | | | | Unreported AIDS cases | | Not AIDS | |
| | | | Number | Percent | Number | Percent | Number | Percent |
| AIDS (279.1) | 4 | 566 | 414 | 73 | 54 | 10 | 98 | 17 |
| *Pneumocystis carinii* pneumonia (136.3) | 4 | 41 | 33 | 80 | 5 | 12 | 3 | 7 |
| Kaposi's sarcoma (173.9) | 4 | 10 | 8 | 80 | 2 | 20 | 0 | 0 |
| Unspecified pneumonia (480.9, 486) | 3 | 53 | 11 | 21 | 1 | 2 | 41 | 77 |
| All other opportunistic infections indicative of AIDS (10–130) | 3 | 4 | 3 | 75 | 0 | 0 | 1 | 25 |
| Non-Hodgkins's lymphoma (200.2, 202.8) | 2 | 12 | 4 | 33 | 0 | 0 | 8 | 67 |
| Medical examiner cases: | 1 | 70 | 0 | 0 | 0 | 0 | 70 | 100 |
| Suicide | | 7 | 0 | 0 | 0 | 0 | 7 | 100 |
| IV drug overdose | | 33 | 0 | 0 | 0 | 0 | 33 | 100 |
| Other | | 30 | 0 | 0 | 0 | 0 | 30 | 100 |

Table 3. Predictive value of various causes of death for AIDS cases

| Cause of death | Method used to select death certificate | Number of AIDS cases (CDC case-defined) | Total death certificates with designated causes | Predictive value (percent) |
|---|---|---|---|---|
| AIDS | ... | 468 | 566 | [1] 83 |
| *Pneumocystis carinii* pneumonia | Underlying cause | 17 | 19 | 89 |
| | Any cause | 21 | 22 | 95 |
| Kaposi's sarcoma | Underlying cause | 5 | 5 | 100 |
| | Any cause | 5 | 5 | 100 |
| Unspecified pneumonia | Any cause | 12 | 53 | 23 |
| All other opportunistic infections indicative of AIDS | Any cause | 3 | 4 | 75 |
| Non-Hodgkin's lymphoma | Any cause | 4 | 12 | 33 |
| Medical examiner cases: | Any cause | 0 | 70 | 0 |
| Suicide | ... | 0 | 7 | 0 |
| IV drug overdose | ... | 0 | 33 | 0 |
| Other | ... | 0 | 30 | 0 |

[1] 468 ÷ 566 × 100 = 83.

there was no difference in the predictive values, whether they were selected as the underlying cause of death or as any one of multiple causes. The predictive value for the other specified opportunistic infections was also high, but the number of deaths was low. The predictive value of non-Hodgkin's lymphoma, unspecified pneumonia, suicide, IV drug overdose, and other medical examiner-investigated causes of death was low.

## Discussion

This study indicates that, in the four participating cities, AIDS case reporting is nearly complete and is much higher than reporting for many other communicable diseases. Marier estimated that the reporting rate for hepatitis was 11 percent; for salmonellosis, 42 percent; and for tuberculosis, 63 percent (*6*). Low reporting rates have also been estimated for other communicable diseases (*7,8*). The validity of the estimates of completeness of reporting depends on how well the two key assumptions of the Chandra Sekar and Deming model used to calculate completeness are met. The first and most important assumption is that the two systems to detect cases are independent. This assumption is valid because none of the cities used death certificates as part of the surveillance during

the study period. Also, there are no data to suggest that AIDS patients who die are any more or any less likely to be detected by a surveillance system than live patients. The second assumption is that the matching procedure can identify all possible matches and that matches that are identified are true matches. Matching was done by the local health officials using a variety of demographic variables in addition to name. In one of the cities, a small percentage of AIDS cases were reported without names, so matching could not be attempted. However, this would tend to underestimate completeness of reporting.

It is difficult to generalize these results to other areas or to other times. All four participating cities have similar active surveillance systems for detecting AIDS cases, and there was little or no underreporting. Other areas with similar active surveillance programs probably also have similarly low levels of underreporting. At least 24 State and local health departments (which have reported 93 percent of cases) conduct active surveillance for AIDS. Therefore, the results of this study probably reflect areas of the country where most of the AIDS cases are occurring.

