Proceedings of the AIDS Conference 1986

Newcastle upon Tyne, UK

Edited by **Peter Jones**

This book is based on a major conference, held in Newcastle upon Tyne in February, 1986, and sponsored by the UK Department of Health and Social Security and the Haemophilia Society. The conference was designed to provide health care workers with up-to-date factual information about the acquired immune-deficiency syndrome (AIDS). The contributors to each chapter are internationally acknowledged experts from the UK and the USA. Their fully edited papers, in conjunction with reports of questions from the floor, panel discussions and special interest group meetings, ensure full coverage in this volume of current developments, techniques and trends in this important area of modern medicine. This volume will be of interest and value to all those who are concerned with any aspect of the social, nursing and medical management of AIDS throughout the world.

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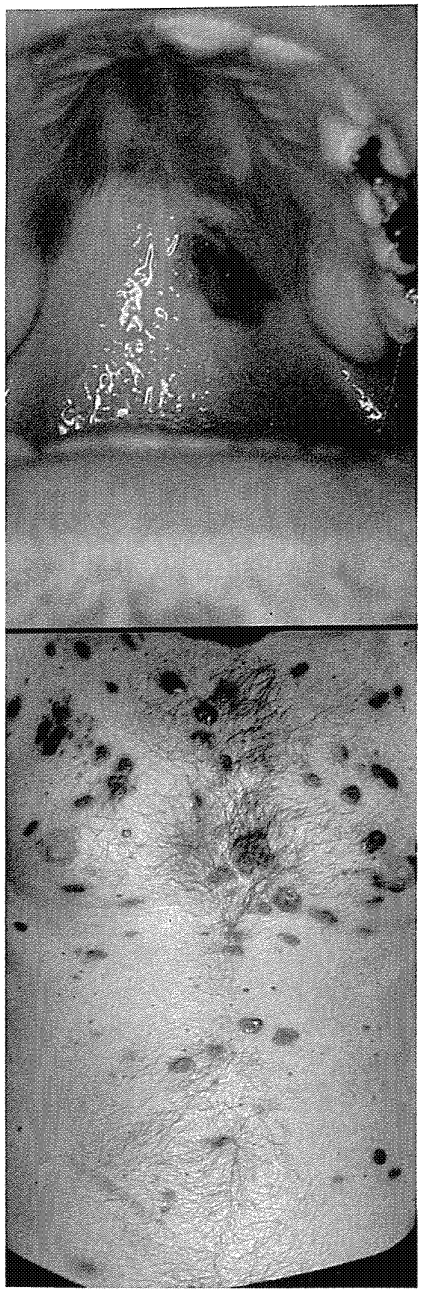
Proceedings of the AIDS Conference 1986



Frontispiece Kaposi's sarcoma: lesions (upper) of palate and (lower) of trunk.

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Newcastle upon Tyne

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Edited by

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Preface

In 1982 three people with haemophilia became ill with infections usually seen only when the body's defence systems have been compromised. The cause of their underlying disease was unknown, but the illness mirrored that appearing with increasing ferocity in young people in America. Many of the latter were male homosexuals and because of their sexuality there is evidence that insufficient notice was taken of their suffering. The cause of their disease, the acquired immune deficiency syndrome, or AIDS, was not found until 1983 when Luc Montagnier and Robert Gallo and their colleagues described the AIDS-related virus, and the antibody test that signalled infection. Since then AIDS has shown remorseless progress in society. The careful work of our public health organizations, notably the Centers for Disease Control in Atlanta, Georgia, has shown the virus to be no respecter of the human being, no matter what sex, age, colour or race: AIDS can kill anyone who becomes infected. To date, there is no cure. To date, there is no vaccine.

In 1985 I visited both New York and San Francisco to see for myself how AIDS was affecting people, their spouses, their lovers, their families and their communities. It was salutary for a doctor whose patients are supported by a National Health Service, both in hospital and at home, to learn of the distress caused to people in communities without a background of continuity in medical or social care. I was left in no doubt that the prejudices and politics of AIDS continue to interfere with the delivery of proper health care to patients and to research in many countries. Much of the support needed comes from voluntary organizations and Americans owe much to the skills and energy of men like Rodger McFarlane of the Gay Men's Health Crisis in New York City, and to foundations like Shanti in San Francisco. In the United Kingdom the Haemophilia Society, the Terrence Higgins Trust and, more recently, the Standing Conference on Drug Abuse (SCODA) have led the way in the voluntary sector. Here at least government has now begun to deploy the only weapon we have at present against AIDS — the informed education of the public.

Much has been written about the role of the media and the approach of journalists and broadcasters to the subject of AIDS. We sometimes forget that tolerance and compassion are individual qualities not dictated by a surfeit of high drama in the newspapers or on television and that what we get from the media is, to a large extent, as good as we are prepared to give. We need the help of professional communicators if we are to make any headway in our attempts to stem the spread of AIDS in the community. The results of a Gallup poll, conducted for the *Daily Telegraph* shortly after the conference reported in this volume, showed that a quarter of those questioned felt that they knew almost nothing at all about the disease, 19% considered it more contagious than the common cold, 36% thought it could be caught by kissing and 30% by associating with someone with AIDS. Behind these misconceptions lay more sinister conclusions: 26% of those questioned opposed allowing students with AIDS to attend school even 'if health officials say there is no danger'; they would keep their children at home if they thought a child with the disease might be attending the same school. And 82% agreed with a statement that 'school officials should tell parents if a child with AIDS is attending their child's school'. So much for privacy and the human rights of individual children and their families. We have a long way to go.

The facts about AIDS are detailed in these Proceedings. The disease is spread only by sexual intercourse or by the inoculation of infected material, most commonly by sharing contaminated needles. The virus is very fragile outside the body, and is easily destroyed by hand washing, by detergents and by the commonly available disinfectants. There is *no* evidence of casual spread in homes, schools, work places, swimming pools, 'pubs' or public lavatories. Only *one* health care worker has become infected as a result of inoculation, and then because of micro-transfusion rather than needle-stick injury. Good working practice, sound hygiene and common sense prevent AIDS.

The other face of the disease is that of concern to us all. Although we are faced with a virus so sensitive that its protective envelope is destroyed by soap, it has a mechanism so subtle that it can reach, undetected, into the heart of the human cell. Here, incorporated into the blueprint of life—the genome—it may lie dormant for years, later to erupt and infect other cells until the balance of health is tipped. After infection, the infected person is infectious to others. Unlike other antibodies, the AIDS-related antibody confers no protection to the body: it is simply a marker of infectivity. The question of whether an individual should be tested or not is one of the subjects of debate in this book.

The one unequivocal message that emerged, clear and enforced by repetition, from the conference was that the need for education is paramount and urgent. The UK Government campaign of public advertising cannot stand on its own: it needs the backing of all of us working in the fields of health and social care. Unless it succeeds, our society —

and especially our sexually active youngsters and those who abuse intravenous drugs — will be at increasing risk of contracting a disease for which, as yet, we have no answer.

PETER JONES
Newcastle upon Tyne
March 1986

The AIDS Conference 1986 was sponsored by the Department of Health and Social Security and by the Haemophilia Society

Acknowledgements

The idea for the UK AIDS Conference for health care workers came during a conversation with Peter McCulloch of LH Fermentation Ltd. At first it was thought that sufficient funding would be forthcoming from an appeal to the pharmaceutical industry. We were anxious that the conference be subsidized with a registration fee low enough to encourage people from all levels of the health and social services to attend. In the event the epidemic began to overtake us, and the DHSS were quick to respond to an urgent request for help. The Haemophilia Society agreed immediately to oversee the conference and in October 1985 planning started in Newcastle. We started with no formal organization and all subsequent work relied on the goodwill and relentless energy of a small group of people, many of them Medical Laboratory Scientific Officers. Their names are listed below, together with others, both individuals and organizations, without whom the success of the conference and the publication of the Proceedings would not have been possible. Everyone worked unpaid and many worked long hours after their usual work. In thanking them and their families for their time, I hope that the friendship and counsel of the conference will help all of us cope more effectively with AIDS and its related diseases. I am especially grateful to my wife Brigitte and to my children for all their help and encouragement.

Organizations

Miles Laboratories (Cutter Division)

Members of the Department of Health and Social Security and the National Haemophilia Society

The Executive of the Terrence Higgins Trust and the Standing Conference on Drug Abuse

The staff of the Newcastle Haemophilia Centre

The Lord Mayor's Office, Newcastle upon Tyne

The staff of the Audio-Visual Centre, University of Newcastle upon Tyne

Newcastle City Council Social Services Committee

The British Medical Association

British Airways

Members of the pharmaceutical industry and other organizations represented in the trade exhibit. I would especially like to thank representatives from the firms of Ortho Diagnostics, Cutter and Sandoz for special contributions made to the organization of the conference:

Abbott Diagnostics Division
Alpha Therapeutic
Armour Pharmaceutical Co. Ltd
Becton Dickinson UK Ltd
Behring Hoechst UK Ltd
Blood Products Laboratory
Coulter Electronics Ltd
DuPont Ltd
Dynatech Laboratories Ltd
Immuno Ltd
Labco Ltd
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Mrs Linda McBride
Mr Alan Oxley
Miss Joan Rockcliffe
Mr Arnold Todd
Miss Lynn Trattles

The speakers

Any conference depends for its success on the quality of its speakers.

Dr Paul Volberding and to Gayling Gee, and to the Chief Medical Officer, Dr Donald Acheson, Professor Michael Adler, Dr John Green, Dr Harold Gunson, Dr Marion McEvoy, Dr David Miller, Dr Philip Mortimer, Dr Anthony Pinching and Dr Richard Tedder.

The publishers

The organizers were fortunate in choosing Intercept (Scientific, Medical and Technical Publications) as the conference publishers. The Directors of Intercept, Professor Gordon Russell and his wife Heather, have done a magnificent job in publishing the proceedings so quickly. The difficulty of their task was compounded by the fact that most of the contributions had to be transcribed from tape recordings, checked by the authors and redrafted before printing. The editing of this book would not have been possible without the great help and expertise of Intercept.

The patients

Finally, I must thank my patients and their families for their forbearance and support in the past six months. The courage and good humour of those with haemophilia and their relatives never ceases to sustain us. I hope that the knowledge gained and exchanged during the conference will help them in the future.

P. J.

Part I
Opening Session

1
Opening Address

DONALD ACHESON

Department of Health and Social Security, London, UK

Haemophilia and AIDS

The sponsors of the AIDS Conference 1986 are the Department of Health and Social Security and also the Haemophilia Society. The tragic way in which haemophilic patients have been exposed to infection with HTLV III and to the attendant risks of AIDS—a problem which is world wide—has aroused widespread and deep sympathy for the sufferers of this illness. Great strides have been made recently in the treatment of haemophilia: only 25 years ago it was a condition which usually ended fatally or with serious incapacity in childhood; now it is possible to offer the prospect of an active lifestyle, with a similar duration of life to that of those of us who are unaffected by haemophilia. This has been achieved by notable medical research, much of which was undertaken in the United Kingdom. Then in 1983 the bombshell dropped and we became aware of the transmission of HTLV III infection via some blood products. This tragedy has by no means been confined to haemophilic patients in the USA and in the United Kingdom: transmission of HTLV III through the use of contaminated blood products in their treatment has affected patients in 87 countries throughout the world. We can now expect that with heat-treated coagulation factors the risk to haemophiliacs in the UK of contracting HTLV III infection via such products has virtually ceased. Dr Philip Mortimer and others recently recorded (Jesson *et al.*, 1986) that no further rise in prevalence of specific antibody to HTLV III has been found in tests on haemophiliacs since 1984, and we are all very thankful for this finding.

Routine screening of donated blood

The introduction in the UK of routine screening of all blood donations,

the blood supply for all. The co-ordinated introduction in the UK went ahead smoothly and without any delay in relation to the planned date which had been set in the Spring. We now have the news that the number of donors found to have positive tests in the Blood Transfusion Service (1 in 45000; *see* Chapter 10) is very low indeed compared with the incidence of positive donations reported in other countries. For this we can thank the long-established tradition of free walk-in clinics for the treatment of sexually transmitted diseases, in strict confidence, which have been available throughout the United Kingdom for 60 years. With no hassle, no form-filling and with strict confidentiality, anyone who wishes can now walk in and have a test done for HTLV III antibody at these clinics. Similar systems are not available in many other countries and in such circumstances some people seem to have donated blood in order to be tested; that is clearly not the case here.

Epidemiological studies

HTLV III infection and its complications have placed an additional burden on haemophilic patients and their families and the doctors who supervise their treatment and, of course, on the doctors in the Haemophilia Centres. I am very appreciative of the work done by nurses, doctors, social workers, the Haemophilia Society and all involved in haemophilia care who provide patients and their families with information about HTLV III infection and its consequences for each affected individual, and who counsel and help them in every way possible. Even tragedies can unexpectedly benefit others: although, I fear, it is little consolation to those affected, nevertheless through knowledge of how HTLV III infection has affected haemophiliacs we have obtained epidemiological information which will be of considerable value to those dealing with the transmission of the virus. Because of the national organization of services for haemophilia patients in the United Kingdom we are uniquely well placed to contribute significantly to this research. The Department has given £60000 to each Haemophilia Reference Centre to help with the counselling which they do, because the regular monitoring of patients to ensure their continued health has clarified many facts about the infection. The co-operation of patients and their families has enabled the Haemophilia Centre directors to determine the prevalence of HTLV III infection amongst haemophiliacs so far tested and this study has shown that about one-third of those tested have specific antibody; fortunately only 1% of these have contracted full clinical AIDS.

