Auditing AIDS reporting. Experience from a central London district 1982-1991

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Abstract

Objective—To evaluate completeness of reporting of cases of AIDS to the Communicable Disease Surveillance Centre (CDSC) between 1982-1991.

Setting—Southside of the Bloomsbury and Islington District Health Authority.

Design—Reconciliation exercise with CDSC of cases reported with those known to have received treatment in the district from 1982 to March 1990. Case note review of unreported cases and follow-up at March 1991.

Main outcome measures—Delayed and non-reporting of cases.

Results—Cumulatively 13% (46/351) of patients whose initial AIDS illness was diagnosed in the District remained unreported by March 1991. Non-reporting increased from 9% (2/23) of cases diagnosed prior to 1985 to 28% (26/92) of cases diagnosed between 1989 and 1990. After September 1987 the proportion of patients with a diagnosis of *Pneumocystis carinii* pneumonia or Kaposi's sarcoma was significantly higher in the reported group than in the non-reported group: 78% (124/158) v 51% (24/49) $p < 0.001$. Nine of 19 (47%) cases of AIDS transferring their care into the district had not been reported by their previous District Health Authority.

Conclusions—Within the district non-reporting of cases of AIDS has risen over time as the numbers of patients treated has increased. The physician must be aware of the full AIDS case definition for surveillance purposes and the implications of non-reporting for the allocation of special "ring-fenced" resources for AIDS care. Adequate investment in information and reporting systems would seem essential.

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Introduction

Since 1982 the number of reported cases of the Acquired Immunodeficiency Syndrome (AIDS) and human immunodeficiency virus (HIV) infection has increased worldwide. Within the UK the epidemic has centred largely on the metropolitan areas of London and Edinburgh, creating a major challenge to community and hospital medical services. The Communicable Disease Surveillance Centre (CDSC) and the Communicable Disease (Scotland) Unit (CD(S)U) have undertaken to monitor this epidemic within the UK, helping

to identify both the extent and pattern of the epidemic over time. The validity of this surveillance data relies on the completeness of voluntary reporting by physicians of all cases of AIDS.

The case definition for AIDS was first established in 1982 by the Centers for Disease Control (CDC) in Atlanta, USA and modified in 1985 when laboratory tests for evidence of HIV infection became available. In September 1987 the definition was revised to reflect changing clinical practice and to represent more accurately for surveillance purposes the varied morbidity associated with HIV.¹ In the UK the Communicable Disease Surveillance Centre (CDSC) in addition requests physicians to report deaths of people infected with HIV but in whom no AIDS indicator disease as specified in the case definition has been diagnosed.

In allocating "ring-fenced" resources for treatment and care costs for AIDS/HIV services the Department of Health relies partly on the number of cases of AIDS reported to CDSC by each District Health Authority (DHA).² The AIDS Control Act of 1987 also makes it obligatory for DHAs to compile and publish annual reports on the number of people with AIDS and HIV infection (non AIDS) first reported locally.

Evidence from mortality data has long suggested that reporting of AIDS is incomplete.^{3,4} Within our DHA the District Information Officer for AIDS/HIV had identified a discrepancy between the cumulative number of reported cases of AIDS submitted to the CDSC and the number of cases known to have been treated within the District. Subsequently the CDSC recognised that some patients receiving terminal respite care at a nearby hospice specialising in HIV-related illnesses had not been reported by their original referring Health Authority.

We therefore undertook an exercise to investigate the extent of under-reporting of cases of AIDS within our DHA in order to remedy existing under-reporting and improve future resource planning and reporting procedures.

Methods

A computerised information system was set up within the Southside (formerly Bloomsbury DHA) of the Bloomsbury and Islington Health Authority in 1986. This established a surveillance database to monitor continuously the number of patients with AIDS and the use of in-patient resources for HIV-related illnesses. Cases of AIDS for this database were identified

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Table 1 Patterns of reporting of cases of AIDS by year of diagnosis 1982-1990. (Delayed reporting: 3-12 months after diagnosis; non-reporting: > 12 months after diagnosis irrespective of subsequent reporting). This table includes only those patients who received their first diagnosis of AIDS in the district

Year of diagnosis (April-March)	Total AIDS cases	Incidence of delayed reporting		Incidence of non-reporting		Cases remaining unreported at 31 September 1990 (31 March 1991)	
		n	%	n	%	n	%
1982-85	23	4	17	2	9	1 (1)	4
1985-86	23	3	13	3	13	2 (2)	9
1986-87	57	12	21	12	21	5 (5)	9
1987-88	72	23	32	8	11	6 (6)	8
1988-89	84	25	30	18	21	15 (11)	18 (13)
1989-90	92	23	25	26	28	30 (21)	33 (23)
Total	351	85	24	69	19.6	59 (46)	17.8 (13)

from individual clinicians treating patients, from liaison with the CDSC, from in-patient returns from the dedicated HIV ward and from an in-house computer system of all out-patients attending the main department of genitourinary medicine. The latter had only been available as a source of data since 1988 when statutory returns to the Department of Health (KC60) included information on the number of cases of AIDS and HIV infection being treated.

