should be more aware of a dancer's limitations and of dancers' needs to rest as soon as injuries occur; and dancers need immediate access to adequate treatment.

The profession of dance is believed to be fairly conservative in responding to recommended changes. The current climate within the profession, however, is ripe for initiating discussions about preventing injuries to dancers, given the awareness of dancers of the high rates of injury and the increasing interest in the potential of sports and dance medicine.

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For Debate

AIDS on the death certificate: the final stigma

Michael B King

Births, deaths, and marriages have been recorded for centuries in England and Wales. The first attempt to keep a record for the whole nation dates from the time of Henry VIII, and even in the Tudor era efforts were made to start a central registry.[1] The main impetus arose from a desire for marriage to be accredited a proper degree of publicity and regularisation by a civil authority as well as for a source of documentary proof of age, legitimacy, and ancestry. Reformers in the early nineteenth century such as Edwin Chadwick were the first to realise the advantage of a central registry for monitoring social conditions and health. Chadwick pressed the government for a cause of death to be included in the death register, partly out of interest in infant mortality, which was known to be a sensitive indicator of social conditions.

Accuracy of certification

Registration thus became constitutional law in 1836, and physicians have been entreated ever since to accurately record the cause of death. Although the system has proved worth while in a legal and medical sense,[2] the accuracy of death certification has been vigorously debated, particularly in this century in medical journals in Europe and the United States. Scrutiny of records has revealed incorrect clinical diagnosis, clerical errors,[3-5] and confusion of "mode" of death with "cause" of death, resulting in imprecision and delay for relatives.[5,6] Cynics have even depicted the statistical data from death certification as "rubbish in—rubbish out."[7] Although findings at necropsy increase the accuracy of medical information,[8] morbid anatomical and histopathological findings may have no direct connection with the fatal outcome.[3] Indeed, death certificates issued by coroners who are not usually medically trained which contain a summary of morbid anatomical findings may conceal the greatest number of errors in relation to the actual cause of death.[9]

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Sir Edwin Chadwick, public health reformer of the early nineteenth century, who realised the importance of notifying the cause of death

Stigma of cause of death

Until the advent of AIDS more liberal attitudes in society had lessened the stigma of most causes of death as an obstacle to their accurate certification.[8,10] Before a change in the law in England and Wales in 1984 chronic alcoholism was considered to be within the broad remit of unnatural deaths due to poisoning and was therefore subject to a public inquest. To avoid

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embarrassment for relatives "relevant facts were often overlooked."[11] Pathologists proposed more acceptable causes of death such as myocardial ischaemia, thus avoiding the need to inform the coroner. Cirrhosis of the liver was attributed to poor nutrition rather than ethanol. Evidence that such practices were widespread was seen in the large differences in mortality due to cirrhosis between England and Wales and Scotland, where the requirement did not apply.[11] A retrospective study of patients in whom liver disease had been diagnosed who died between 1976 and 1984 showed that although non-alcoholic liver diseases were recorded accurately on death certificates, in only one third of cases of irreversible alcoholic liver disease was this cause of death certified.[12]

Besides guilt and embarrassment certifying suicide as the manner of death can result in reduction or loss of life insurance benefits for the victim's dependents. Reliability of death certification of suicide has been questioned since the time of Durkeim's original sociological study of the phenomenon.[13] In the 1930s Zilboorg considered that the statistical data were "nearly useless" as suicides often appeared to be accidents, were often not recorded when the victim died some time after the attempt, and were concealed by families.[14] Doctors, coroners, and registration officials may be unwilling to certify suicide where the facts are uncertain or to spare families the stigma.[15] In the USA medicolegal officials may be sued for certifying a death as due to suicide when there is serious doubt. It is debatable whether this systematic bias is a main source of error when statistics are used to study patterns and possible aetiological factors in suicidal behaviour.[15-18]

Certification of AIDS

With AIDS has come the greatest stigma to affect death certification for decades. Public fear of any disease can be difficult to overcome, but particularly in the case of AIDS where people at risk may also be feared or stigmatised serious medical, psychological, and ethical problems may result for physicians, patients, and relatives.[19-21] AIDS or HIV infection will usually appear on the Cause of Death Certificate as the underlying condition that started the process leading to death (part I) or possibly as another condition not directly causing death (part II). The distress for families or close friends begins with the legal requirement on them to register the death. In my experience concerned doctors who complete this certificate may try to preserve the dignity of relatives by substituting other causes of death or not stating the underlying diagnosis of HIV infection.