Control of spread of HTLV III infection

Although a small number of spouses of haemophiliacs are known to have acquired HTLV III infection, research, both at home and abroad, shows that there has been no spread of infection in normal domestic contact between haemophiliacs and other members of their family. One of the purposes of this Conference is to increase factual information and to diminish misunderstandings and fear about this disease. There is no doubt that the AIDS outbreak presents all of us with what is probably the greatest challenge to public health in the field of communicable disease this century. Although only 287 cases of clinical AIDS so far have been reported in the UK, we know that the viral infection underlying it has affected many more: it is probable that about 20000 people have already been infected with the virus. The fact that most of them are well and unaware of their infection, which they are capable of transmitting sexually to others, adds greatly to the problems of controlling spread.

The role of the voluntary sector is an essential element in the work we are doing to control the spread of the disease. The Department of Health and Social Security is giving financial support to the work of the Terrence Higgins Trust (*see* pages 223–231) and I would like to pay tribute to their efforts in this field. It is largely due to them, and to the work of the Health Education Council and others, that those in the high-risk groups are responding in such a responsible and positive way to the practical health education messages on HTLV III infection. The recent appearance of specific antibodies in drug addicts at high prevalence in certain cities in Scotland is a serious development which is being looked into urgently.

We must now look to the future. Valuable research is going on in this country and elsewhere to seek a vaccine and an effective treatment for the infection. In the meantime our principal weapon to reduce the rate of spread of infection must be public education and understanding of the nature of the infection. The UK Government is at the moment developing proposals for a national public information campaign on AIDS which we plan to launch shortly, and £2·5 million has been allocated for this purpose. The aim will be to inform both the general public and those in the high-risk groups about the nature of the infection and the ways in which its spread can be controlled. All health professionals, right across the board, as well as members of the public, have a role in controlling the spread of the infection.

Reference

JESSON, W. J., THORP, R. W., MORTIMER, P. P. AND OATES, J. K. (1986). Prevalence of anti-HTLV-III in UK risk groups 1984/85. *Lancet* **i**, 155.

2
Introduction

PAUL VOLBERDING

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Introduction

My contributions to the Conference can be divided into three parts: first, in this chapter, an introduction; second, in Chapter 13, the clinical approach to patients with AIDS, which is the subject that interests me the most; and finally, in Chapter 19, a summary of information of general interest. I will deal with such politically charged issues as antibody tests, the development of vaccines, and the risks of AIDS to health care workers and to heterosexuals.

Epidemiology

First, I want to discuss the epidemiology of AIDS, and the nature of the disease. This very general introduction relies heavily on data from the Centers for Disease Control (CDC) in Atlanta. Dr Acheson (Chapter 1) has already stated why he is so concerned about the disease. Unfortunately, AIDS is still rapidly increasing and, in its fully developed form, has almost invariably killed affected persons. The potential for the spread of this epidemic is something that concerns all of us. AIDS represents such a striking phenomenon, such a dramatically new disease, that both it and its investigation cannot help but tell us some important things about other diseases, including cancer, that have plagued us for a very long time. These, of course, still remain more common than AIDS and, as an oncologist, I have long been concerned about the relationships between the immune system and the formation of cancers in humans. It is our hope and sincere expectation that, by studying AIDS, we will learn more about that process, and thus will be able to offer information and help to many people.

AIDS is much *more* than a medical problem. Although it is such a

and all our abilities are being tested so that we can come to grips with a new situation that the population at large finds frightening. As we try to communicate our own concern to the public in a way that promotes effective changes in behaviour and effective research programmes without causing undue concern or hysteria, we look for help from the media, which in the United States has proved very useful in this respect.

The city of San Francisco is in many ways similar to that of Newcastle upon Tyne. For example they have similar population sizes and, until the AIDS epidemic, were both very proud of their liberal approach to a variety of lifestyles. A result in San Francisco in the early 1980s was a situation that set the stage for the AIDS epidemic that was to develop. Several factors in San Francisco, and indeed in Western culture generally, ranging from political to sexual, and from medical to geographical, led to the rapid appearance and rapid spread of this new disease. The city has a very active homosexual population, which was characterized in many cases by the practice of having sexual relations with multiple, often anonymous, partners. Sexually transmitted diseases were especially common in this gay community, as was the frequent use of recreational drugs. We think that these factors increase the chance of encountering viral infection, and probably increase the chance that a new viral infection will cause more severe damage to the individuals concerned. At the beginning of the epidemic, not only was the medical profession inexperienced in dealing with homosexuals, but it was also totally unprepared to cope with the kind of problems presented by AIDS; the obvious example of this was Kaposi's sarcoma (KS), a disease about which even oncologists knew little. Such infections and cancers were very seldom seen in 'healthy' people. In addition to the factors that contributed to the rapid spread of the disease, therefore, there was a slow reaction of the medical profession to mount an effective response to the new situation, made more difficult by the increasingly easy, cheap and frequent travel, which contributed greatly to the rapid spread of AIDS throughout the world. AIDS is now a worldwide problem.

Early in 1979, physicians in San Francisco and other areas of the United States began to encounter gay men with diffuse reactive lymphadenopathy, a condition not reported in the medical literature until the existence of AIDS itself was recognized. Although we had begun to see other unusual problems in 1980, especially unusual opportunistic infections, it was not until the middle of the following year that we realized, in conjunction with reports from Los Angeles and New York of similar infections and unusual tumours in homosexual men, that an AIDS epidemic had been with us in San Francisco for some time.

Definition of AIDS

It was at this point that the Centers for Disease Control (CDC), the branch of the US Government that is responsible for monitoring epidemic infectious diseases, established a definition of AIDS which has stood the test of time remarkably well (*Table 2.1*). In brief, AIDS was defined as an unusual infection, or unusual cancer, which affected somebody who had previously been in good health. This very simple definition has been a powerful tool for tracking the epidemic: from the earliest days of the epidemic, it has been possible to trace with confidence the spread of AIDS to new areas of the USA and to new population groups.

Many infections and cancers are included in the CDC definition of AIDS (*Table 2.2*). The list of medical problems is very long and I think that the most striking thing shown by *Table 2.2* is the amazingly complex series of problems that face the patient with AIDS. It is not a single infection or a single cancer that the person encounters, but numerous infections and often numerous cancers in the progression of the disease. Those problems that are marked with an asterisk in *Table 2.2* require that, in order to fulfil the CDC definition, testing for the AIDS-related

Table 2.1 AIDS: the CDC surveillance definition

AIDS can be diagnosed when an *opportunistic* infection or an *unusual* malignancy occurs in an *otherwise healthy* person

Table 2.2 CDC-defined AIDS

AIDS infections	AIDS malignancies
Parasitic	Kaposi's sarcoma
Pneumocystis carinii	CNS lymphoma
Cryptosporidia	High-grade B-cell lymphoma*
Toxoplasma gondii	
Bacterial	
Mycobacterium avium complex	
Viral	
Invasive cytomegalovirus	
Invasive herpes simplex virus	
Fungal	
Cryptococcus	
Histoplasmosis*	

* Requires confirmation of AIDS virus infection

virus be carried out. Until very recently, the diagnosis of AIDS could be made without any laboratory testing whatsoever; the doctor had merely to find one of the unusual cancers or opportunistic infections in the appropriate immunosuppressed risk group, in order to make a diagnosis. This is still true, but there are now certain situations which require testing for the AIDS-related virus using the antibody test. In California this is strictly regulated by law, and raises complex questions of personal choice and confidentiality.

Incidence

As the incidence of AIDS increased, it became evident that the doubling time of the AIDS incidence, initially thought to be about 5 months, is about 12 or 13 months in both the USA and Great Britain (*Figure 2.1*). An optimistic feature of the epidemic is that in some areas of the USA the epidemic is beginning to plateau, and even to decline. In San Francisco, where the disease has remained largely a problem of the gay community, we have seen no increase in the number of new cases during the past six months, suggesting that some of the educational programmes that we have been conducting locally in a very aggressive fashion are beginning to pay off. Education alone may therefore help

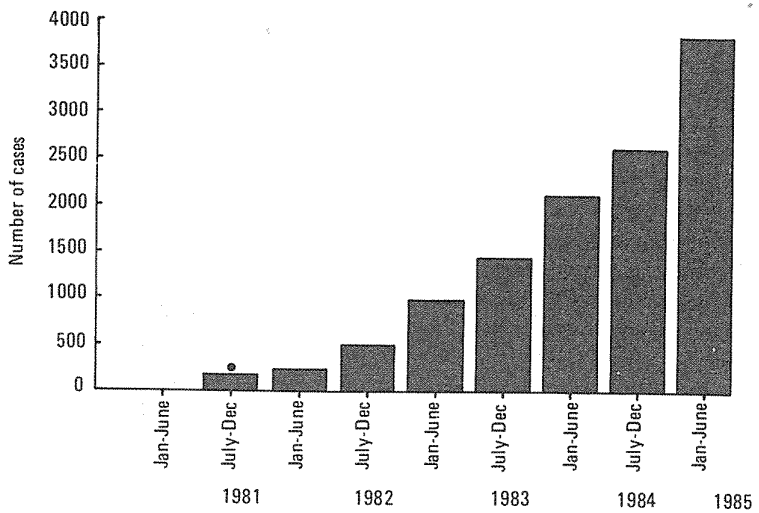

Figure 2.1 Reported cases of AIDS [illegible]

to stop the epidemic. Nevertheless the disease remains common in San Francisco. In 1981 we had often to justify our requests for additional funds for AIDS research, because it was considered such an uncommon disease; we are no longer asked to do this, because the disease is now so incredibly common. We now have nearly 2000 cases out of a total population of 700 000; AIDS is so prevalent among the gay population that many of our patients know personally about 10 people who have died during the epidemic.

Figure 2.2 shows the severity of the AIDS situation in San Francisco, in terms of both the increase in cases and the number of people who were diagnosed as having AIDS more than three years ago, and who have since died. Mortality of 100% has been recorded in some AIDS-infected populations, and we think that *overall* mortality rates for AIDS will approach this figure.

In the United States, AIDS started in fairly discrete areas. Although initially we thought that the epidemic affected only three cities—New York, San Francisco and Los Angeles—it soon became clear that AIDS had spread to many smaller cities and towns across the country. This is important, because I think that the pattern of spread of the disease that we have experienced in the USA will be repeated in other parts of the world, where the epidemic is only now beginning to develop. From what I understand about the situation in Great Britain, it seems

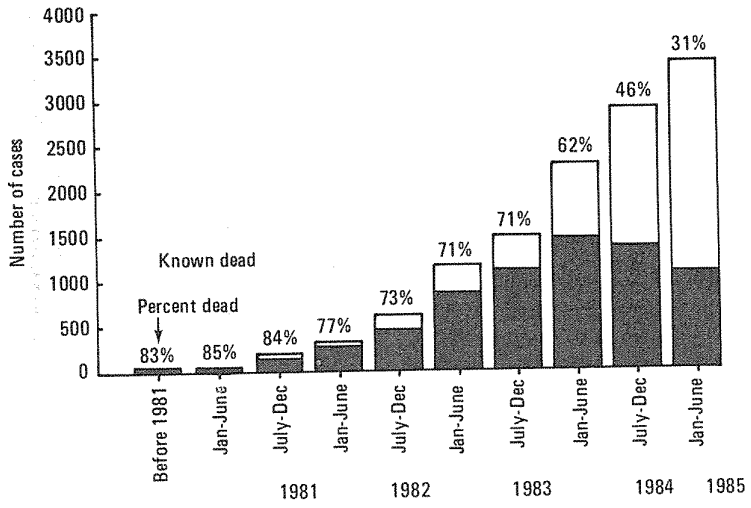

Figure 2.2 [illegible]

that the epidemic started 2–3 years later than in San Francisco. Our experience in San Francisco may therefore help to show how the developing epidemic should be approached in the UK and other countries. *Table 2.3* summarizes the fact that AIDS is now truly a nationwide problem in the United States, affecting cities in the heartland, in addition to those on the coasts.

Table 2.3 Reported cases of AIDS, United States, by Standard Metropolitan Statistical Area (SMSA) of residence, 1981 to 1 October 1985

SMSA of residence	Cases	Percentage of total cases	Cases per million population*
New York City	4457	33	488·7
San Francisco	1519	11	467·3
Miami	443	3	272·5
Newark	351	3	178·5
Los Angeles	1161	9	155·3
Elsewhere, USA	5680	41	27·8
Total	13611	100	59.8

* Based on 1980 Census

ASSOCIATED TUMOURS

The cancers associated with AIDS are particularly interesting, because at present they affect primarily the homosexual community rather than haemophiliacs. To date AIDS has predominantly affected males; indeed, 95% of cases in the developed countries are in men. We think that this is not just because the population that is most affected is gay, but may indicate a male predisposition to this disease, especially to some of the malignancies that are associated with it. This association is reflected in the KS rates. *Table 2.4* shows that females with both AIDS and KS are rare, in contradistinction to the opportunistic infections which are common to AIDS patients of both sexes.

High-risk groups

In the United States, cases are predominantly in homosexuals, although this situation is changing; one of the more ominous things that we have seen, particularly in New York City and the surrounding metropolitan

Table 2.4 Reported cases of AIDS by disease category and sex, United States, 1981 to 1 October 1985. PCP = *Pneumocystis carinii* pneumonia

Disease category	Males (%) (N = 12648)	Females (%) (N = 963)	Total (%) (N = 13611)
Both KS and PCP	6	1	6
KS without PCP	20	4	19
PCP without KS	57	65	57
Other opportunistic diseases	17	30	18
Total	100	100	100

venous (i.v.) drug users. This suggests that the success of educational campaigns, and therefore our ability to control the epidemic through education, has been limited to the gay community. We are not optimistic about achieving a similar success with i.v. drug users. A major challenge facing us is how to tackle the problem of AIDS in this group, which is very difficult to educate. How do we reach the community that is using i.v. drugs? In the United States, black and Hispanic populations are greatly over-represented in the i.v. drug groups, and this is responsible for the great surge of new cases in New York City, where more than 50% of cases nowadays occur among i.v. drug users.

