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Commentary on current issues

The Epidemiology of AIDS

> "[Figures for HIV prevalence] show 640 people known to be HIV positive up to 30 June this year through heterosexual contact, but no fewer than 330 of these had been exposed to infection abroad and 114 had partners with high risk factors, while 164 fell into the undetermined category .... The reply to my Parliamentary Question showed that there had been only one case [of heterosexual AIDS without known risk factors] among the eight corresponding cases. If the same fraction applied to the HIV positive it would leave just 4, or 0·037%, outside those in at-risk categories or with partners in at-risk categories" (Lord Kilbracken, *Independent*, 25.11.89)

It is often suggested that AIDS, with its unholy association of sex and death, revulsion and compassion, is a unique syndrome. Certainly, it is an area where prediction has had a conspicuous lack of success, with estimates of future prevalences of HIV infection varying by a factor of 10 or more being bandied about over the years, serving only to confuse the public and policy makers alike. Largely, the difficulties arise from the lack of information—though it is accumulating rapidly—in so many clinical and virological areas: the seroconversion rates associated with different modes of infection, the latency period of the virus, infectivity at various stages, the effect of cofactors, possible gender differences, rates of mother-child transmission, the possible lengthening of life that treatment may achieve, the prognostic meanings of clinical manifestations, even the specificity and sensitivity of diagnostic criteria. And above all, of course, the probable rates of existing HIV infection in the population can only be guessed. All these present unique difficulties for predictive models.

It could, however, be argued that there is another sense in which this disease syndrome is unique. Is there any other condition for which it would be possible for an official spokesman to offer, as a serious exposition of its epidemiology, the statement which heads this Commentary? Are there other conditions where the merit of collecting baseline data essential for the mapping of prevalence could have been the subject of so much debate and conflict for so long? Or where government could take such an active role, often seeming to be impelled by moral and ideological factors, in the control of health education material? Or where a Research Council's sponsorship of a national survey, essential for understanding the probable spread of infection, could be vetoed on the grounds that it was an invasion of individual privacy, and not an appropriate use of public funding? In short, are there other conditions where epidemiology is so misrepresented and the progress of knowledge seen not as a scientific, but as a sociopolitical issue?

In fact, the particular feature of HIV/AIDS is that knowledge about prevalence and prediction for the future depend, to an unusual degree, on information provided by social and behavioural sciences. And, of course, it is precisely these disciplines which are most vulnerable to the sort of pressures described.

The area of life which is relevant—largely, sexual behaviour—is not one in which social sciences have a particularly good record. It has been seen as difficult, unlikely to attract funding or serious attention, and awkward to justify if the motivation is simple curiosity about the world. Much of the information which is now most relevant relates to groups that are stigmatised and to activities which are private or even illegal. It is not surprising that the reliability and validity of conventional social science methods may be questioned.

In fact, a great deal of work has been done, with unusual speed. This is not perhaps as coordinated as it might be, and for various reasons—fear of media misrepresentation, a consciousness that much is as yet tentative, inability to refer to a well developed knowledge base—has not received very much publicity. It is therefore perhaps worth rehearsing some of the relevant facts which we now believe, from replicated studies, to be true, which were not known only a few years ago.

Information has accumulated, particularly about homosexual and bisexual behaviour, about the lifestyles of drug users and prostitutes, and about the sexual behaviour of young people. A feature of all these studies is that they demonstrate the depths of our previous ignorance. We know, for instance, a great deal about the nature and variability of homosexual lives. We know that it is not helpful to characterise gay men as invariably "active" or "passive" in their sexual interactions. We know that a change in sexual mores *is* possible, and that a decline from a peak of HIV infection (and other sexually transmitted diseases among homosexual men can be attributed to some reduction in the typical number of partners and a decline in the proportion of penetrative partners. We know something of the mechanisms of this change: for instance, that it certainly began before strong media and educational campaigns. We also know that change is not universal, nor can its mechanisms be extrapolated to other groups of the population.

On injecting drug users, researchers in, for instance, London, Manchester, Glasgow and Edinburgh have managed to penetrate the subcultures and study those outside service identified "clinic" populations. We know that it is possible to effect some change amongst these groups too, in the direction of risk reduction by sterilising or not sharing equipment. The evidence suggests that the availability of needles and syringes is a prominent factor, though not the only one: needle sharing is part of a social activity, with clear subcultural differences among different groups. We also know, however, that the sexual behaviour of injecting drug users has shown only modest change; the perceived focus of risk is on transmission of HIV through needles rather than through sex.

