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AIDS: sense not fear

Nowadays when we ask our students what disease has the following features—appeared suddenly, an American origin, sexual and vertical transmission, a carrier state with or without chronic disease, 2000 deaths a year, and said by one commentator¹ to be “intended as a punishment for our sins and we should not interfere in the matter”—they all answer AIDS (acquired immune deficiency syndrome). The correct answer is syphilis, which, to take a historical perspective, was much more of a health hazard than is AIDS and killed thousands more than this “new” disease ever will. Outbreaks of cholera, smallpox, the black death, and, more recently, Lassa fever all generated hysteria and fear. These historical comparisons are not made to suggest that AIDS is unimportant but to underline that infectious diseases with high mortality, disability, and generating considerable public anxiety have always been with us.

Why do hysteria and fear surround AIDS, who shows these reactions, and how can we cope with them? To some extent the apprehension is founded on the reality that in the United States the disease has a doubling time of six months with an eventual mortality of virtually 100%. Homosexuals are justifiably frightened, and there is some evidence from the United States that this high risk group has started to modify its sexual behaviour.² Most of the alarm over AIDS, however, is generated by the non-sufferers as opposed to the sufferers. We all need to examine and understand the hysteria, witch hunting, and moralising. Some of the reactions stem from the fact that society is ambivalent, moralistic, or even aggressive in its attitudes towards homosexuals, but some arise out of ignorance and fear. Patrick Buchanan, of the *New York Post*, is an example of the first category, writing about “the poor homosexuals, they have declared war upon nature and now nature is exacting an awful retribution.”³ We recognise that many others in society may share this view. We would, however, appeal to them not to allow their preconceived ideas to alter the ability of those looking after sufferers from AIDS to care for them humanely. Surely as a society we have progressed since the following was said, again about venereal disease, at the beginning of the century: “You have had the disease one year and I hope it may plague you many more to punish you for your sins, for I would not think of treating you.”⁴

So much for the aggression towards minority groups, but ignorance and fear have also to be reckoned with. In America

sufferers from AIDS have been evicted from housing, children of patients expelled from their schools, and court cases have been held by closed circuit television—all “to prevent” the public from becoming infected. Britain is new on the scene of AIDS (36 cases by February 1984).⁴ Even though our experience of patients is limited, we have our own examples of hysteria taking over from reasoned judgment of the facts. At times over the past six months we have found it difficult to transport, feed, investigate, and bury our patients. Ambulance, domestic, medical, and undertaking staff have all exhibited fear of contracting AIDS. Attention needs to be drawn to these problems, not so that we can hector or harangue our colleagues, but in an attempt to allay their fears. This is best achieved by examining the facts.

The epidemiological features of AIDS conform with it being due to an agent, probably a virus, which is transmitted sexually, parenterally, and perinatally. Early case-control studies in homosexual men showed that a high number of different sexual partners was a significant risk factor.⁵⁻⁶ A case cluster study, linking by sexual contact 40 cases of AIDS in 10 cities in the United States, reinforced the case-control findings.⁷ Other groups in whom sexual transmission is implicated are regular female sexual partners of men with AIDS or those in other groups at risk. Evidence of parenteral transmission comes from the cases in intravenous drug abusers, haemophiliacs, and adults and infants who have received blood transfusions.⁸⁻¹¹ Perinatal transmission is suggested by the occurrence of the disease in infants (including sibships), born either to mothers with AIDS or to those who were intravenous drug abusers or Haitian.¹²⁻¹³

Some 94% of American patients so far belong to the main risk groups of homosexual and bisexual men, intravenous drug abusers, Haitians, and haemophiliacs. The remaining patients belong to a small miscellaneous group, which in addition to sexual partners, infants, and those infected by transfusions includes some with Kaposi's sarcoma but a normal immune state and others in whom information about risk factors is insufficient.¹⁴ This small group has proportionately remained reasonably constant since the beginning of the AIDS outbreak, suggesting that spread beyond the main groups at risk is unusual.