The data in *Table 2.5* which summarizes the breakdown of groups at risk, are as true today as they were 4 years ago during the early days of the epidemic. The epidemic, despite the fact that AIDS has spread so rapidly, has remained confined to the same high-risk groups to a remarkable degree. The threat of AIDS to the general public therefore seems to be relatively small, because the proportion of cases outside the major risk groups, currently less than 6%, has remained very small; many of these patients died before their risk group could be identified. Cases of AIDS are largely confined to the adult, sexually active population, with a few cases in the very young paediatric group

Table 2.5 AIDS: US incidence and risk

Group	Percentage
Homosexual males	74
Intravenous drug abusers	14
Haitians	5
Haemophiliacs	1
Children	1

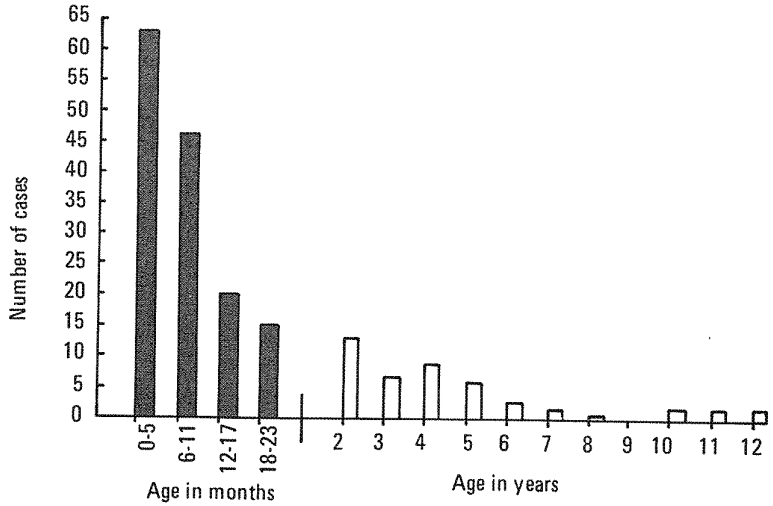

Figure 2.3 Paediatric AIDS: age at diagnosis, 1 October 1985 (N = 191)

(*Figure 2.3*). The distribution of paediatric AIDS cases shows that those most at risk are children born to women using intravenous drugs. This is an increasingly serious problem, and we should try to stop it, because these babies are completely innocent victims of this disease. A woman who is infected with HTLV III carries a high chance of giving birth to a child who is also infected, and who will probably develop AIDS.

Mortality statistics

Another way to show the seriousness of AIDS is to look at the mortality statistics (*Table 2.6*). Nearly all patients with opportunistic infections

Table 2.6 Mortality rates in AIDS, reflecting severity of immune deficiency (helper cell number or helper: suppressor ratio are useful estimates)

Group	Two-year mortality (%)	Ultimate mortality (%)
ARC	≤ 10	??*
AIDS		
Kaposi's sarcoma	70–80	~ 100
Opportunistic infection	~ 100	~ 100

and AIDS die within 24 months, although the situation is better with KS. Patients usually succumb to opportunistic infections, especially pulmonary infections, although there is an increasing involvement of the central nervous system in AIDS patients. Relatively few people die of KS itself (*Table 2.7*). An area of increasing concern is the prognosis for that group of patients with the lesser form of AIDS, which has been called the AIDS-related complex or ARC. Figures relating to ARC are shown in *Table 2.8*. Affected people have a relatively low mortality rate in the short term, with fewer than 10% of patients dying within two years. On the other hand, it is not known what happens to people with ARC, or indeed asymptomatic HTLV III infection, in the longer term.

The virus

Figure 2.4 demonstrates the concept of the 'AIDS iceberg', which was developed by the CDC long before anything was known about infection with HTLV III, or about the epidemiology of AIDS. We realized from looking at our patients in the gay population of San Francisco that, for every one that was diagnosed with AIDS, there were many more who were affected by other medical problems. These were clearly not AIDS, but we thought that they might be related to it, and therefore to the

Table 2.7 Cause of death in AIDS (various studies)

Cause	Percentage
Respiratory	60
Pneumocystis	
Cytomegalovirus	
LIP	
Bacterial	
Central nervous system	20
Toxoplasma	
Encephalopathy	
Kaposi's sarcoma	10
Other	10

Table 2.8 Outcome in persons positive for HTLV III antibody

Outcome	Estimated percentage
AIDS	4–10

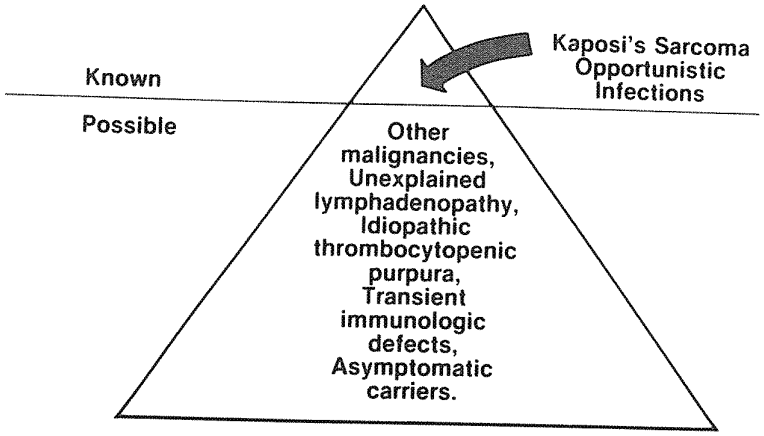

Figure 2.4 Spectrum of AIDS — the 'iceberg'

infection probably causing the end-stage disease. That we were correct was demonstrated only when the virus, termed the lymphadenopathy-associated virus (LAV) by Dr Montagnier, and the human lymphotropic T-cell virus type III (HLTV III) by Dr Gallo, was discovered independently at the Pasteur Institute in Paris and the Cancer Institute in Bethesda, USA. This discovery changed our approach to the illness, our understanding of its epidemiology and our ideas for therapy. The virus can now be recognized easily and can readily be cultured in the laboratory. HTLV III is a unique human retrovirus, which *may* have originated in central Africa, possibly in the African green monkey, or another animal species, from which it found its way into the human population, later to spread rapidly by travel throughout the rest of the world; this theory has yet to be proven.

Even before the causal virus had been identified, we suspected the involvement of an infectious agent, which probably attacked certain types of lymphocyte and thus caused immunodeficiency. Although we can now identify the virus, we still do not know why some infected people develop this immunodeficiency and die quickly, while others appear able to cope with the virus infection very effectively, and remain in good health for many years after becoming infected. Another clinical challenge is to determine what governs the type of problem we see, once the immunodeficiency is established. What co-factors, beyond infection with the virus itself, are associated with predisposition to the

New definition of AIDS

We have reached a point where we can broaden our definition of AIDS from the original CDC surveillance definition (*Table 2.1*). AIDS can now be defined as a primary infection of the T-lymphocytes, especially of one helper type, by a human retrovirus (*Table 2.9*). In other words, it can be diagnosed from the presence of immunodeficiency that results in an increased risk of infection or malignancy. The difference between the two definitions may be subtle, but the broader definition may help us to identify people at high risk and, as we develop therapies to change the progression of the disease, to treat people at an earlier stage of the disease, with more hope of successful intervention. The incubation period of AIDS is uncertain because we cannot often determine the exact date of exposure to HTLV III. Estimation of the incubation period is a little easier after blood transfusion, or in some cases of haemophilia, where estimates range from a few months in the case of infants, to 5 years or more in adults. I suspect that the incubation period, from the time of infection to the onset of disease, is 2–3 years in most cases.

Table 2.9 AIDS: a modified definition

AIDS is caused by a chronic infection of the T lymphocytes (especially helper subtype) by a novel human retrovirus. AIDS can be diagnosed when this infection has caused damage sufficient to increase the risk of malignancies and opportunistic infections

The magnitude of the problem

Until HTLV III was identified and we could begin to test for its presence, all we could do was suspect that we were dealing with a much broader problem than we were seeing clinically. The ability to test for the virus enabled us to answer some very important questions. For example, are we sure that AIDS is a new disease? How big is the epidemic? How rapidly is it infecting people? The San Francisco Health Department and the CDC looked again at the results of the 'Hepatitis Cohort Study', which involved sexually active gay men at a City STD clinic. This study began in the late 1970s, its purpose being to examine the risk of hepatitis B, as part of a hepatitis B vaccine trial. Thousands of men were interviewed to ascertain their sexual and health histories, and serum samples from them were frozen. The CDC subsequently

samples for antibodies to HTLV III, to determine when the virus first appeared in San Francisco. What was found was truly remarkable (*Table 2.10*): as recently as 1978 there was no record of viral antibodies, so we can conclude that AIDS is a new disease caused by the HTLV III virus. We can also estimate the rapidity of the viral spread through the population. From a zero level of anti-HTLV III antibody in 1978, by the middle of 1984 50% of a selected group of very sexually active gay men had developed antibodies to the virus and, by October 1985, 73% of this group had become infected. There was thus a very rapid spread through a large community and we now estimate that in San Francisco 50% of randomly selected gay men are infected with this virus. As we have 70000 gay men in San Francisco, we believe that we

Table 2.10 The scale of the AIDS problem

In principal risk group, *no* antibody in 1978
In same group, 50% carried antibody in mid-1984
Seropositives 60–80% culture-positive for AIDS virus; even more may be capable of transmission
Estimated 1000000 infected individuals by early 1985
Risk of AIDS in carrier at least 10%, ARC higher, long-term health risks unknown (?lymphomas, ?late reactivation)
Lifelong risk of transmission to offspring

are dealing with an epidemic already involving 35000 infected individuals. Considering that we do not really know the long-term prognosis for such infected people, this is obviously a matter of the greatest concern to us and a major reason why we are so interested in developing new therapies for the underlying infection.

Although, as I have stressed, we do not yet know the long-term effects of the viral infection, this does not stop people from making predictions, albeit very crude ones. There are estimates that AIDS will develop in 4–20% of infected people over a period of several years, and also estimates that the AIDS-related complex (ARC) will develop in about 25% of infected people.

Natural history of AIDS

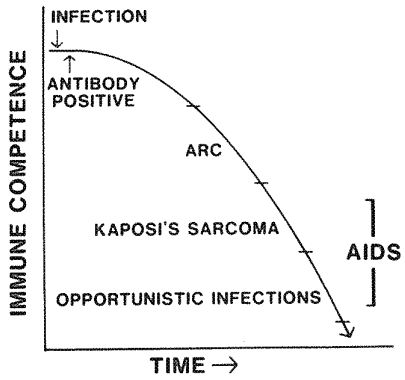

Figure 2.5 Natural history of AIDS virus infections

relates to the antibody. The mean incubation period from infection of the individual to the onset of the disease is thought to be 2–3 years. The incubation period from infection to the appearance of antibody — from the time that the person is infected until it can be *proved* with a positive antibody test — is much shorter: it is in the range of 1–2 months in most cases and certainly is less than 6 months in almost all cases. Thus, because a positive result appears very quickly after infection, we can usually be reassured if the test proves to be negative. Once the individual is infected, a number of things can happen. Initially, many people remain in apparently good health. However, it is thought that people who are infected show a minor dip in their immune status, followed by a plateau (*Figure 2.5*). In the person who develops AIDS there is evidence of a continual decline in immunocompetence. After infection the immune system gradually breaks down and, after a certain level of immunodeficiency has been established, the infections and cancers appear. *Figure 2.5* is important because it suggests that there are some populations that may be more successfully treated than others; it is those people that are being increasingly focused on for trials of new (especially antiviral) therapies. There is much less optimism with regard to those with fully established AIDS.

The AIDS iceberg

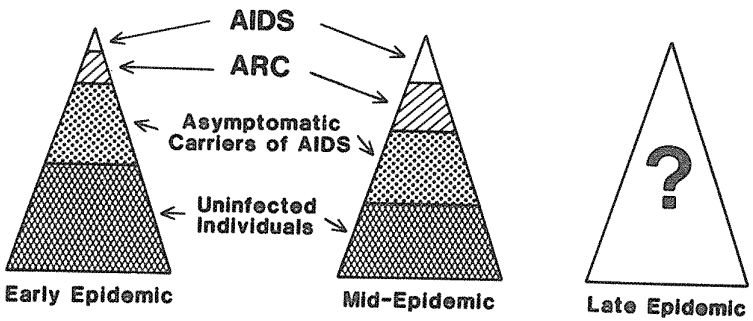

Figure 2.6 AIDS virus 'icebergs'

San Francisco in the evolution of AIDS-related disease. The iceberg appears to change size, depending on the position of a certain population in relation to the epidemic. Thus, early in the course of the epidemic there are relatively few people with AIDS (the 'tip' of the iceberg) or with ARC and, for a while at least, there is a relatively large group of asymptomatic carriers of the virus. As the epidemic evolves, more of the previously asymptomatic people become ill, and also more uninfected people will become infected. This change illustrates what people in Great Britain will be facing if attempts are not made to modify the spread of the virus. One problem is that we do not know whether we will *continue* to see a gradual erosion of the uninfected population, with more and more people becoming infected and developing the disease.

Tackling the problem

How, then, do we approach the disease now? *Figure 2.7* is a diagram of our organization in San Francisco. What we have tried to do is to develop a system that encompasses both basic and clinical research groups, with patient care underpinning the whole process. We have based all that we have done on our own clinical approach to patients.