Until recently, we have had little information about prostitutes and their clients. It has to be noted that HIV seropositivity is low, in Britain, among prostitutes who are not drug users. However, "sex workers" themselves are obviously conscious of vulnerability, and there must be concern about the association of drug use with prostitution. There is accumulating evidence that since the advent of AIDS many prostitutes have adopted a more directive and safety conscious role with their clients. On the other hand, this is not, again, one homogeneous group: factors shown to be important in the negotiation of "safer sex" include age and experience, locale and social organisation. Those most at risk appear to be the youngest, the most isolated, and the lower status workers, who

may also be drug users. Young male prostitutes appear to be at special risk, adopting a passive role and susceptible to intimidation. As with drug users, it is universally found that the practices of prostitutes with their regular partners (as opposed to clients) have not changed: condoms are a symbol of "work", not to be confused with personal relationships. At least one study has been able to study the clients of prostitutes, finding that most had non-prostitute partners with whom condoms were not used.

All this has implications for the spread of HIV. For all these groups, "network analysis" and study of geographical movement are particularly important areas of research. A "closed" group, who may, on the worst prediction, become "saturated", is one thing: a pattern of movement in and out of the group is quite another. We are beginning to learn, for instance, that the use of prostitutes, or both sexual and needle sharing contacts between drug users, are more widely dispersed geographically than perhaps we thought.

It has to be added that we are clearer about many of the relevant issues among drug users, or among homosexual identified men, than we are about the sexual behaviour of the population as a whole. Even here, however, some evidence is accumulating. We do know that same gender sexual experience is widespread, with figures around 20% of men (though this would include adolescent experience) commonly declared. We know that the general population is perhaps surprisingly ready to describe themselves as not exclusively attracted to one gender. We know that those who practice heterosexual anal or oral sex are not a perverted minority, but members of a majority. We know that there is little evidence of any behavioural change in the general population—though awareness and knowledge are high—and some evidence of risk taking even among those most vulnerable, such as the partners of those known to be HIV positive. We are confirmed in our commonsense knowledge that young people *are* likely to be sexually active, and we begin to understand some of the problems they experience in negotiating their relationships.

Most importantly, we are beginning to accumulate knowledge about the difficult methodological issues. They are not, of course, unique to this topic. Simple survey questions asking about alcohol consumption are no more reliable than questions about sexual activity. But in the field of alcohol studies there has been long term research effort, and standard instruments and techniques are available. In the area of sexual behaviour, this development has had to take place with exceptional speed. However, we do now know something of the reliability of self reports, and the way in which retrospective recall tends to be selective. There has been much careful research on the vocabulary which has to be used with different groups of the population, and of the meaning given to terms like "sexual intercourse" or "sexual partner"—issues which seemed, mistakenly, to be obvious before they were investigated. We know, incidentally, that the great majority of the population are *not* offended by being asked questions about their sexual lives, and are indeed anxious to talk about them in this context.

The aim of all this work is not only, of course, to assist in the building of predictive models. This knowledge must also serve the purposes of prevention and health education. Here, a new phase of research into general theories of health related behavioural change has been promoted. We certainly know that conventional paradigms have no conspicuous success in this area. For instance, knowledge and attitudes have been shown to have equivocal relationships to action: this complex area of life cannot be equated with simpler health promoting behaviour. We know that public campaigns have had problematic results, partly because there are special reasons why the messages of AIDS education cannot be altogether clear and unambiguous. We know that perception of risk is complicated: broadly, that general and personal risk cannot be equated. We know that we need to understand the dynamics of sexual interactions as social encounters, questions of the balance of power in relationships, and sexuality's place in identity formation and reinforcement.

All the topics briefly reviewed above have implications for the epidemiology of AIDS. In particular, this research has thrown doubt upon the initial concept of "risk groups", which, it is now generally agreed, ought to be replaced by "risk behaviour". Because our models of the spread of the disease syndrome came first from the United States rather than from Africa, and because the groups first identified were homosexual men and injecting drug users, the notion that this is essentially a problem of clearly defined groups has been pervasive. The quotation which headed this Commentary was clearly wedded to the risk group approach, appearing to say that the only people who were not in risk groups were the small minority who did not know (or had not been persuaded to say) how they became infected. A probability, however small, can in fact be attached to *any* individual of acquiring a partner who may in turn have had a partner who may in turn ... To put numbers on these probabilities is the crucial issue.

The epidemiology of AIDS is bedevilled by uncertainties, and when we do not know exactly what the size and nature of the problems are, it is easy for factors outside science to come into play, and responses to be shaped by official ideologies and common myths. Thus it is extremely difficult to do research into the sexual lives of young people below the age of consent (because of course they have no sexual lives), or those in prison (because of course sexual activity in prisons, being forbidden, cannot take place). There are many situations which, it could be suggested, we ought to know more about, but the individuals concerned are not in conventional "deviant" groups, and so a focus upon them is seen as intrusion into privacy: for instance, the effect upon subsequent behaviour of "voluntary" HIV testing for insurance, employment, or travel purposes, or the sexual lives of those who work away from home, or frequently travel abroad, or are confined by employment into unnatural lifestyles.

Of course, those who are specialising in the epidemiology of AIDS are aware of all these issues. For the wider community, however, it is perhaps important to stress that a narrow concern with social book keeping will not be enough. The growing, if still limited, expertise of social and behavioural science must be fostered and supported if sexual conduct is to be understood in the context of AIDS.