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Completeness of reporting of AIDS cases

Doctors should beware of "reporting fatigue"

In the United Kingdom the surveillance of AIDS is based on a voluntary confidential reporting scheme. For each confirmed or suspected case doctors are asked to complete a special clinical report, which is then forwarded to the Public Health Laboratory Service Communicable Disease Surveillance Centre (CDSC) in England and Wales or to the Communicable Diseases (Scotland) Unit. For purposes of surveillance cases of AIDS are defined by the presence of specified indicator diseases in people who usually have laboratory evidence of infection with HIV-I.¹ Since mid-1989 doctors have also been asked to complete clinical report forms on deaths in people known to have been infected with HIV-I but in whom no indicator disease was diagnosed. As an extra safeguard for preserving the confidentiality of a patient's surname reporting doctors are encouraged to use the Soundex alphanumeric code as an alternative.*

These reports provide an insight into the pattern, extent, and trend of the HIV-I epidemic and give information necessary for providing services^{2,3} and evaluating prevention programmes. Reports on deaths of people infected with HIV-I but without AIDS allow better estimates of the impact of the HIV-I epidemic and contribute to the evaluation of the case definition for AIDS.⁴ Doctors appreciate the need for the scheme: by the end of April over 750 doctors throughout the United Kingdom had reported 4568 cases of AIDS.

Evidence exists, however, that the reporting of AIDS is incomplete.⁵⁻⁸ As making AIDS a statutorily notifiable disease would not necessarily lead to complete reporting⁹ what other strategies are available for improving reporting?

Supplementary ascertainment of cases is one such method. Possible cases of AIDS are ascertained from death registration data received at the Office of Population Censuses and Surveys and by the registrar general for Scotland; laboratory reports of opportunistic infections; clinical information in laboratory reports of HIV-I infections; reports by directors of haemophilia centres to the secretariat at the Oxford Haemophilia Centre; and regular returns by paediatricians to the British Paediatric Surveillance Unit.⁴ Doctors of patients identified by these methods are invited to complete a clinical report.

Comparing the number of cases of AIDS obtained by supplementary ascertainment with the number that has been reported to national registers gives an estimate of underreporting, although interpreting the difference is difficult for several reasons. Firstly, cases of AIDS are frequently ascertained through multiple channels and are

*Copies of the current case definition, clinical report forms, Soundex code guide, and guidance on reporting are available from the CDSC (081 200 6868) and Communicable Diseases (Scotland) Unit (041 946 7120) and from local consultants in communicable diseases, genitourinary medicine, infectious diseases, and microbiology.

usually reported eventually; thus the boundary between validation of surveillance and surveillance itself is blurred. Secondly, for any condition of long duration with an increasing incidence a delay between diagnosis and reporting will be inevitable and underreporting constant. For example, of the 358 cases of AIDS reported during the first three months of 1991, 30 had been diagnosed in 1989, 15 in 1988, and six in 1987 or earlier. (Mathematical techniques can adjust for this delay.¹⁰)

Thirdly, some methods of ascertaining suspected cases—such as the use of death entries—are relatively quick, and this should be allowed for when comparisons are made. Fourthly, unreported "possible cases of AIDS" are a heterogeneous group comprising diagnosed cases, unrecognised cases, severe disease related to HIV-I infection not meeting the criteria for AIDS, coincidental diseases unrelated to HIV-I infection, and diseases in people not infected with HIV-I.

The CDSC has adopted several approaches to estimate underreporting. Since 1989, 1414 possible cases of AIDS from 20 districts have been sought in the national register: 1102 (78%) had been reported. A further 113 (8%) were later reported, and, given that many of the remaining subjects had yet to develop AIDS, the underreporting rate for established cases of AIDS in these districts would be less than 14%. Last year extensive case searching in three districts found that only 28 (4%) of 666 cases of AIDS diagnosed locally in 1988 or earlier had not been reported to the CDSC. Of the patients with AIDS who had received respite and terminal care at two London centres, about one in 10 had not previously been reported. At the time of a study of laboratory reports of selected opportunistic infections in people who were also infected with HIV-I about 10-15% had not been reported as having AIDS.

In this issue McCormick has compared estimated excess deaths from 86 medical causes possibly related to HIV-I infection with the number of reported deaths from AIDS and concluded that 92% of deaths from AIDS in 1989 were reported (p 1375).¹¹ As more deaths from AIDS in 1989 will probably be reported in 1991 and 1992 the underreporting rate will fall further. Current data therefore suggest that the rate of underreporting of cases of AIDS in the United Kingdom lies between 5% and 20%.