For those of us who have been working with AIDS, there have been two breakthrough points in this epidemic: first, when the virus was discovered; secondly (at least in the United States) when Rock Hudson

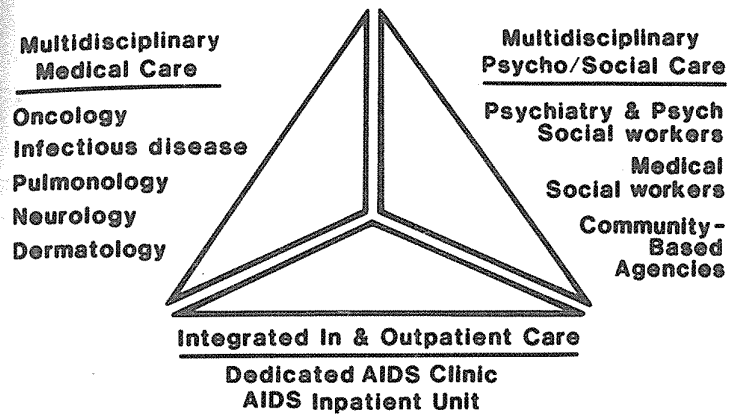

Figure 2.7 Elements of optimum AIDS care

general population—those people who had not previously considered that AIDS was any concern of theirs—suddenly found that they 'knew' somebody with the disease. Because people who appear on our movie or TV screens are our 'friends', we saw a clear change in the public reaction to AIDS — a useful change because it has allowed us to deliver education to people who previously had not been receptive. There is a new anxiety about their own risk, although this risk is still minimal, and that has opened the door to more effective teaching and to the possibility of control.

3

The Virus

RICHARD TEDDER

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Introduction: the 'AIDS iceberg'

It has often been said that those who used to work with hepatitis B — and I am one of that breed — have recently been 'recycled' to work on a new virus. That is probably as true of clinicians and epidemiologists as it is of virologists.

In the light of the 'AIDS iceberg' concept discussed already in Chapter 2, AIDS itself is an unimportant disease. Those readers who remember the history of the ill-fated liner *Titanic* will also remember that she sank, not as a result of that part of the iceberg visible above the waterline, but because she impaled herself on that massive amount of the iceberg that sits undetectably beneath the waterline: she foundered because she encountered what was not perceived and what was not visible. This is true for our species in relation to HTLV III infection: if we are going to sink, it will be as a result of what we do not perceive, rather than what we do perceive. Only the tip of an iceberg is recognized and Dr Volberding has shown that the appreciation of the iceberg changes during the evolution of an epidemic. In the absence of a vaccine and in the absence of a specific antiviral treatment, unless we recognize *now* the epidemic and the true size of the iceberg, there is very little that we, as a species, can do. Recognition is essential as a stimulus to change our behaviour patterns in a fundamental way. The human is a sexual animal and we must bring into the open the understanding that the AIDS virus is transmitted sexually. The close physical contact which occurs when two people make love, irrespective of how they make love, and whether it is between a boy and a boy, or a boy and a girl, enables this virus to be transmitted.

Understanding the transmission of germs is helped by our knowledge of their structure. A virus is a particularly small germ and has no

piece of information enclosed in an envelope. As this envelope is delicate and soon damaged when outside the cell, the virus is easily rendered non-infectious.

Retroviruses

Viruses come in many shapes and sizes. The viruses that we are concerned with here are called retroviruses. Until a few years ago, retroviruses were the concern chiefly of veterinarians and were known to cause certain types of cancer or leukaemia and to be transmissable in animals. At the beginning of this decade, two independent discoveries were made of a retrovirus which infected human lymphocytes and which caused a rare form of leukaemia in adult humans — adult T-cell leukaemia. This virus, called ATLV (adult T-cell leukaemia virus) or HTLV (human T-cell leukaemia virus), was the first human retrovirus to be described. It is quite a common infection in two areas of the world — the Caribbean and the Japanese archipelagos; there, up to 25% of people in certain areas are infected. Besides this virus, there is one very closely related, called HTLV II. Until the beginning of 1983, these were the only retroviruses known to occur in man. Although both have the initials HTLV, they differ from the virus which causes AIDS. The AIDS virus also lives in human T lymphocytes (a particular type of white blood cell) and is therefore lymphotropic. Because these viruses all infect human T lymphocytes it is generally agreed that they should now be called Human T-cell Lymphotropic Viruses. Types I and II are the old *leukaemic* viruses. Type III is the *lymphotropic* virus or lymphadenopathy-associated virus (LAV), which is the causative agent of 'epidemic AIDS'. The term 'epidemic AIDS' is used because there are other clinical diseases which can masquerade as AIDS. It is important to remember this when studying disease in different populations. For example, this is particularly true of Africa where there are both epidemic and endogenous forms of Kaposi's sarcoma (KS): only the former, epidemic KS, is related to HTLV III/LAV infection.

HTL viruses

There is little visible difference between the immature virus particles of types I, II and III. However, in the mature virus particle there is a distinct difference between the types, with HTLV III carrying an internal component which is bar-shaped compared with the

II. A common attribute of these three viruses is an envelope which indicates that they are likely to be susceptible to physical denaturation by, for example, heat, detergents or organic solvents such as acetone and alcohol. The necessity of integrity of the envelope for infection implies that the virus is relatively easily rendered non-infectious. Indeed, it does not like being dried out and it has to be stabilized to survive this process. Unfortunately, in the manufacture of factor VIII for the treatment of haemophilia, proteins must be stabilized for freeze drying: this procedure probably also stabilizes HTLV III/LAV as well. Fortunately, heating and the action of detergents and solvents, besides common household bleach (hypochlorite), formaldehyde and glutaraldehyde, are all able to inactivate this virus.

Besides the morphological differences between the HTLV viruses, there is a difference in the effects on cells of infection. It is commonly accepted that HTLV I (and probably HTLV II) is a transforming agent; the effect of HTLV III/LAV appears to be lytic. In other words, HTLV III/LAV damages the cells it infects, although the mechanism is not known. Although the concept that HTLV III/LAV causes damage to infected cells, especially to T-cell lymphocytes, is useful, it is probably an over-simplification as the major derangement of the immune system found in these patients suggests that more virus and more virus-infected cells should be present than are evident on study.

The British virus (*Figure 3.1*) isolated from a patient in the United Kingdom is very similar to the French LAV isolate and to the American HTLV III isolates. There is probably a greater difference between these isolates and those from patients on the West Coast of America. Such differences are likely to reflect how various introductions of virus have become adapted in different human populations. Perhaps we are witnessing the development of an ecological system in which the virus is evolving into geographic variants. This speculation needs to be investigated by characterization of geographically diverse isolates.

Besides the envelope, there is an internal protein component — the core. Assays which are currently used for detecting antibodies (anti-HTLV III/LAV) are based on a mixture of all of these parts of the virus extracted from the cells in which the virus is being cultured. Therefore, the antigen extracted comprises fragments of protein from the envelope, some from the internal core and, significantly, material from the cells used to grow the virus. It is antibody to these cellular components, which are incorporated into the virus during budding, that has given false positive reactions in some tests. With special techniques, these component parts may be sorted by size and it then becomes possible to recognize antibody patterns: that is, which bit of virus is

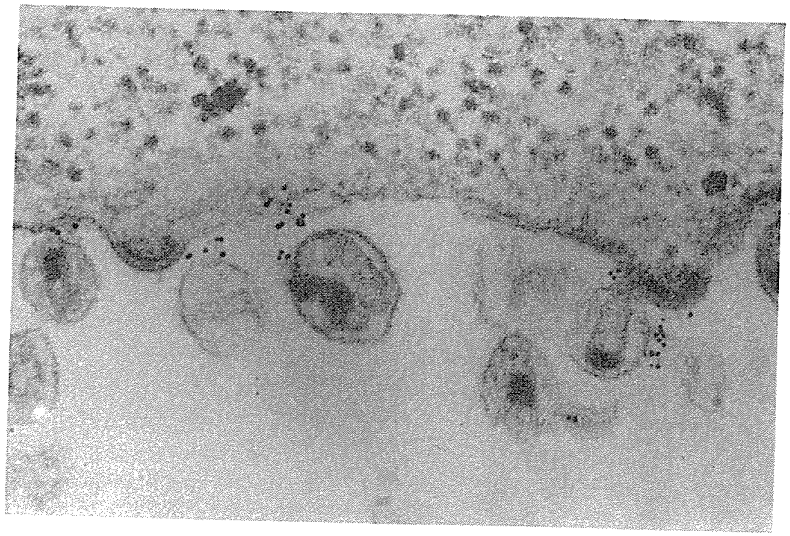

Figure 3.1 The British HTLV III virus (× 100000). (Courtesy of Professor R.A. Weiss, ICR).

infection. While we continue to work on the virus, the only way to deal with HTLV III-related disease is to control the spread of the virus.

We can say that HTLV III/LAV is causally related to the diseases, including AIDS, for the following reasons: (1) it is isolated from patients with severe immunodeficiency and from those with generalized lymphadenopathy; (2) patients with AIDS have evidence in their blood of HTLV III/LAV infection; (3) the evolution of seropositivity and disease occurred at the same time in Western AIDS-risk groups; (4) *in vitro* laboratory data show that the virus is particularly able to attack the T4 helper lymphocytes, one of the main components of the defence, or immune, system; (5) in addition, HTLV III is neurotropic, both *in vivo* (it grows in brain cells and in neurones, damaging them) and *in vitro*.

Virus life cycle

Outside cells, viruses are passive. They get somewhere only by being carried into the body through mucous membranes or by parenteral injection. For infection to occur, the virus needs to get into the lymphocytes and it does so by attaching itself to a receptor on the surface

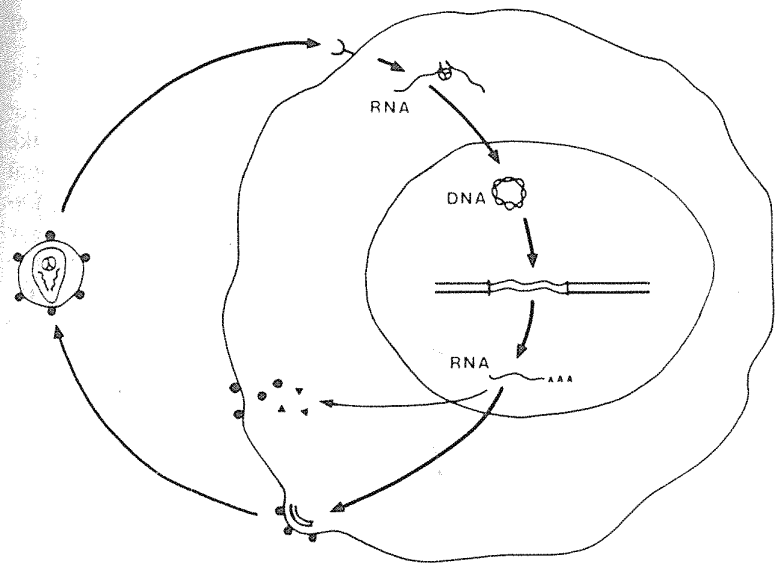

Figure 3.2 Diagram of HTLV III virus entering, and replicating in, a T4 lymphocyte. (Courtesy of Professor R.A. Weiss, ICR).

the virus gains access to the lymphocyte. Blocking this receptor denies the virus access to its target cells; this may have therapeutic implications. Too efficient a blockade could cause other problems as this receptor has a very important biological function in T4 cells: it is a kind of 'shorthand' by which one lymphocyte recognizes other cells. If that shorthand were to be destroyed, the communication system needed for the intact immune system to function might be disrupted and the possible therapy to prevent virus infection could lead, on its own, to immune suppression.

As mentioned earlier, HTLV III/LAV is a retrovirus, and this term has a special meaning. DNA (which is the blueprint for life) usually makes RNA, which is then translated into protein in the body's cells. It used to be thought that this was an inviolable rule of life: HTLV III/LAV and other retroviruses break this rule. The virus message (RNA), in order to replicate in infected cells, is reverse (retrograde) transcribed back to DNA. The DNA copy is then inserted into the host chromosome. The virus is able to do this because it carries an enzyme called reverse transcriptase, allowing the information to be

to affect recognition, reverse transcription, insertion, the assembly of new virus, or its release.

There are two major problems to be addressed urgently. The first is the question of vaccine. The outside of the virus contains a number of antigens which are well recognized by infected humans but, unlike those on other human retroviruses, they do not stimulate the patient to produce antibodies to block the infectivity of the virus. These blocking or neutralizing antibodies are not totally absent in antibody-positive sera but their level is a fraction of what would be expected by comparison with HTLV I and HTLV II. Possibly there is some mimicry between the cell receptor on the virus and cell-surface antigens, perhaps class II. If that is so, it becomes very difficult to see how to make a vaccine which will prevent infection. It may require very subtle changes to be made in viral antigens, so that they become immunogenic without in turn breaking the body's tolerance of the class II antigens which it mimics.

The other problem concerns the integration of the virus genome into the DNA of the lymphocyte, which leads to a persistent infection. HTLV III/LAV belongs to a group called the lentiviruses, or 'slow' viruses, so called because the diseases they cause take a long time, sometimes many years, to be manifest. Indeed, in some animal infections, the disease may not always become apparent within the lifetime of the host. In other words, the incubation period of the disease is sometimes as long as the lifespan of that animal.

Lentivirus replication itself is not slow. The time from infection to seroconversion, the first latent period, may be quite short — indeed, it may be only two to three weeks — and we now recognize that a small proportion of infected people get acute illness during the seroconversion (*Table 3.1*). The first case described was an unfortunate nurse who seroconverted as a result of an unusual needle-stick accident. She suffered an acute glandular-fever-like syndrome now known to occur in a small proportion of people acutely infected with HTLV III. It is possible that integration could occur before the production of antibody and, if that happened, the person might become an antibody-negative virus carrier with a latent infection. Whether they would be infectious sexually or could transmit infection by blood transfusion, is not known. If with early integration there is little or no antigenic expression, the individual could remain antibody negative for a long time until virus expression is triggered and antibody production would follow a long time after exposure. This phenomenon may account for the occasional haemophiliac who is found to seroconvert months, or even years, after exposure. This very long period to seroconversion is rare, but may account for some of the apparent seroconversions among

Table 3.1 Sequelae to infection

Phase	Antibody status
1. Latent phase	Anti-HTLV III negative
2. Acute illness	Seroconversion for anti-HTLV III
3. Clinical latent phase	Anti-HTLV III positive
4. Chronic illness	Anti-HTLV III positive

After seroconversion there is a clinical latent period, during which virus expression continues despite production of antibody. It is not known what proportion of people in the clinically latent period will eventually progress to chronic disease. Co-factors may be needed but there is a school of thought which considers that they are unnecessary and that it is the virus alone which causes disease. The situation is not simple as, for example, pregnancy hastens the onset of HTLV III-related disease and certain seropositive cohorts have different rates of development of disease.