From this database a discrepancy between the number of cases of AIDS known to have been reported to the CDSC and the total number diagnosed within the District up to 31 March 1990 was identified. Reconciliation of District data with that held by the CDSC by use of soundex alphanumeric code of patients and their date of birth confirmed those who had been reported.

On completion of this exercise a list of cases which remained unreported by October 1990, at least 6 months after the initial AIDS diagnosis, was compiled. The case notes of these patients were then examined to confirm the diagnosis of AIDS.

In October 1990 the unreported cases were notified to clinicians and following this in March 1991 a further review was undertaken to take into account those cases which had subsequently been reported. In line with the proposal by Evans *et al*⁵ delayed reporting was defined as three to 12 months interval between diagnosis and report, and non-reporting as greater than 12 months interval irrespective of whether they were subsequently reported or not. The cumulative under reporting group are those who remained unreported at time of analysis irrespective of time from diagnosis.

Results

Of a cumulative total of 399 probable cases of AIDS within the District and recorded on the

database to 31st March 1990, 107 had not been reported to the CDSC. In addition the CDSC had been notified of 13 other cases (3.8%) which had not been identified by the database. Seven of these 13 had been reported by general/private practitioners. Of the 107 unreported cases 87 were confirmed by the audit exercise to fulfil the criteria for a diagnosis of AIDS. Of the 20 cases who did not meet this surveillance definition two had died, one from a Hodgkin's lymphoma and the other from overwhelming bacterial sepsis. Of the remaining 18 cases, eight received in-patient treatment for either a bacterial pneumonia or pulmonary tuberculosis and 10 had been incorrectly assigned a diagnosis code (KC60) indicating AIDS by the clinician.

Thus 23% (87/379) of the total number of AIDS cases seen up to 31 March 1990 had not been reported by the District to the CDSC by October 1990. Of these 87 cases 28 had their first AIDS defining illness diagnosed and treated outside the District. Following a reporting drive 13 of the remaining 59 were subsequently notified to the CDSC by 31 March 1991 reducing the cumulative percentage who remained unreported and whose initial diagnosis occurred within the district to 13%.

By year of diagnosis the incidence of non-reporting increased from 9% of cases diagnosed before March 1985 to 28% diagnosed between April 1989 to March 1990. Cumulatively the percentages remaining unreported by year of diagnosis are smaller as a result of very late reporting and efforts to improve reporting (table 1).

Similar proportions of patients reported or who remained unreported to the CDSC had either attended the two main departments of genito-urinary medicine in the district or the HIV designated in-patient ward (90% v 94%).

The AIDS surveillance definition was modified in September 1987. Of the 351 patients with AIDS 207 were diagnosed after this date. In this group of patients *Pneumocystis carinii* pneumonia (PCP) was the AIDS defining illness in 55% reported within 12 months but in only 37% of those who were not (non-reported) (table 2). The proportion of patients presenting with lymphoma, AIDS related dementia, wasting syndrome and opportunistic infections other than PCP was higher in the non-reported group than the reported group ($p < 0.001$).

Of the 28 cases with an initial diagnosis

Table 2 Initial AIDS defining illness of reported and non-reported (> 12 months) cases diagnosed between 1 September 1987 and 31 March 1990

AIDS diagnosis*	Reported		Non-reported	
	n	%	n	%
<i>Pneumocystis carinii</i> pneumonia (PCP)	87	(55)	18	(37)
Kaposi's sarcoma (KS)	37	(23)	7	(14)
Opportunistic infections (Excl PCP)	21	(13)	12	(25)
Lymphoma	5	(3)	5	(10)
HIV encephalopathy	6	(4)	3	(6)
Wasting Syndrome	2	(1)	4	(8)
Total	158		49	

*Comparison of proportions of PCP, KS or other in reported and non-reported groups: $\chi^2 = 14.01$, $p < 0.001$.

outside the District, 19 had transferred their continuing care into the District and nine were visitors from outside London receiving care temporarily of whom five were from overseas. Ten of these 19 transfers and three of the nine visitors had been reported to the CDSC by doctors in other Health Authorities.

Thus overall 15.5% (58/379) of all patients with AIDS treated within Bloomsbury prior to 31 March 1990 remained unreported by 31 March 1991. The CDSC in an ascertainment exercise with a nearby hospice specialising in HIV-related illnesses had been able to identify 14 of the 58 patients reducing the proportion unknown to the CDSC to 12% (44/379) or if only those initially diagnosed in the District are included to 10% (35/351).

Discussion

This audit exercise established that the District had failed to report to the CDSC approximately one in five patients diagnosed with AIDS who had received or were currently receiving care at 31 September 1990.