The study of completeness of reporting was limited to a 3-month period for each of the four cities. However, the surveillance systems being evaluated had been in operation for several years. Thus, it may be possible to generalize the results to other times when active surveillance was in use. In New York City, few unreported cases were found in a validation study done in 1983 with the use of laboratory records (*1*). In San Francisco, consistently low levels of underreporting were found (0 to 3.1 percent) in a variety of validation studies conducted over a 5-year period (*9*).

Unreported cases found in this study were similar to reported cases with respect to sex, race, risk factor, and disease. This similarity, in addition to the high levels of reporting found, gives us added confidence in interpreting AIDS surveillance data. In general, nonreporting resulted from problems that could be resolved by (*a*) increasing communication between reporting sources and the health department, (*b*) ensuring that reporting will continue when primary reporting personnel are absent, and (*c*) establishing well-defined systems of reporting in all institutions treating patients with AIDS.

Of concern among persons conducting surveillance of AIDS is the extent to which cases are not being counted because they are not diagnosed according to confirmatory methods that meet the criteria of the current CDC case definition. The deaths found in this study that were attributed on death certificates to AIDS, PCP, or KS but were not definitively diagnosed indicated that the strictness of the current case definition may have resulted in an underestimation of total AIDS cases in these four cities. The total amount of underestimation is difficult to quantify from our data because we studied only patients who died, but additional studies are under way to determine the extent of underestimations.

Our results also indicate that a small number of patients (less than 4 percent of those with deaths attributed to AIDS) have presumed HIV-related illnesses that are severe enough to cause death but are not presently included in the case definition. As more becomes known about the spectrum of HIV-associated illness, the case definition can be modified so that all the most serious manifestations of infection will be counted.

Because surveillance for AIDS is important and is continually evolving, it is necessary to evaluate surveillance efforts periodically. For areas with ready access to vital records, the review of death certificates provides an easy and rapid means of evaluation. Alternatively, the review of death certificates could be a useful adjunct to other surveillance methods. For this purpose, it may be best to limit the review to certificates that designate AIDS, PCP, or KS as causes of death because they were found to be highly predictive of AIDS as defined by CDC and were the most useful in identifying cases not reported through the other surveillance mechanisms.

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# The Voluntary Acceptance of HIV-Antibody Screening by Intravenous Drug Users

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**Synopsis**

*Intravenous drug abusers in a methadone program in Minnesota were offered HIV-antibody screening to determine the degree of interest in screening and extent of infection. Thirty-nine (85 percent) were willing to be tested. Only seven refused. All patients were aware of acquired immunodeficiency syndrome (AIDS) and their high risk of exposure to the AIDS virus through sharing of injection paraphernalia. None reported exposure to additional risk factors, such as homosexual or bisexual activity or having received a blood transfusion.*

*Of the patients tested, none was positive for HIV antibodies. The high degree of patient interest in screening was unanticipated as was the lack of positive laboratory findings for HIV antibodies. Factors associated with acceptance of testing included patient awareness of high seroprevalence rates, indifference to potential negative social consquences of positive HIV-antibody status, and the voluntary nature of the testing. These findings raise a cautious sense of optimism about HIV-antibody screening for similar risk groups.*

CONSIDERABLE PUBLIC ALARM HAS BEEN created by the fear of widespread exposure to acquired immunodeficiency syndrome (AIDS). The number of cases meeting surveillance criteria of the Centers for Disease Control is predicted to double within the year (*1*). Data indicate extensive exposure to the AIDS virus human immunodeficiency virus (HIV) or HTLV-III/LAV in high-risk populations (*2*). In reaction, some local and national political figures have urged the passage of laws for the mandatory screening of individuals in the two primary high-risk groups—homosexual and bisexual males and intravenous (IV) drug users. In contrast to this stand, the Public Health Service has recommended voluntary testing for persons in high-risk groups (*3*).

Intravenous drug users are identified as the second highest risk group for the development of AIDS, constituting as many as 32 percent of reported cases in some areas (*4*). An estimated 270,000 IV drug users are infected in the United States alone (*5*). Spira and coworkers (*6*) found that among 86 New York City IV drug users in a drug detoxification program, 87 percent were seropositive for HIV antibodies in laboratory screening (ELISA) (*7*). In contrast, it has been reported that less than 10 percent of 35 methadone patients in New York City were seropositive (*8*).

Based on these reports, it was estimated that a number of patients currently active in an outpatient methadone maintenance program would test positive for HIV antibodies. In addition, clinic staff anticipated difficulty in securing voluntary patient cooperation with laboratory screening.