Dr Volberding introduced the concept of the iceberg effect. The importance of the iceberg is not the identification of people with AIDS 'above the waterline', but is the recognition that there is a vast reservoir of hidden infection 'beneath the waterline' in the community. Although some of the infected persons will have minor illnesses, the only precise way in which these individuals can be quantified is by the appropriate use of serology. The demonstration of a high percentage of infection in certain groups enables decisions on health resource planning *and* personal behaviour to be taken objectively.

AIDS in Africa

The major global AIDS epidemic is occurring not in North America but in Africa. This is not to minimize the importance of the infection in the United Kingdom, but numerically, and in terms of the impact on primary health care, the true AIDS epidemic is occurring in some countries in central Africa. There, as elsewhere, the virus and its disease are *new*. The evidence that implicated central Africa as the *source* of AIDS was based on the inappropriate use of inappropriate technology on inappropriate sera, and is now widely perceived as being incorrect. This is unfortunate as it oversimplified the problem and made countries in central Africa feel that there was international blame attached to being the 'source of AIDS'. Recent serological evidence in

lations in other parts of the world could have been the source, is not known. The infection in central Africa, then, is just as new and just as horrifying as it is in the AIDS risk groups in Europe and North America. The seroprevalence rate is approximately equal between men and women, and it appears that the infection is passed as casually as 'conventional' sexually transmitted diseases in Europe and America. The magnitude of the problem is considerable. The fundamental difference in the epidemiology is the ease with which the virus spreads in central Africa. The reasons for this change in viral behaviour are not known. In contrast, it should be emphasized that this is *not* a highly contagious, easily sexually transmitted disease in the United Kingdom or in North America. On the other hand, one cannot afford complacency and should not assume that the infection will never enter populations outside the high-risk groups. If the pattern of spread seen in Africa were to happen elsewhere, perhaps through a change in the virus, a much more widespread epidemic could occur. In the absence of antiviral therapy and a vaccine at present, it behoves us to treat this virus with respect and not to underestimate the impact it may have on all human populations.

4

First Question Session

Dr Srivastava (Cornwall): I would like to ask about Government policy on finance and on research. Is there going to be provision for each district to have a health counsellor, and what is the Government doing in terms of providing the monies required for AIDS research?

Dr Acheson: With regard to the first question, money specifically for counselling and other aspects of the prevention or treatment of AIDS has been given to three of the London Regions. I think, nevertheless, it is important that in each district there should be at least one trained counsellor. I hope that further information about how each district should tackle the AIDS problem will be forthcoming soon from the Department of Health.

In answer to your second question, I can tell you that the substantial sum of £500000 a year for three years has recently been donated by four Government Departments — the Department of Health and Social Security, the Health Departments of Scotland and Wales and the Department of Education and Science — to the Medical Research Council for research into the epidemiology of AIDS.

Dr Gunson (Manchester): Dr Volberding, you showed the incubation period following transfusion as varying between 2 and 59+ months. Did the patients in the early incubation period suffer the same symptoms as Dr Tedder described for the acute illness of seroconversion, or symptoms of classical AIDS?

Dr Volberding: My data were from a number of sources and suggest that the incubation period appears to be very variable, especially after blood transfusion. The shortest incubation period to actual AIDS is seen in infants after transfusion, probably because the infants are immunonaïve when they encounter the virus. The incubation period in adult patients following transfusion of infected blood can be very long. We still do not know the fullest extent of the incubation because we are only five years or so into the epidemic.

Professor G.E. Russell (Newcastle): Dr Tedder's remarks about the strains of HTLV III struck me, as a plant virologist, as perhaps not

because such differences are due to differences in the nucleic acid sequences rather than in the antigenic proteins. Is work being done to identify different strains of HTLV III using methods other than serology? Secondly, by analogy with the epidemiology of many plant virus diseases, I would expect some kind of virus vector to be involved in the AIDS epidemic in tropical Africa. I am not thinking only of mosquitoes, but also of other invertebrate parasites, including other blood-sucking pests and gut nematodes. Are these possibilities being looked at?

Dr Tedder: I would agree that the elegant way to show differences in virus isolates is to look at the nucleic acid sequence. However, there is a pitfall in this because what, in genetic engineering terms, may be considered to be a significant difference may not, in terms of the molecular structure of the antigenic sites of the virus, be so important or so relevant. The outside component of the virus, the envelope (the *env* gene) of this virus actually codes for two major proteins, an intact polyprotein which is highly glycosylated and which purifies at about 120 kilodaltons, and there is a transmembrane insertional protein which is also a polypeptide. The gene which codes for the outside component, the envelope antigens, certainly is quite variable on the nucleic acid basis from other isolates, particularly the cohort of viruses on the West Coast of America. Having said that, when you do antibody assays in a quantitative way against various components of the virus in various ways, including looking for neutralizing antibody activity, you might predict that an African virus with an African serum would give a greater neutralization signal than, say, an African virus with a North American or British haemophilic serum, but you do not find this. You find that the cross-talk between virus isolate and virus antibody and serum in general appears to be the same, no matter where the serum or where the virus come from. This is rather like the problems associated with cytomegalovirus; analysis with restriction endonucleases on CMV shows that there are very many different types of virus, but gives no clue as to what is important and what is not.

Dr Volberding: Dr Levy in San Francisco has also been very active in this work. He has avoided the term 'strain' and has used the term 'isolate', as you have, as a way of getting around this problem. We have found that individuals can be infected with several distinct isolates of the virus simultaneously, showing no difference in antibody reaction with these different isolates.

Dr Tedder: With regard to the question of vectors, the data for Central Africa are not complete. However, there is little or no evidence of seropositivity from the age range of 2 or 3 years up to puberty. That is at present clear and unequivocal. It will become confused as the

commonly. If a vector was involved, one would not expect the present seronegativity in this group of young.

Dr Volberding: The statement has often been made that perhaps this virus has been around in Africa for a long period. The lack of seropositivity in young children in Africa speaks strongly against that, because if the virus had been there, more vertical transmission would have been seen.

Dr Acheson: Before we leave this point, may I ask my colleagues whether any differences between viruses in Africa and Europe could be related to the obvious differences in the epidemiology of the outbreaks?

Dr Tedder: They could be but there is no evidence to suggest that at present. It could equally well be the nature of the infected human and potentiating factors in the different countries which make the virus more easily expressed and, therefore, easier to spread.

Dr Volberding: This must be one of the most important questions of the day, why there is such a different epidemic in Africa compared with the rest of the world. Is it because of co-factors, or is it because of viral factors? I do not pretend to know, but I would hope that it is because of co-factors — because that would suggest that AIDS is not going to become the same type of epidemic elsewhere that it is in Africa. However, I agree with earlier comments, that this would be very dangerous to assume, and that we should probably assume that the opposite theory is correct until we know more.

Delegate from North Staffordshire: May I ask Dr Tedder about the differences in the virus in Africa and Western civilization? What does he feel could be the effect of different life-styles, for instance differences in sexual activity and birth control? Are these factors a possible explanation of the increase in viral spread? I would also like to ask Dr Volberding if he feels that the present decrease in incidence in San Francisco might indicate that the disease will eventually die out?

Dr Tedder: To say that Africans are all the same is rather like saying that Europeans are all the same. The countries that I have visited in Central Africa abjure homosexuality and are not promiscuous. The seropositivity and the disease which I have seen is not related to the number of sexual encounters any more. Years ago, it may have been — and I am talking about only 2–3 years' difference — but nowadays you do not have the need to have a large number of sexual partners. Indeed, some of the cases that I saw were in young men and women who had only one or two sexual partners a year. Anal intercourse is not a recognized sexual practice in the particular country that I visited, and there is strong evidence that this is true because of an absence of rectal or anal pathology in both men and women. All I can say is that the epidemiology is very different. How the virus got there I do not

the more westernized people in Central African countries who are seropositive. That leads me to believe that the source of the infection may well have been introduced from outside.

Dr Volberding: The second question was 'Is it true that there is a plateau of the disease in San Francisco and what are the implications of that?' For the past 6 months the number of new cases per month has been in the 60–65 range, in contrast to previous years of the epidemic which saw a continual increase in the number of newly reported cases. We are not sure whether this is because of viral saturation in the gay community, or education. I prefer to think it is because of education and I strongly believe that this is, in fact, the case. Prospective studies have shown that gay men are now seroconverting at a rate of about 5% per year, so of gay men that were seronegative a year ago, only 5% are seropositive now. This is much better than in the past, because to get from zero to 50% — our estimate of the gay men who are now seropositive — the rate had to be between 10% and 15% per year. We think that the fall has a lot to do with education and with fear of the disease. The gay community in San Francisco is devastated by AIDS and everyone knows about it and how it is transmitted. Our concern lies in the fact that we have a large population of intravenous drug users. They are now 10% seropositive in contrast to 0% at the start of the epidemic. At present we are not sure how to get to that group and how to educate them to stop sharing needles. We expect to see i.v. drug abuse become a much more significant part of our epidemic, as has been the case in New York. In New York City, 51% of cases are now i.v. drug-using heterosexuals, and this is a dramatic contrast to the situation several years ago.

Dr Pattman (Newcastle): Could you comment on the recent reports from South America on the finding of HTLV III antibody seropositivity in Amazonian Indians who have not, apparently, had previous contact with the outside world.

Dr Tedder: While I can comment on it, I am afraid that it will not be a very favourable comment because I do not believe the serological results in the studies that you have heard about. We have looked at Central Amazonian Indians in an adjacent area and found no evidence of any form of seropositivity for HTLV I or III. I think that there is very great danger in using an antiglobulin assay and then confirming it with a Western blot (which is another form of antiglobulin assay). I think that what we will see in the popular scientific press over the next year is a proliferation of 'me too' reports from people who have bought a kit, perhaps a kit for Western blotting as well as a kit for antiglobulin assays, and have then tested 75 sera from some tribe and got a 5% seroprevalence rating. It just does not make epidemiological or viro-

Delegate from Aberdeen: Dr Acheson referred to the recent worrying spread of the virus among intravenous drug users in Scotland. Could I ask if there are any lessons that can be learned from America in tackling this problem?

Dr Volberding: I wish there were. The first lesson to learn is that if you do not do something about it, it will get worse. We are very afraid indeed in San Francisco because of what we see when we look at New York, where it is estimated that at least 75% of i.v. drug users are now seropositive. It is hard to get a good estimate of seroprevalence in that group, but it is clearly very high. In Scotland, as in other parts of Europe, i.v. drug use is a major problem and is likely to be a major source of the future spread of AIDS. I have had a great deal of experience with this group in our hospital and think that it is a very difficult group to educate. There is no sense of community such as one finds in the gay community, and while we are praised for our care of patients in San Francisco, our job is relatively easy because we are dealing with that very unified community. The problem in these other groups is going to be much more difficult to control.

Dr Acheson: At another conference on AIDS in another place, the speaker from the World Health Organization pointed out that there is a very marked degree of variation in the proportion of intravenous drug abusers who are seropositive in different cities in Europe. For example, in Amsterdam where there is a great deal of drug abuse and also some HTLV III infection, there is practically no evidence of infection of the drug abusers, whereas in other cities, like New York and in some cities in Scotland, as we have heard, it is very high. This may very well point to differences in the way that these groups behave, which could be of importance in any preventative procedure. Clearly, there is an urgent need for research.

Dr Tarrant (Cambridge): Dr Luc Montagnier recently gave a lecture in Cambridge and suggested that his LAV virus was, in fact, different from the HTLV III virus. I got the impression from Dr Tedder that he thought the two were basically the same. Have I misunderstood him, or are there differences between the two?

Dr Tedder: It depends on whether you want to make them the same or different! The nucleotide percentage difference is of the order of 1–2%. This is, theoretically, well within the possibility of multiple sequential passage with one virus isolate. Equally well, it is certainly within the possibility of two simultaneous isolates that are geographically different.

Dr Volberding: My understanding from talking to Dr Montagnier is that he is increasingly strong in his belief that his virus is not like HTLV I and II. Whether it is significantly different from HTLV III, I think

Part II

The Public Health

5

Investigation: the Work of the Laboratories

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Introduction

This chapter is on the topic of HTLV III/LAV infection and its detection, rather than the narrower field of AIDS. It is very important, especially now that there is a virus to study and therefore a 'handle' to the disease, that we think of AIDS in a much wider context than as the immunosuppressive illness that has been so usefully defined by the Centers for Disease Control. We have to learn to think of an infection with a spectrum of effects ranging from the wholly asymptomatic, sometimes through an acute illness, then back to a state of latent infection, and then through a series of clinical symptoms and signs of increasing gravity towards — at least in a proportion of individuals — an end-stage disease. Instrumental in the formation of this concept has been the development and application of good diagnostic tests and, in particular, of antibody tests for infection with HTLV III/LAV.

This chapter will attempt to answer two questions: first, how accurate are the tests that are available; second, what are their limitations? Although the first question may have a scientific answer, the answer to the second is more a matter of personal opinion.

