



Acquired immunodeficiency syndrome: case reporting at a university hospital

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- **BACKGROUND** Planning and allocating resources for care of patients with acquired immunodeficiency syndrome (AIDS) requires accurate assessment of disease incidence.
- **OBJECTIVE** To assess the accuracy and completeness of AIDS case reporting at our institution, we reviewed all inpatient and outpatient records of patients with AIDS seen at University Hospitals of Cleveland, Ohio, between January 1983 and July 1990.
- **METHODS** The patients were identified through review of hospital discharge summaries, ambulatory clinic listings, and laboratory identification of opportunistic infections.
- **RESULTS** We found that 24 of 291 AIDS cases (8%) seen at this institution had not been reported to state health departments. Of the 24 patients with unreported AIDS, 16 had received an AIDS diagnosis at other institutions, 11 had never been hospitalized at this institution, and 2 had used pseudonyms.
- **CONCLUSIONS** Review of AIDS case reporting can ascertain the magnitude of underreporting; the profile of patients who were unreported may be used to evaluate the accuracy of reporting elsewhere and to identify systematic problems in case reporting methods.

■ **INDEX TERMS:** ACQUIRED IMMUNODEFICIENCY SYNDROME; PUBLIC HEALTH ADMINISTRATION; DATA COLLECTION; MEDICAL RECORDS ■ CLEVE CLIN J MED 1993; 60:202-206

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AS THE ACQUIRED immunodeficiency syndrome (AIDS) epidemic grows, accurate and complete case reporting is essential to assess the incidence of the disease. To evaluate the accuracy of AIDS case reporting in a major university teaching hospital, we reviewed all AIDS cases seen at this institution.

University Hospitals of Cleveland is a 950-bed university-affiliated teaching hospital that provides medical services to a catchment area that includes poor urban and affluent suburban communities. The hospital is also a tertiary referral center for Northeast Ohio.

University Hospitals is one of the largest AIDS care providers in Ohio. Its ambulatory AIDS clinic, the Special Immunology Unit (SIU), provides ambulatory care for all adult, nonhemophilic patients seen at University Hospitals who are seropositive for human immunodeficiency virus (HIV). Hemophilic patients with AIDS are managed in the Hemophilia Clinic, and children with AIDS are cared for by the Pediatric Infectious Disease Group; both of these

clinics provide ambulatory care.

AIDS reporting at University Hospitals is coordinated by an infection control nurse who identifies cases through rounds with the infectious-disease team, personal notification by physicians, laboratory detection of opportunistic infections (eg, cryptococcal antigenemia or isolation of *Mycobacterium avium-intracellulare*), and notification by personnel in the three ambulatory care clinics.

The SIU AIDS program coordinator identifies new AIDS cases by reviewing patient intake forms filled out by patients on their initial visit to the SIU and submits a monthly update to the infection control nurse. Similarly, pediatric infectious disease specialists and the Hemophilia Clinic coordinator report each pediatric and hemophilic case of AIDS to the infection control nurse.

The infection control nurse reports newly diagnosed cases to the Ohio Department of Health within 1 month of identification. An AIDS reporting form is filled out for the new cases; if a case may have been previously diagnosed in another state, the Ohio Department of Health confirms the reporting status by contacting the health departments of states where the patient may have been diagnosed. The Ohio Department of Health then removes personal identifying information and forwards the data to the Centers for Disease Control.

METHODS

To verify the completeness of AIDS case reporting at University Hospitals, we used ambulatory clinic listings, medical records listings, and clinical laboratory records to identify patients with AIDS who were diagnosed from January 1, 1983 to July 15, 1990.

Ambulatory clinic listings of AIDS patients were obtained from patient care coordinators in the SIU, the Hemophilia Clinic, and the Pediatric Immunology Clinic. Hospital medical records were reviewed to identify patients whose discharge summaries had been coded under AIDS-defining or

TABLE 1
CASES OF ACQUIRED IMMUNODEFICIENCY SYNDROME (AIDS)
IDENTIFIED THROUGH REVIEW OF HOSPITAL DISCHARGE CODES

ICD-9*	Diagnosis	Cases		
		All	Non-AIDS	AIDS
042.0	AIDS with infection	66	0	66
042.1	AIDS causing infection	21	0	21
042.2	AIDS with malignant neoplasm	23	0	23
042.9	AIDS, unspecified	139	0	139
136.3	Pneumocystosis	137	31	106
173.0	Kaposi's sarcoma	5	0	5
130.0	Toxoplasmosis of brain	5	0	5
279.19	AIDS before 1986	15	0	15
Total AIDS-related discharge codes		411	31	380

*International Classification of Disease (ninth revision)

AIDS-related codes of the International Classification of Disease, ninth revision (ICD-9).