The most effective way of ascertaining cases locally is to review the clinical state of people known to be infected with HIV. As Hickman and colleagues show, the number of people known to be infected with HIV may be substantially greater than the number reported nationally (p 1376).¹² Although the authors recognise that the size of the discrepancy may be unique to Riverside district, their results emphasise the value of audit.

Other work reported in this issue shows the need for

heightened clinical awareness that certain diseases may be related to unrecognised infection with HIV-I. Compared with data for 1984, McCormick found an excess of 295 deaths in 1989 from 11 specified causes (which included deaths from pneumonia, specific neoplasms, and external causes) in men aged 15-54 in England and Wales (p 1365).¹³ She estimated that if these 295 were infected with HIV-I then in only 40% had the infections been diagnosed. Doctors should therefore consider underlying HIV-I infection in any young or middle aged man in whom either pneumonia or certain malignant neoplasms have been diagnosed.

The information provided by the surveillance of cases of AIDS is important for the primary prevention of this fatal disease. Moreover, earmarked funds for direct treatment and care are allocated in proportion to the number of people with

AIDS¹⁴—the chief medical officer has stated that under-reporting could lead to the inappropriate allocation of resources, ultimately compromising the care of patients.¹⁵ As the epidemic of AIDS intensifies doctors should guard against “reporting fatigue” and continue to report cases of AIDS promptly.

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Who decides for those who can't?

The Law Commission wants advice on making decisions for the mentally handicapped

Recent cases on the sterilisation of mentally handicapped women have revealed a yawning gap in the law.¹ In England and Wales, at least when it comes to medical decisions, no one—not relatives, doctors, or even the court—has the legal power to take a decision on treatment when the patient is mentally incompetent. As the sterilisation cases showed, the court's powers are limited to declaring that in the circumstances of the individual cases the doctors carrying out the operation would not be acting unlawfully.

The law on all types of decision making for mentally incompetent adults is outdated, fragmented, and full of holes. Canada, the United States, Australia, and many western European countries have overhauled this aspect of the law. In Britain both the Law Commission, the official law reform body for England and Wales, and its Scottish counterpart are formulating proposals for reform. In some aspects of life—for instance, decisions on accommodation or relationships—there are no legal procedures at all. In others the law operates so unsatisfactorily that it is ignored or rarely used. “As a consequence,” the commission says, “the decision making process is largely unregulated and is open to exploitation and abuse. At times decisions which need to be made may not be made at all, or may be made too late. If this is so the law is frequently failing the very people it is intended to help and protect.”²

The law fails not only mentally handicapped and mentally ill people but also those brain damaged by accident or with degenerative brain disorders such as Alzheimer's disease. Firstly, as the commission points out, it fails to address the problem of what tests should be used to decide whether a person is or is not capable of taking a particular decision. Many mentally impaired people will be able to take some decisions for themselves, but the way doctors decide capacity needs looking at, the commission suggests.

The absence of any mechanisms for appointing a substitute to take decisions on treatment stems from a move towards more autonomy for the mentally impaired in the early 1980s. Under the Mental Health Act 1959 a local authority or private individual could be appointed guardian, with the powers of a parent, including the right to consent to treatment. But under the 1983 act, which replaced it, guardians can be appointed only for specific categories of mentally impaired patients and have no right to consent to treatment on their behalf.

What should be done? The commission is canvassing a wide range of options, on which it wants the views of doctors and others concerned in the care of mentally incapacitated people.² Advance directives would help ensure that those who once had the capacity to take decisions but lose it—sufferers from senile dementia or those brain damaged by accident, for example—are treated as they would have wished. As in the United States, people could make living wills, declaring whether or not they wanted life prolonging measures used if there was no hope of recovery. Enduring powers of attorney, which allow a capable person to appoint a proxy to manage his or her financial affairs in the event of incapacity, could be extended to medical decisions.

A statute could be enacted laying down a procedure for obtaining a substitute consent to treatment. A precedent already exists in the Mental Health Act, which requires independent second opinions before psychosurgery or surgical implantation of hormones to control the male sex drive can be carried out. MENCAP has proposed a scheme under which decisions would be taken by the patient's most appropriate relative together with the doctor proposing the treatment.³ In the event of disagreement the case would be referred to a multidisciplinary local ethics committee, which would also take decisions on particularly serious treatment in accordance