Evaluation of the accuracy of tests for anti-HTLV III/LAV

When the implications of telling someone that they have antibodies to HTLV III/LAV are considered, it is obvious that we must ensure that the tests available should be as accurate as possible. *Table 5.1* shows some of the measures that have been adopted in an attempt to ensure this accuracy. In the first place, the UK Department of Health wisely

Table 5.1 Sources of information on anti-HTLV III/LAV assay accuracy

1. Virus Reference Laboratory evaluation
2. Blood Transfusion Service evaluation
3. Quality control panel distributions
4. Data from confirmatory centres

coming on to the market in the United Kingdom should be evaluated for their efficacy, both in diagnosis and in blood transfusion screening. This has meant that each of the nine or ten commercial assays currently available has been evaluated in the PHLS Virus Reference Laboratory at Colindale and, on a more selective basis, in the laboratories of the National Blood Transfusion Service. It was also felt to be important to have continuing evaluation of the performance of the tests. This has involved the Division of Microbiological Reagents and Quality Control at Colindale distributing a series of control sera and coded panels of sera to all the laboratories that are doing the tests. The results obtained in the various laboratories are being collated and the information is being fed back to the users. Finally, a network of laboratories in England and Wales has been designated where confirmatory tests by independent techniques are being applied. This should help to ensure that the tests that are apparently positive in the primary testing laboratories, be they diagnostic or transfusion laboratories, are checked by other assays to confirm that the initial results are correct.

RESULTS FROM COMMERCIAL KITS

The histograms shown in *Figures 5.1, 5.2* and *5.3* attempt to express how populations of sera behave on testing. Three groups of sera were used: the first is a series from blood donors; the second is a series of specimens taken from individuals within high-risk groups; the third is a series from other individuals with diseases which might give false positive results in anti-HTLV III/LAV assays. The three groups of sera have been tested using various commercial kits. *Figure 5.1.*, which summarizes the results with a single commercial assay, exemplifies what we are looking for in an effective test: the blood donor group are all segregated on the left, whereas many individuals in the high-risk groups give a strong signal in the test, representing a positive result, and lie on the right side of the histogram. Between these two zones is a wide area in which no specimen from any group gives a signal. There is thus very good discrimination between a population of

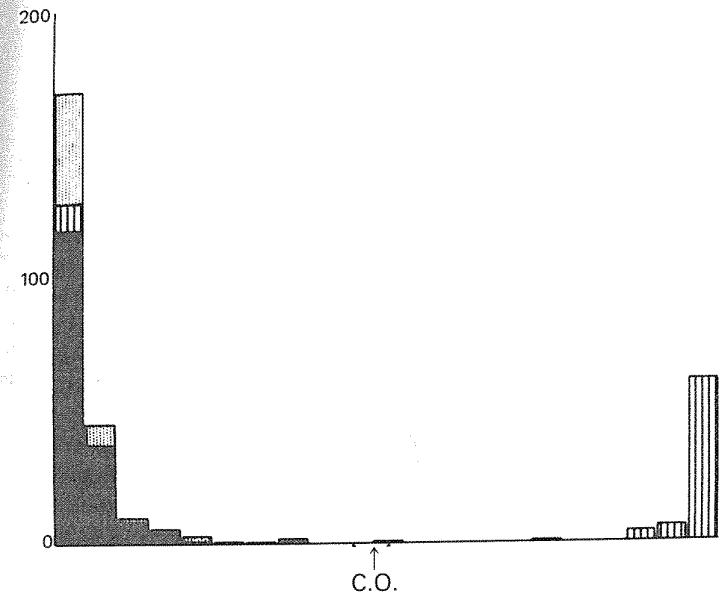


Figure 5.1 Populations of sera tested for anti-HTLV III/LAV: ■ blood donors; ▥ high-risk group individuals; ▩ possible false positives. *x* axis, optical density: minimum OD 0·045; cut-off (c.o.) 0·489; maximum > 2. *y* axis, numbers of samples.

assays perform in a similar manner to this. However, not all commercial assays give such good results. The results from a kit that was rated less highly are shown in *Figure 5.2*. It can be seen that some of the blood donors (who are all presumed to be seronegative) have crossed the midpoint into the positive region of the assay. In addition, the Figure as a whole shows rather poor discrimination between the populations of reactive and unreactive sera. Results that cluster in this way around the cut-off point can give rise to many problems, particularly when the test is used for screening in a transfusion laboratory.

The effects of maltreatment of sera

It is also the case (and this has been important in the context of determining the spread of infection in tropical Africa) that some sera give anomalous and false positive results in many commercial assays. There are several reasons for this, but basically they all involve abuse

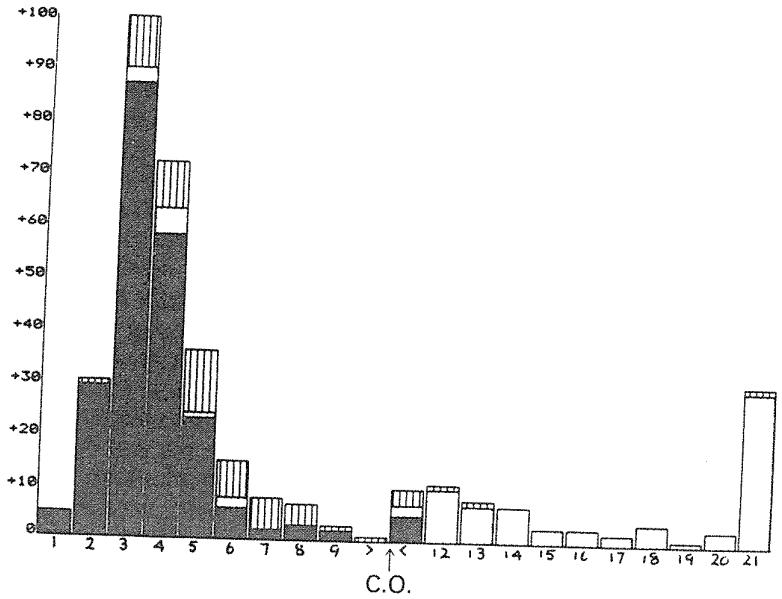


Figure 5.2 Same populations of sera as in *Figure 5.1*, tested for anti-HTLV III/LAV with a less highly rated kit: ■ blood donors; □ high-risk group individuals; ▥ possible false positives. *x* axis, optical density: minimum OD −1·246; cut-off (c.o.) 10 units; maximum > 137·7 units. *y* axis, numbers of samples.

been left out in the sun; it may even have been heated deliberately in the laboratory because a local safety committee has decided that heating is necessary to make the sample less hazardous to those handling it. *Figure 5.3* depicts what happens when specimens used in a commercial assay are heated to 56°C for 30 minutes to make them safe for laboratory handling: the population of blood donors has virtually all moved to the right, beyond the cut-off point of the assay, i.e. they are apparently seropositive. It should be realized that, at least in the case of some of the commercial assay systems, such treatment of sera is not compatible with getting an accurate serological result.

Sensitivity of assay systems

The sensitivity of commercial assays is a matter of special concern to those with the responsibility of screening blood donations. This problem has been studied in a number of ways. It can be thought of in

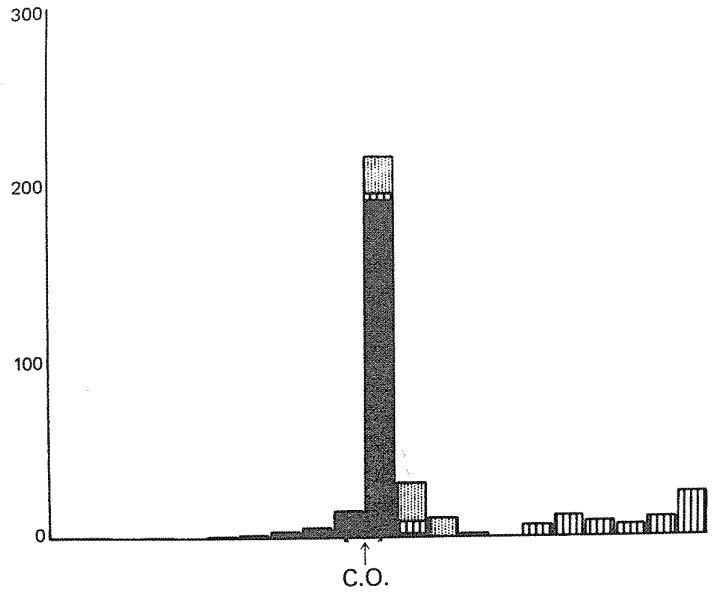


Figure 5.3 Effect of heating specimens on the specificity of a commercial assay: ■ blood donors; ▥ high-risk group individuals; ▦ possible false positives. *x* axis, optical density: minimum OD 0·065; cut-off (c.o.) 0·489; maximum > 2. *y* axis, numbers of samples.

negative serum (i.e. material which is of the same kind as the specimen itself) and seeing to what dilution the signal from a positive specimen can still be detected. This does reveal something about the sensitivity of an assay system, but it is inferior to the information that might be obtained from testing fresh, weakly positive specimens from individuals who have very recently been infected and then seroconverted, or perhaps from individuals who are at the end-stage of infection and whose immune system is so compromised that they have very low titres of antibody. At Colindale we have attempted to evaluate sensitivity by both quantitative and qualitative criteria. There were three commercial assays that performed relatively poorly, whichever form of assessment was applied, whereas there were six from which it was not really possible to select one or two assays which were outstandingly better than the others, by both criteria. The conclusion drawn from this small study is that there were six commercial assays that were particularly sensitive and were therefore of most value to those involved in blood

CONTINUING EVALUATION

Within about a year of the start of antibody testing in England and Wales and less than one year after the introduction of commercial assays, well over 60 laboratories were performing the antibody test on a regular basis; 57 of these collaborated in an exercise in which 10 sera were distributed in duplicate under code. The results from the first distribution of such quality control specimens in this programme of continuing assessment are now being analysed. In looking at the results, it must be remembered that, in this type of exercise, both the competence of the laboratory and the accuracy of the commercial kit are being tested and it is impossible to separate one from the other. What one therefore looks for are changes with time, as individual laboratories gain experience and become more competent. As that variable becomes less important it will become clearer which commercial kits are really the most accurate.

INDEPENDENT CONFIRMATORY TESTS

The fourth aspect of our assessment is the confirmation of antibody test results obtained in the primary laboratories. In the confirmatory laboratory methodologically independent tests are applied to specimens so that, using the diverse range of assays that are now available, it is possible to say whether or not specimens are reactive in several assays or merely in one of them. The implication of the specimen being reactive in only one assay must certainly be that the result is questionable, and it may well be falsely positive.

The methodologies available are shown in *Table 5.2*. They have been divided into three types, of which Type 1 is most familiar. The viral antigen is adsorbed on a solid phase, the specimen is added, and finally a reagent which will detect the binding of human immunoglobulin is used to elicit the result. Type 1 assays may be done on a plastic surface, on a glass slide as a fluorescence test, or on nitrocellulose paper in the

Table 5.2 Solid-phase assays for anti-HTLV III/LAV

Type	Procedure
1	Ag—specimen—anti hu Ig enz
2	Ag—specimen anti-HTLV III/LAV enz
3	Anti hu—specimen—Ag—anti-HTLV III/LAV

form of a Western blot test; however, the basic methodology is the same, whichever system is used. In Type 2 assays, exemplified by the Wellcome assay, a solid phase is coated with antigen and exposed simultaneously to both the test specimen and to antibody to the virus. This antibody is labelled with an indicator system, either an enzyme capable of generating a colour, or a radioactive tracer. Specimen and labelled antibody are added together and are allowed to compete for the antigen on the solid phase. In this test the signal arises *not* from a positive specimen but from a negative one (which is the reverse of what occurs in a Type 1 test), because only the antibody-negative specimen will allow unimpeded binding of the labelled reagent to the antigen. The Type 3 assay is one in which the Type 1 methodology is inverted: antibody to human immunoglobulin is put on to the solid phase, the specimen is added and then the antigen. An indicator system to detect binding of antigen to specimen is then brought into play.

What information do these assays give about an individual? *Table 5.3* shows the results on specimens from a homosexual man who appears to have been exposed to the virus in September 1985. Three specimens were sent to our laboratory for examination. On 7 November there was a negative result from the Type 1, Type 2 and Type 3 assays (note that the Type 3 assay can take two forms: in one, specific IgM antibody is measured; in the other it is specific IgG antibody that is measured). About a month later another specimen was tested and a remarkable difference in the reactivity was seen: there was a positive result from the Type 1 assay, a positive (albeit weak) result from the Type 2 assay, and the presence of both specific IgG and IgM in the Type 3 assay. Then, in a third specimen, taken some time later, all assays were positive but there was a decline in specific IgM.

Confirmatory testing appears to arouse much controversy, and *Table 5.4* draws attention to the fact that English practice is rather unorthodox. The view in the United States would be that results on initially reactive specimens should be confirmed by application of the Western

Table 5.3 Male homosexual exposed to HTLV III/LAV

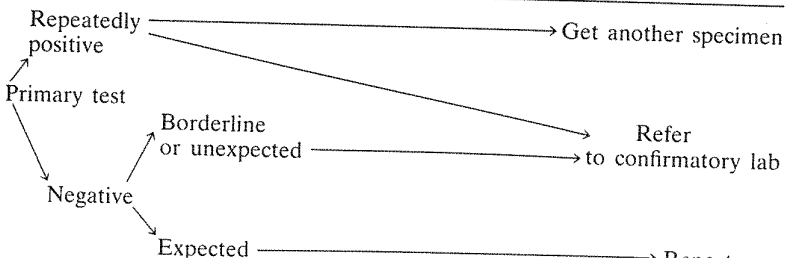
Date	Type 1	Type 2	Type 3	
	Elavia (OD)	Compria (% inhibn)	Macria T:N	Gacria T:N
7 Oct	0·04	−1	0·9	0·9
19 Oct	1·01	65	3·8	9·9

blot technique together with an assessment of the clinical and epidemiological background of the patient or blood donor. My own view, and that of my colleagues in the other confirmatory laboratories here, is that we should make full use of all the different methods available to us, in our system for confirmatory testing (I have used the word 'English' advisedly as we have yet to persuade our Scots colleagues that we are right about this). *Table 5.5* shows how the confirmatory procedure operates. A primary test is carried out in a hospital laboratory or in a transfusion laboratory and, if a positive result is obtained, our advice is that it should be checked from another specimen. We advise both that the test is repeated and also that the specimen is referred to one of the confirmatory laboratories. If, on the other hand, a negative initial result is obtained, we ask a number of questions. First, is it an expected and entirely negative signal? If so, it seems reasonable to report a negative result. If, on the other hand, it gives a borderline result coming fairly close to the cut-off point in the assay, or if the result is not the one that might be expected, the procedure for a positive result should be followed.