Clinical laboratory diagnoses of opportunistic infections were reviewed. These included (1) cultures from any site positive for *M avium-intracellulare*; (2) cryptococcal antigen titers > 1:4 in blood or cerebrospinal fluid; (3) bronchoalveolar lavage samples positive for *Pneumocystis carinii* by Gomori-methenamine silver stain; and (4) biopsy specimens compatible with *Cryptosporidium* on hematoxylin-eosin stain or stool specimens positive for *Cryptosporidium* by modified acid-fast stain. Charts of all patients identified with cryptococcosis or *M avium-intracellulare* infection were reviewed to distinguish AIDS patients from patients with other underlying conditions.

AIDS cases revealed through these reviews were checked against the current Ohio Department of Health line listing of AIDS cases reported from University Hospitals. Cases not on this line listing were investigated by the Ohio Department of Health to see whether they had been reported in any other states. Cases not reported to the Ohio Department of Health or to other state health departments by August 15, 1991, were designated as unreported AIDS cases.

RESULTS

Review of discharge diagnoses by ICD-9 codes identified 411 hospitalizations of patients with AIDS (Table 1). Charts of these patients were reviewed to exclude other underlying non-AIDS immunosuppressive illnesses. Thirty-one of 137 cases of pneumocystosis occurred in patients with other un-

TABLE 2
EFFECTIVENESS OF REVIEW IN IDENTIFYING UNREPORTED CASES
OF ACQUIRED IMMUNODEFICIENCY SYNDROME (AIDS)

Source reviewed	AIDS cases			
	Identified in review	Not identified in other reviews	Unreported	Unreported, not identified in other reviews
Discharge codes	194	10	9	1
Laboratory listing	122	1	1	0

TABLE 3
CASES OF ACQUIRED IMMUNODEFICIENCY SYNDROME (AIDS) IDENTIFIED
THROUGH REVIEW OF LABORATORY RECORDS OF OPPORTUNISTIC INFECTIONS

Infection type	Cases		
	All	Non-AIDS	AIDS
Cryptosporidiosis	6	0	6
Cryptococcosis	87	56	31
<i>Pneumocystis carinii</i> pneumonia	49	0	49
<i>Mycobacterium avium</i> intracellulare infection	146	68	78

derlying disorders; all other codes identified only AIDS patients. Excluding these 31 hospitalizations yielded 380 hospitalizations of patients with AIDS.

The 380 hospitalizations identified by review of discharge codes were distributed among 194 patients with AIDS (Table 2). Ten of these patients were not identified through the other reviews. Of the 194 hospitalized patients, 9 had not been reported to the Ohio Department of Health or other state health departments.

Review of laboratory diagnoses identified 288 cases of opportunistic infection (Table 3). Review of hospital records revealed that 68 of 146 *M avium-intracellulare* infections and 56 of 87 instances of cryptococcal antigenemia occurred in patients without clinical or laboratory indication of HIV infection. In 4 patients with cryptococcal infection, the information available was insufficient to establish or exclude a diagnosis of HIV infection. Thus, of 288 cases of opportunistic infection identified through this review, 164 were found to be in patients with AIDS.

These 164 infections occurred in 122 patients (Table 2); 1 of these patients was not identified through other reviews. Only 1 of the patients identified from laboratory diagnoses had not been reported to state health authorities; this patient was also identified by review of ambulatory clinic lists.

Review of ambulatory clinic lists identified 276

AIDS patients seen at this center (253 at the SIU, 4 in the pediatric infectious disease clinic, and 19 in the Hemophilia Clinic). Eighty AIDS patients were identified only through this review. Twenty-three of the 276 patients seen in the ambulatory clinics had not been reported to state health authorities; 16 of these were identified only through review of SIU records.

Altogether, review of hospital discharge codes, laboratory records, and ambulatory clinic records identified 291 patients with AIDS who received care at University Hospi-

tals of Cleveland between January 1, 1983 and July 15, 1990. Of these 291 patients, 24 had not been reported to any state health authorities as of September 15, 1990.

The 24 unreported patients all presented between March 1988 and July 1990. Their AIDS-defining illnesses were *P carinii* pneumonia (12 cases), Kaposi's sarcoma (5 cases), cytomegalovirus infection (2 cases), dementia (2 cases), cryptosporidiosis (1 case), *Candida* esophagitis (1 case), and persistent herpes simplex virus infection (1 case). Eleven patients had been hospitalized from one to three times for treatment for an AIDS-related condition; all but 1 had visited the SIU for AIDS care. The mean number of SIU visits was 6.9 (range 1 to 21). Sixteen of the 24 unreported patients had their AIDS diagnoses established at other institutions; 13 of these institutions were in other states.

DISCUSSION

Planning and allocating resources for AIDS care requires accurate assessment of disease incidence.^{1,2} The incidence of AIDS may be estimated by adjusting reported cases to correct for anticipated reporting delays.³

Case reporting rates vary significantly between states and hospitals, and studies of the state and local

reporting systems have demonstrated ways to improve incident AIDS case reporting. Active surveillance methods substantially improved statewide case reporting rates in South Carolina and Oregon.⁴⁻⁶ These methods also improved case reporting in Philadelphia hospitals.⁷ Periodic active surveillance can improve current case reporting and might identify mechanisms to improve reporting in the future.