As the epidemiological pattern of AIDS has emerged its parallels with hepatitis B infection have become apparent. No evidence has appeared of transmission of AIDS by droplet

or casual contact, so that safety precautions for the care of patients have been adopted on the lines of those already in use for hepatitis B. In November 1982 the Centers for Disease Control formalised this approach by issuing safety guidelines for clinical and laboratory staff. These served to identify the potentially affected groups at risk and the precautions required to avoid infection with the putative AIDS agent, using the hepatitis B model.¹⁵ The recommendations were "not meant to restrict hospitals from implementing additional precautions," and, for example, our district has made some minor modification while still recognising the essential good sense of the American guidelines. Possibly further precautions may be required to combat the potential transmission of opportunistic pathogens which patients with AIDS may be excreting.¹⁶ In particular, other patients and staff may be at risk because of their own immune state—for example, those with diseases or receiving treatment associated with immunosuppression, and pregnant staff, in whom cytomegalovirus infection should be avoided.

With the exponential increase to well over 3000 cases in the past four years in the United States, increasing numbers of health care workers have been exposed to the blood (including needle stick injuries), secretions, excretions, and tissues of patients with AIDS. No reports have been confirmed of patients having transmitted the disease to those who care for them. The future occurrence of such cases remains a theoretical possibility—AIDS seems likely to have a long disease free incubation period. The incidence of disease, however, among health care staff seems no greater than in the general population as a whole. Cases have occurred in health personnel, but all belong to groups at risk or with insufficient information to exclude known risk factors, and none of these has had direct contact with patients with AIDS.^{17 18}

We seem, therefore, to be dealing with an agent of low infectivity similar to hepatitis B virus—which, if handled sensibly, is not a risk to health workers. The epidemiological data from the United States have enabled us to use the safety precautions already largely established through experience with hepatitis B. Examination of the facts does not support the contention that health workers coming into social or caring contact with patients run a risk of developing AIDS. These facts should now allow all of us to be able to carry on caring for extremely ill patients in the usual medical tradition. None of us would like to adopt attitudes and postures towards our patients based on ignorance which, with hindsight, may make us feel ashamed.

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Problems of hospices

Hospices and other specialist units for the care of patients dying from cancer have grown in numbers dramatically in the past two decades—with near universal approval from doctors, nurses, and the public. Indeed, "the hospice movement" has about it an odour of goodness that upsets many of its members. For, in practical terms, terminal care units are hospital units like any others. Their staff have to be paid, buildings repaired, and bills met for food, laundry, and heating. Sadly, some of the independent hospices are facing financial problems.

Twenty years ago there were only 12 hospices in Britain; now there are 81, with 30 more in the planning stage. Many of these were built with capital raised locally by a community and some are still funded entirely from charitable sources. Others have contractual arrangements with the NHS which pays the cost of some beds. Those built in association with the National Society for Cancer Relief provide 300 beds in units constructed by capital raised locally but on the sites of NHS hospitals and with the intention all along that they should be run by the NHS. Almost exactly half the 1730 hospice beds are currently funded by the NHS, either directly or contractually. Five hundred and thirty one beds are in Sue Ryder and Marie Curie homes (of which 89 are funded by the NHS) but of the 40 other independent units 18 have no contribution at all to their costs from the NHS. In the past five years the National Society for Cancer Relief has helped to start and finance domiciliary nursing services as an extension to hospice care—and again its policy has been pump priming, with the NHS agreeing to pick up the revenue costs after three years.

At present, therefore, whether or not an individual patient can be given specialist care when dying depends on geographical chance. He (or she) may find himself in an NHS unit, possibly attached to an oncology department—or in a religious foundation, many miles from the nearest hospital (though such foundations nowadays admit patients of all denominations—or none). His doctor may be a full time consultant or a general practitioner who attends a few times each week. Or he may be looked after at home by nurses trained in the skills required before and after death. Some hospices are well endowed;