Table 5.4 Confirmatory procedures

I	US pattern	
	Type 1 screen → repeat	→ Western blot + Patient assessment
II	English pattern	
	Type 1 or type 2 screen	→ type 2 or 1 solid phase assay
	plus	→ i) type 3 assay ii) fluorescent antibody test iii) Western blot iv) patient follow-up

Table 5.5 Confirmatory procedures



The limitations of antibody tests

What are the limitations of these tests? Clearly, the test for HTLV III/LAV antibodies gives certain information. It indicates that a seropositive individual has been exposed to the virus at some time. It certainly implies that such an individual is continually infectious for HTLV III/LAV — continually rather than continuously, because there can never be proof that the individual is excreting the virus in significant quantities all the time, although the potential for transmission of the virus must always be present in a seropositive individual. On the other hand, the test does not give any measure of the *degree* of infectivity: it does not have the same role, for instance, as the e antigen–antibody system has in hepatitis B infection. Nor does it say anything about an individual's prognosis. It is possible to give a tentative prognosis on the basis of clinical appearance, but it is not possible to do so on the basis of the antibody result. That statement has to be qualified a little, however, in that recent work on the Western blot profiles of seropositive individuals suggests that there are certain patterns which correlate with changes in clinical state; that work is, however, still at a preliminary stage.

Figure 5.4 shows, in schematic form, a typical infection with HTLV III/LAV virus. What we believe happens is that, over a period of a few weeks or perhaps more, at the time when the individual is probably

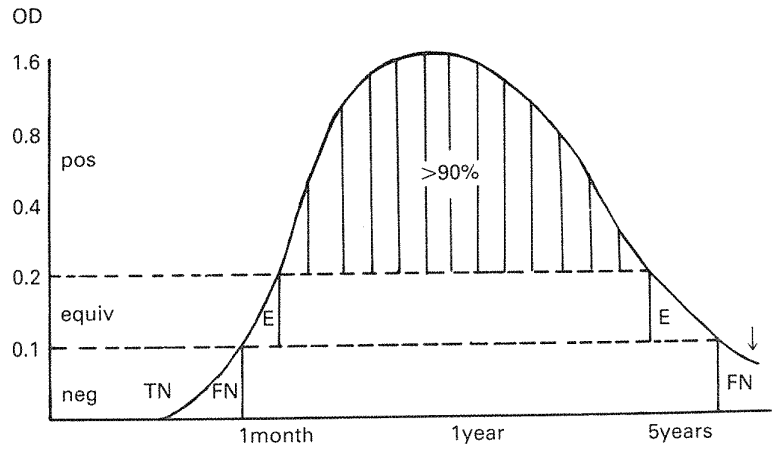


Figure 5.4 Evolution of the anti-HTLV III/LAV response measured by a type

having a considerable viraemia, there is no antibody detectable by *any* test, no matter how sensitive. In other words, there is a true antibody-negative phase in an infected person. That phase is followed by a period of false negativity — one which may be of particular significance in the context of blood transfusion work. We have learned the hard way, especially in the transfusion field, that infections with hepatitis B are especially difficult to identify at this phase of early infection; yet they are the ones that have given rise to most of the transfusion-transmitted hepatitis that has occurred since hepatitis B screening of blood donations was introduced. The period during which the patient undergoes seroconversion, when the results may be in the equivocal range, is therefore an important phase in HTLV III/LAV infection. There follows a very long period, which may exceed 5 years, when the individual gives a strong antibody signal by any test applied, from the crudest and most simple to the most sophisticated. Thereafter may follow a period at the end-stage of the infection when the succession of phases that an individual has gone through will recur in reverse, although most individuals with the end-stage disease of AIDS still have readily detectable antibodies.

Turning to a broader assessment of what antibody tests can or cannot do: Dr Acheson (Chapter 1) has estimated the number of seropositive individuals at present in the United Kingdom to be about 20000. *Table 5.6* attempts to break down this mass of individuals into its component groups. First, there is a relatively small population of recipients of (mostly) commercial clotting factor concentrates who have become infected as a result of the transmission of the virus by blood product. Of the approximately 4000 haemophilic patients in the United Kingdom, about 1000 are seropositive. That has been a calamitous outcome of the use of clotting factor concentrates, but it is pleasing to be able to say that the risk has been dramatically reduced, if not completely abolished, by heat treatment of the concentrates. With regard to the recipients of transfused blood, there are about one million

Table 5.6 Estimated HTLV III/LAV infected, United Kingdom 1985

Risk group	Size	Anti-HTLV III/LAV positive	Percentage positive	Risk trend
Haemophiliacs	4 000	1 000	25	↓
Blood recipients	1 000 000	60*	0·06	↓
Drug abusers	20 000	1 000	5	↑
Homosexuals	500 000	15 000	3	↑

each year and it can now be estimated from the figures given in Chapter 10 that about 50 of these recipients were infected as a result of receiving blood during 1985 before antibody testing of donations was started. That, of course, represents a very low risk. Now that the screening of all donated blood has been introduced, we can expect the risk to decrease.

The two risk groups for whom there is no such good news are those who abuse drugs intravenously and the very large risk group of male homosexuals. The numbers shown in *Table 5.6* are guesses but it is evident that the figure of 5% for drug abusers is low compared with what is happening in the rest of Europe, and what is beginning to be seen in the United Kingdom in 1986. Numbers of infected i.v. drug abusers in the UK are likely to increase rapidly. Similarly, we have no clear idea of the numbers of homosexual men at risk and the figure that I have suggested is a conservative one. We can confidently assume that at least 15000 homosexual men in the United Kingdom have already been infected. The overall prevalence of infection is low, but in certain parts of the country seropositivity is very common and the trend is relentlessly upwards.

Although antibody testing enables us to produce sets of figures on which to base informed guesses and estimates, it cannot of itself do very much to contain the spread of HTLV III/LAV. The following example may serve to highlight this. A decision was made that all donated blood in the United Kingdom should be screened, and such screening began in mid-October 1985. We have since learned that only about one in 50000 donations is seropositive (*see* Chapter 10). This means that we shall be spending about £3 million in 1986 to pick out 50 positive donations. It also means that it will cost £50000–£100000 to prevent each potential transfusion-transmitted infection. In Chapter 1, the Chief Medical Officer referred to plans to spend £2·5 million — a sum similar to that which we shall be spending annually on screening blood donors — to launch a national programme of health education about AIDS. Such an education programme must surely be far more cost effective than the screening of blood. I am not suggesting that we should stop screening blood — such screening is necessary and inevitable, and has concentrated minds on the threat which this virus poses to society. Nevertheless, in the absence of specific treatment or a vaccine, health education is probably the most useful approach. Today young people in general, and young homosexual men in particular, are probably more concerned about the integrity of their bodies and good health, than previous generations have been. There is a general trend within society to take a more positive interest in health. In the light of this trend, and because it is young people who should be most con-

emphasizing safe sexual practice is absolutely crucial in stemming the spread of infection. It has been suggested that 20000 individuals are already infected and I estimate that another 20000 will be added to the pool in 1986. If health education helps to prevent only 1000 of those new infections, it will have been about 20 times more cost effective than the screening of blood.

Conclusion

The threat of AIDS is absolutely indivisible: it affects both sexes; it affects both sexual orientations; it affects any i.v. drug user and, potentially, any recipient of human tissue. This is an infection that will be seen in every country of the world and it represents a particular hazard to people travelling to hyperendemic areas. No-one should think that they will not be touched by the effects of this virus in one way or another.

Although laboratory tests will do a great deal if they are appropriately used and have already heightened individual and public awareness of the problem, they are not the key to the control of the AIDS epidemic. The key to that is education, both of the groups at highest risk, and of young people who are entering those groups — and, indeed, of everyone else. If there is no response to the health education message, then, to quote the great communicator, 'You ain't seen nothin' yet!'

6

Surveillance: the role of the PHLS Communicable Disease Surveillance Centre

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Introduction

During 1981 increasing numbers of reports of a new syndrome were received from the United States of America (USA). Opportunistic tumours and infections such as Kaposi's sarcoma and *Pneumocystis carinii* pneumonia were diagnosed in young, previously well homosexual men (CDC, 1981). The first case of AIDS in the UK was documented in December 1981 (Dubois *et al.*, 1981) and soon after, morbidity and mortality data were reviewed retrospectively at the PHLS Communicable Disease Surveillance Centre (CDSC), in order to detect indications of a possible future outbreak. No increase in reporting of opportunistic infections in young persons in the previous 5 years was found, neither was there any change in the number or pattern of death entries mentioning Kaposi's sarcoma received at the Office of Population, Censuses and Surveys (OPCS). However, it was concluded that existing surveillance should be augmented in order that the early stages of a future national outbreak would be recognized. The purposes of this chapter are to describe the surveillance schemes for the acquired immune deficiency syndrome (AIDS) and human T-lymphotropic virus III (HTLV III) infection currently in operation at the CDSC, to provide an update on the United Kingdom (UK) and European statistics and to discuss national predictions for future numbers of cases.

The United Kingdom

SURVEILLANCE METHODS

in 1982. The case definition compiled at the Centers for Disease Control, Atlanta (CDC) (CDC, 1982), was adopted and three sources of data were used: copies of death entries kindly provided by the OPCS; laboratory reports of opportunistic infections, and clinical reports received on a voluntary basis in strict medical confidence from physicians. When cases in patients without recognized risk factors were reported, their permission and that of the admitting clinical consultant was sought and epidemiological interviews were carried out by a medical epidemiologist from CDSC in order to identify the relevant exposure factors. In 1983 the isolation of lymphadenopathy-associated virus/human T-lymphotropic virus III (LAV/HTLV III) (Barre-Sinoussi *et al.*, 1983; Gallo *et al.*, 1984) and the subsequent development of serological testing, preceded the revision of the case definition (CDC, 1985a). It was possible to extend the CDSC surveillance to include the analysis of reports of positive antibody tests and to initiate a prospective study of health care workers with accidental parenteral or mucosal exposures to blood or body fluids potentially infected with LAV/HTLV III.

RESULTS

Chronology

Although the first case of AIDS was described in 1981 (CDC, 1981), cases which presented in previous years were subsequently diagnosed. *Figure 6.1* shows the annual numbers of cases by dates of presentation for medical advice. The initial slow rise in the numbers presenting to mid-1982 was followed by a continuous upward trend which has continued up until the present time (February 1986).

Geography

Since surveillance began, more than 75% of cases have been reported from hospitals in the four Thames health regions. This proportion has not changed significantly over time, but case reports have been received from all health regions in England and from Scotland, Wales and Northern Ireland.

Patient characteristics

Up until 31 January 1986 a total of 287 cases were reported. Age, sex and ethnic origin are shown in *Table 6.1*. The age range was from 11 months to 69

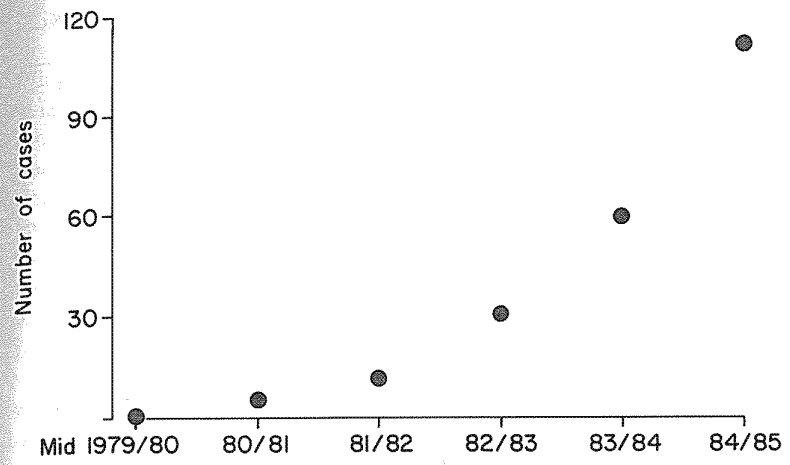

Figure 6.1 AIDS, United Kingdom. Annual cases according to date of presentation (compiled by CDSC)

Table 6.1 UK cases of AIDS reported to CDSC by 31 January 1986, according to age, sex and ethnic origin

Age (years)	Male		Female		Total
	Caucasian	Other	Caucasian	Other	
0–5	1	0	0	0	1
6–19	0	0	0	0	0
20–29	49	0	1	1	51
30–39	93	1	3	0	97
40–49	92	1	2	1	96
50–59	25	0	1	0	26
60 + over	2	0	1	0	3
Not stated	13	0	0	0	13
Total	275	2	8	2	287

cases were reported in females and the sex ratio of 27 : 1 was similar to that observed in the USA and Europe. There were 283 cases in white Caucasian patients, two in Africans and two in Caribbean nationals. Patient characteristics are shown in *Table 6.2*: 255 (89%) cases were in homosexual men, 11 were reported in patients with haemophilia and five, of whom two were transfused overseas, in recipients of

Table 6.2 UK cases of AIDS reported to CDSC by 31 January 1986 by patient characteristics

Patient characteristic	Number of cases		Total	Deaths
	Male	Female		
Homosexual/bisexual	255	—	255	123
Haemophiliac	11	—	11	8
Recipient of blood	4	1	5	4
IV drug abuser	2	—	2	1
Heterosexual contact	—	2	2	1
Visited USA/Caribbean at possible risk	3	—	3	1
Associated with Africa:				
Direct	1	5	6	6
Indirect	—	2	2	—
Other	1	—	1	—
Total	27	10	287	144

drug abusers and two in female heterosexual contacts of infected men. Three men who had visited the USA/Caribbean in the recent past denied potential exposures but were thought by the interviewing epidemiologist to have recognized risk factors. There was a small group of patients associated with sub-Saharan Africa, having lived or travelled there or having had contact with those who had visited Africa. One male patient gave a history suggestive of acquisition of infection through heterosexual contact.