Underreporting

Our review of ambulatory patient records, laboratory diagnoses of opportunistic infections, and discharge diagnoses revealed that at least 291 AIDS patients received care at University Hospitals between January 1, 1983, and July 15, 1990. Of these identified cases, 24 (8%) had not been reported to state health departments. Review of these cases identified factors that may have contributed to underreporting (Table 4).

Of the 24 unreported patients, 16 presented with a diagnosis of AIDS already established elsewhere. This finding indicates that AIDS care providers should not assume that patients with AIDS are routinely reported as required by law.

Patients with AIDS who had never been hospitalized were less likely to have been reported to state health departments. Of 97 AIDS patients who had never been hospitalized, 11 (11%) had not been reported. In contrast, 9 of 194 hospitalized AIDS patients (5%) had not been reported to state health departments. The difference is significant ($P < .05$, Fisher's exact test); the additional surveillance and reporting mechanisms provided for hospitalized patients may account for this difference.

All of the unreported patients presented with AIDS-defining conditions after March 1988, no earlier than 2 years before this review. The lack of unreported AIDS cases before 1988 suggests that as patients develop multiple AIDS-defining conditions and require hospitalization, they are more likely to be identified and reported to state health authorities.

On the other hand, our reporting system may have become less thorough: increasing AIDS case loads may have diverted attention from case reporting responsibilities. Changes in the Centers for Disease Control AIDS case definition (which has been expanded to include patients without defined opportunistic infections or neoplasms) probably did not have a substantial effect on reporting, since all but two patients who were not reported had major

TABLE 4
CHARACTERISTICS OF 24 PATIENTS WITH ACQUIRED IMMUNODEFICIENCY SYNDROME (AIDS) WHO WERE NOT REPORTED TO STATE HEALTH AUTHORITIES

Characteristic	n
AIDS diagnosed elsewhere	16
Never hospitalized	11
AIDS dementia complex	2
Pseudonym used	2
Public prominence	1
Clerical oversight	1

opportunistic infections or AIDS-defining malignancy and therefore would have been included under earlier definitions.

Additional issues also may have contributed to underreporting. Two patients had a clinical diagnosis of AIDS dementia complex; the information available to the infection control nurse, however, was insufficient to fulfill Centers for Disease Control criteria for this AIDS-defining condition. Two of the unreported patients had hospital records under pseudonyms. Another patient was a prominent public figure who may not have been reported for this reason. Yet another patient, who was first seen on an emergency basis in the late stage of disease, was admitted to the hospital directly through the SIU; an admitting form was not filled out for this patient and consequently the coordinator of the SIU did not identify this patient through the usual system of reporting.

Improving case reporting accuracy

It remains to be seen whether the major revisions in AIDS case definitions currently under consideration will affect the accuracy of case reporting. Although mandatory reporting of patients with positive serologic tests for HIV infection may provide better estimates of prevalence of infection, accurate reporting of AIDS incidence will still require careful attention to clinical and laboratory events.

At our institution, review of ambulatory records identified 23 of 24 unreported AIDS cases (Table 2). Review of hospital discharge summaries identified 9 of 24 cases, and review of laboratory diagnoses of opportunistic infections identified only 1 of 24 unreported cases. Thus, review of ambulatory records provided the most productive and efficient means of identifying unreported cases at our institution.

Because the SIU has a defined, well-organized protocol for case reporting, fewer than 10% of all AIDS cases seen at the SIU were unreported. A simple review of the reporting protocol would not have identified procedural problems: a methodical cross-check of cases reported to the state department of health was required to identify underreporting.

Ambulatory AIDS programs at other institutions may be organized differently; nevertheless, our findings suggest that a selective sampling of an ambulatory center's reporting accuracy might identify reporting problems. Selecting referred patients whose AIDS-defining condition was diagnosed elsewhere and patients who had not been hospitalized might provide a relatively efficient means of assessing the completeness of reporting.

As a result of our survey, several strategies have been implemented at this institution to ensure more thorough reporting in the future. All patients who present with a diagnosis of AIDS that was made elsewhere are now considered to represent unreported cases (coordination of reporting by state

health departments minimizes the chance that a patient will be reported to the Centers for Disease Control more than once). Moreover, the SIU AIDS program coordinator no longer depends only on patient intake forms as a source of new patient listings; instead, the SIU registry, which lists all SIU patients regardless of AIDS status, is now reviewed monthly for new AIDS cases.

The results of this study demonstrate that at an institution well organized to provide AIDS care, 8% of AIDS cases were not reported to state health departments. Surveillance and updating of AIDS case-reporting systems can be routinely applied at hospitals providing AIDS care and may help to maintain and improve the accuracy of AIDS case reporting.

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