Following a concerted drive to remind clinicians of unreported cases and excluding those cases diagnosed outside the District the cumulative percentage that remained unreported at 13% is similar to and confirms the rate estimated by other ascertainment exercises undertaken by the CDSC.⁶

For purposes of surveillance this figure is an overestimate as the CDSC have been able to identify patients from sources other than from the reporting forms submitted by the District. In addition, it also does not take into account a proportion of the unreported cases who later transferred their care out of the District (9/59) who may have been reported subsequently by other Health Authorities. However, none of these cases would be attributed to the District for the purposes of resource allocation.

There has, though, been a proportionate increase in non-reporting of AIDS cases by the District as the number of cases of AIDS has increased each year. Thus approximately one in four of patients with AIDS presenting between April 1989 and March 1990 had failed to be reported within one year of the initial diagnosis compared with approximately one in 10 between April 1985 and March 1986. Some of these cases have subsequently been reported reducing the overall rate, and the District is not alone in reporting cases with considerable delay. For example, of cases reported to the CDSC in the first three months of 1991, one in seven had been diagnosed in 1989 or earlier.⁶ The increasing incidence of non-reporting per year could in part be secondary to the rising number of cases diagnosed per year. Physicians may be more likely to omit the reporting as their caseload increases. The number of cases of AIDS per year is projected to continue to rise⁷ the implication of non-reporting for the larger centres may mean they disproportionately lose out in the annual round of resource allocation if the under reporting is proportionally lower in other Districts.

Although we did not specifically examine the

reasons for individual clinicians not reporting, analysis of cases suggests that two factors on which this may depend are the initial AIDS defining diagnosis and whether this diagnosis first occurred outside the district.

In 1987 the case definition of AIDS¹ was expanded to include HIV encephalopathy, HIV wasting syndrome and a more extensive range of specific AIDS indicator diseases including presumptive diagnoses in an attempt to improve the surveillance data on severe morbidity associated with HIV infection. This extension of the case definition may have contributed to the non-reporting over time. After September 1987, of those cases reported within 12 months, 21% had a diagnosis other than PCP or Kaposi's sarcoma compared with 48% in those not reported. Physicians may not be sufficiently aware of the full WHO AIDS surveillance definition and this problem may become greater if the less common AIDS indicator diseases become more prevalent. Although *Pneumocystis carinii* pneumonia remains the most common initial AIDS defining illness⁸ changing medical practice may influence this in the future. Primary PCP prophylaxis for patients with mild symptomatic disease or those asymptomatic with a low CD4+ count⁹ is increasingly being used and may in the future decrease the proportion of patients presenting with PCP. Therefore it is likely that other AIDS defining diseases will in time become more common as the initial diagnosis.

As over 90% of the patients with AIDS both reported and non-reported attended either the two main departments of genitourinary medicine or the HIV designated in-patient ward in the district, it would seem essential, that clinicians working in these departments should undergo regular training into whom and how to report. If the database underestimated the number of patients with AIDS attending outside these core departments, then such training should be extended to other clinicians most likely to come into contact with patients presenting with AIDS.

Approximately one fifth of unreported patients transferred their continuing care into the District but had their initial diagnosis established by another Health Authority. Physicians may have assumed that such cases had been previously reported by their original Health Authorities but in only a half was this the case. For surveillance purposes it is important for the CDSC to be aware of all cases and a reporting doctor will be informed if the report is a duplicate of one previously received from elsewhere. More importantly for the District Health Authority providing care, "ring fenced" resources are allocated from central funds in proportion to the number of live patients with AIDS initially reported by the District.² Evidence from the District resource use database indicates that the person transferring will consume similar levels of resources overall as those persons whose AIDS defining illness was diagnosed in the District (Anne Hawkins, personal communication 1991) though at present funds do not follow an AIDS

patient previously reported on transfer of care.

Physicians should be aware that allocation of central resources and adequate provision of care are dependent on the completeness of reporting. Despite efforts to remind physicians individually of their unreported cases in October 1990, after 6 months only 13 of the 59 cases identified as unreported were notified to the CDSC. However, the projection reports previously published^{7 10} allowed for 20% under reporting and the cumulative total within the District is well within this figure. We wish to note that by the end of 1991 the majority of the remaining 46 cases had been reported or were known to the CDSC.

This audit exercise has highlighted the need for a local monitoring system which readily identifies unreported cases within a time period and succeeds in achieving timely reporting by physicians.

Such a system could rely in part on the use of identification codes signifying a reported case either within the patients notes or on a computerised information system onto which clinical diagnosis codes (KC60) are entered. The CDSC allocate a number to the report of a patient with an AIDS defining illness, this CDSC number had been incorporated into the District database allowing for non-reported cases to be identified. Use of any identification

code must ensure confidentiality of diagnosis and avoid labelling of patients.

For both the planning of service use and the provision of adequate resources training of clinicians in reporting procedures and local investment in good information and reporting systems which readily monitors the AIDS/HIV caseload would seem essential.

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