The dilemma is illustrated by the case of a 37 year old homosexual who knew that he was positive for HIV antibodies, having agreed to testing during a routine visit to a clinic for sexually transmitted diseases three years earlier. Although he had informed his sister and close friends, he had not discussed either the test result or his homosexual lifestyle with his parents. He became ill, was admitted to hospital, and died. The medical staff had met his sister and parents to explain to them the gravity of their son's condition. The coroner overruled the concern of the medical staff to keep the diagnosis of AIDS or HIV infection off the Cause of Death Certificate. The parents were legally obliged to present this certificate to the Registrar of Births and Deaths, whose office was located in the neighbourhood where they were well known. The death certificate clearly stated the cause of death and subsequently had to be produced for their son's former employer, insurance corporation, mortgage company, solicitor, and others. Any hope of privacy was illusory.

Death certification of AIDS clearly has ramifications for the bereaved. Where AIDS has caused the death of a parent or child it may also have implications for surviving family members with regard to placement of children in foster homes.[22] Many doctors believe that by informing the Centre for Communicable Diseases of the case they have fulfilled their public duty and may omit the diagnosis of AIDS from the certificate.

For the historical reasons discussed the Register of Deaths is a public record, although access is possible only by purchasing certified copies of individual entries. It is not uncommon for journalists to establish the causes of deaths of prominent people from the Register of Deaths. They are free to publicise the information without fear of action. Should this invasion of privacy be tolerated? Clearly, cause of death is important in AIDS for many reasons, not least for mortality statistics[22] and for insurance payments. It is not of concern to employers, bank managers, or journalists.

AIDS and statistics

A review of death certificates is an easy and rapid means of evaluating AIDS surveillance.[23] Certificates can be a useful adjunct to other methods of surveillance of AIDS if they are accurate, clearly distinguishing between deaths from AIDS where there are clinically apparent consequences of immune deficiency meeting diagnostic criteria for AIDS or AIDS related complex and deaths where HIV infection merely coexists.[22] If we wish to increase the accuracy of medical certification of AIDS we must consider issues of privacy. There have been many suggestions to improve the accuracy of death certification,[2-4 5 9 15] including educating doctors concerning the administration of death certification, the correct use of the International Classification of Diseases, and the functions of the Office of Population Censuses and Surveys. It has been suggested that senior doctors should complete certificates instead of delegating the task to the most junior and least experienced member of the hospital team. But in disorders where a public stigma persists it is rarely considered that ensuring privacy for the bereaved might clear the way for doctors to be more frank. If confidentiality of medical information is considered sacrosanct in life there is no justifiable reason why this view should change after death.

Two part certificates

In the USA the use of a two part death certificate has been suggested—one part for disposal and immediate legal purposes and the other for medical certification.[8] This might reduce delay for relatives when further clinical or necropsy findings are required and also ensure greater privacy. Relatives would receive a two part certificate, one part giving evidence of death without stating cause for the administrative requirements after death. Although public records would still be open to scrutiny, this would help to reduce the agony of partners and families who are required to produce the certificate for many purposes.

Government proposals

A recent government green paper[24] suggests that it should be made easier for members of the public to scrutinise registration records, particularly genealogists and solicitors who are trying to trace ancestry, to settle wills and estates, or to establish pedigrees. Recognising the "sensitivity" of allowing greater access to records of those who have recently died, the green paper recommends changes only for records made at least 75 years ago. Furthermore, with an explicit reference to "sensitive" causes of death such as AIDS the government has suggested that records of recent

deaths should be available only to "those who have a legitimate reason for wanting them." Applicants would be asked to provide details which could not be derived from public indexes, such as the full name of the deceased, date and place of death, age or year of birth, and occupation. Unfortunately, it is unlikely that such measures will go far enough to stop the "intrusions into privacy, personation and fraud" with which the government is concerned.

A final right to privacy

The right to privacy, although not a part of the Constitution of the United States, has been recognised as defendable in American law for almost 100 years.[25] In the United Kingdom it is also important to protect what some might regard as our diminishing right to privacy. People with AIDS face many social and psychological difficulties,[19 26] and the importance of confidentiality is highlighted in clear guidelines from the American Medical Association,[27 28] the General Medical Council of Britain,[29] the BMA,[30] and the Royal College of General Practitioners.[31] In their present form death certificates provide no safeguard for people after death and thereby render efforts to preserve confidentiality during life ultimately impotent.

I thank Mrs G T Marsh, Registrar of Births and Deaths, Camberwell, London SE5.

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