Up until 1982, 70% of homosexual men in whom cases occurred had had contact with nationals of the USA, but the proportion decreased over time and by 1985/86 only 30% of men had such contact. Although this suggests that transmission is now taking place within the UK, it may also indicate that British gay men have reduced the extent of their sexual contact with American men.

Mortality

Overall mortality was 50% (144/287), but for the early years of the outbreak was in excess of 90% and possibly up to 100%, allowing for patients lost to follow-up. The case fatality for patients presenting in 1985 is currently 26%.

SEROLOGY

When analysing data provided by serosurveillance, it should be borne in mind that the incidence of infection with HTLV III/LAV in particular groups may be determined only by special studies and that reports of positive serological tests are used to provide an indication of trends in time, place and personal characteristics of infected people. Although antibody testing was introduced in 1984 it was not widely available until October 1985: by the end of that year 1765 reports had been received. The age and sex of the patients concerned are shown in *Table 6.3*. Data were incomplete for 470 (27%) patients. Of the remainder, 759 (59%) were aged between 25 and 44 years. Altogether 1643 reports were received for male patients (*Table 6.4*): 704 (56%) of those for whom data were complete were homosexual men and a further 509

Table 6.3 Reports of anti-HTLV III seropositivity received at CDSC from laboratories in England, Wales and Northern Ireland to December 1985: age and sex

Age (years)	Number antibody positive			Total
	Male	Female	No record	
<15	90	1	2	93
15–24	295	7	1	303
25–44	741	17	1	759
45+	138	1	1	140
No record	379	4	87	470
Total	1643	30	92	1765

Table 6.4 Reports of anti-HTLV III seropositivity received at CDSC from laboratories in England, Wales and Northern Ireland to December 1985: males

Patient characteristic	Number of reports
Homosexual/bisexual	704
Haemophiliac	509
Other bleeding disorders	4
Intravenous drug abuser	27
Other	5
Several risk groups	3
No record	391
Total	1643

(41%) were patients with haemophilia. Only 30 reports were received for female patients (*Table 6.5*) and half of these were intravenous drug users.

PROSPECTIVE STUDY OF HEALTH CARE WORKERS

Between 1 January 1985 and 31 January 1986, accidental parenteral or mucosal exposures had been reported in 101 health care workers in the UK (*Table 6.6*). None of those who enrolled in the study seroconverted. The range of follow-up was from 1 to 12 months and the median length of follow-up was 5 months. Altogether 60 of the 101 exposures were in medical, nursing or laboratory staff.

Table 6.5 Reports of anti-HTLV III seropositivity received at CDSC from laboratories in England, Wales and Northern Ireland to December 1985: females

Patient characteristic	Number of reports
Intravenous drug abuser	14
Sexual contact, haemophiliac	5
Sexual contact*	8
Bleeding disorder	1
Child of 'at risk' mother	1
No record	1
Total	30

* Includes one prostitute, one contact of i.v. drug user

Table 6.6 Reports of exposures of health care workers to HTLV III reported to CDSC by January 1986 according to occupation and type of exposure

Type of exposure	Number of exposures				
	Nurse	Doctor	Lab. worker	Other	Total
Needle-stick	28	15	10	0	53
Other sharp	3	2	2	0	7
Splashes	10	7	5	0	22
Aerosols	1	1	7	0	9
Other	2	1	0	7	10
Total	44	26	24	7	101

Europe

European data are collated and analysed at the World Health Organization Collaborating Centre on AIDS in Paris. Up until January 1986, 2006 cases of AIDS had been reported from 23 participating countries. Detailed analysis was available for 1573 case reports received before 30 September 1985. The rate of increase in the numbers of cases reported over time was similar to that seen in the UK. Incidence rates per million population are shown for 10 countries in *Table 6.7*. These rates are unstandardized and, although the UK has the third highest number of cases, the national rate appears to be relatively low. Cases are shown by country of origin in *Table 6.8*. The 124 African cases without recognized risk factors were in patients who presented for treatment in Belgium and France during the early years of the European outbreak. In northern European countries the number of cases is increasing most rapidly in homosexual men, while in the countries of southern Europe the increase in intravenous drug users has been noticed (R. Ancelle, personal communication). Case fatality rates for Europe have been similar to those experienced in the UK (Curran, Meade Morgan and Hardy, 1985).

The United States

Up until January 1986, 16 574 cases had been reported to CDC. Altogether, 11 998 (73%) were in homosexual men compared with 255

Table 6.7 Cases of AIDS reported to the WHO European Collaborating Centre on AIDS by September 1985*

Country	No. of cases	Rate/million
Denmark	57	11·5
France	466	8·5
Germany, Rep. Fed.	295	4·8
Greece	10	1·0
Italy	92	1·6
Netherlands	83	5·7
Spain	63	1·6
Sweden	36	4·3
Switzerland	77	11·8
United Kingdom	225	4·0
Total	1404	5·4

(89%) of the 287 British cases. Although 2778 (17%) of the USA cases occurred in intravenous drug abusers, only two (1%) of the UK cases were reported in this risk group (*Table 6.9*). These differences in the risk groups between the two countries is reflected by a difference in the proportions of the presenting diseases (*Table 6.10*): 44% of the

Table 6.8 Cases of AIDS reported to the WHO European Collaborating Centre on AIDS by September 1985 according to patient characteristic and country of origin*

Patient characteristic	Geographical origin				
	Europe	Caribbean	Africa	Other	Total
(1) Homo/bisexual men	1031	4	11	39	1085
(2) Intravenous drug abusers	90	—	—	—	90
(3) Haemophiliac	52	—	—	1	53
(4) Transfusion recipient	30	—	5	—	35
(5) (1) and (2) associated	21	—	1	2	24
(6) None: Males	59	24	81	3	167
Females	31	10	43	—	84
(7) Unknown	16	1	16	2	35
Total	1330	39	157	47	1573

* Data compiled by WHO Collaborating Centre on AIDS, Paris

Table 6.9 UK cases of AIDS reported to CDSC and USA cases reported to CDC by January 1986 according to patient characteristics (percentages in parentheses)

Patient characteristics	Cases	
	USA*	UK
Homo/bisexual men	11 998 (73)	225 (89)
Intravenous drug users	2 778 (17)	2 (1)
Haemophiliac	132 (1)	11 (3)
Heterosexual contact	185 (1)	2 (1)
Transfusions	263 (2)	5 (2)
Paediatric	231 (1)	0 (0)
Africa association	0 (0)	8 (2)
None/other	987 (5)	4 (2)
Total	16 574 (100)	287 (100)

Table 6.10 UK cases and deaths reported to CDSC, and USA cases and deaths reported to CDC, by January 1986 according to disease group (percentages in parentheses)

Disease	USA		UK	
	Cases	Deaths	Cases	Deaths
Kaposi's sarcoma (KS)	3056 (18)	1167 (38)	68 (24)	30 (44)
Pneumocystis carinii pneumonia (PCP)	9539 (58)	4986 (52)	129 (45)	60 (47)
Both KS and PCP	920 (6)	598 (65)	19 (7)	12 (63)
Other opportunistic diseases	3059 (18)	1672 (55)	71 (25)	42 (59)
Total	16 574 (100)	8423 (51)	287 (100)	144 (50)

British cases (almost all being gay men) had Kaposi's sarcoma, compared with 18% of the American cases. Although only two of the gay men reported in the UK were also intravenous drug users, a 12% overlap between these two groups has been documented among the cases reported to CDC (Curran *et al.*, 1985).

The future of the outbreak

There are difficulties in making statistical predictions of the future course of the outbreak in the UK on the basis of previous experience. However, until recently the epidemic curve was log-linear and a regression analysis was used to extend the curve and calculate the number of cases which might be expected in future years. The main limitations of this method are that it can take no account of changing epidemiological patterns and that the confidence intervals for each prediction are wide. These problems have been described in detail elsewhere (McEvoy and Tillett, 1985a,b). At the current stage of the outbreak there are insufficient data to use alternative methods and it would seem wise to plan for approximately 2000 cases by 1988. The logs of the cases are plotted by time in *Figure 6.2* and it is interesting that the shape of the plotted points is beginning to suggest that the curve may be approaching the point of inflection. However, the predictions of

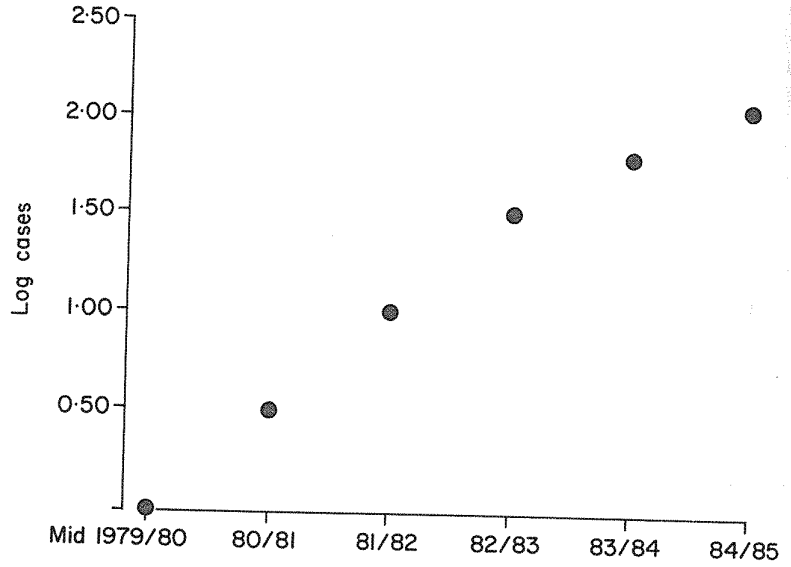

Figure 6.2 AIDS, United Kingdom. Log annual cases according to date of presentation (compiled by CDSC)

there will be many seropositive persons who will present a public health problem and who are likely to require increasing resources for their health care.

Discussion

The results of surveillance in the UK suggest that there is a growing outbreak, with many cases in London but with increasing numbers of seropositive persons elsewhere. A rising seroprevalence has been demonstrated among clinic populations of homosexual men (Carne *et al.*, 1985; Mortimer *et al.*, 1985). Public Health Laboratories around the country have recorded various rates in this group, ranging from 5% in predominantly rural areas to more than 35% in some London clinics. Seroprevalence of 10% and less has been recorded in some groups of intravenous drug users but results of a recent study in Edinburgh, where seropositivity rates in excess of 50% were found, suggest that there may be hyperendemic foci for this group (Jesson *et al.*, 1986; Robertson *et al.*, 1986). Similarly, national results for patients with haemophilia suggest a seroprevalence of around 25%

1985; Jesson *et al.*, 1986). Although transmission by sexual, parenteral and perinatal routes have been clearly defined, anxiety about spread into the general population remains among some lay persons. At present there is no evidence of such spread in the UK. It is reassuring that the number of seropositives among blood donors, who are asked not to donate if they might belong to a group at increased risk of developing infection, is estimated by the Blood Transfusion Service as being less than 1 in 50000 (*see* Chapter 10). The only case which strictly fulfils the criteria for the definition of occupationally acquired infection with LAV/HTLV III, compiled at the CDC (CDC, 1985b), was described in a British nurse, who received a mini-inoculation injury while carrying out a venepuncture on a patient who contracted infection in Africa (Anonymous, 1984). In the UK no seroconversions were demonstrated in the 101 health care workers with needle-stick and other injuries sustained during the course of caring for patients with AIDS. In the USA, surveillance of health care workers identified two who had had possible exposures, were found to be seropositive and denied having recognized risk factors. Seroconversion was not demonstrated in either of these persons, who are thought to have probable, but not proven, occupationally acquired infection (CDC, 1985b).

It is important that national epidemiological surveillance is continued in order to monitor trends, to provide statistics and to complement specific research projects on transmission and natural history. Available evidence indicates that the outbreak of AIDS in the UK will continue to present a challenge to all those involved directly and indirectly in patient care, prevention and health promotion for many years to come.

References

ANONYMOUS (1984). Needlestick transmission of HTLV III from a patient infected in Africa. *Lancet* **ii**, 1376–1377.

BARRE-SINOUSSI, F., CHERMANN, J.C., REY, F. *et al.* (1983). Isolation of a T-lymphotropic retrovirus from a patient at risk for acquired immune deficiency syndrome (AIDS). *Science* **220**, 868–870.

CARNE, C.A., WELLER, I.V.D., SUTHERLAND, S. *et al* (1985). Rising prevalence of human-T lymphotropic virus type III (HTLVIII) infection in homosexual men in London. *Lancet* **i**, 1261–1262.

CDC (1981). Kaposi's sarcoma and *Pneumocystis* pneumonia among homosexual men — New York City and California. *MMWR* **30**, 305–308.

CDC (1982). Update on acquired immune deficiency (AIDS) — United States. *MMWR* **31**, 507–514.

CDC (1985a). Revision of the case definition of Acquired Immune Deficiency Syndrome for national reporting — United States. *MMWR* **34**, 373–375.

CDC (1985b). Update: Evaluation of HTLVIII/LAV infection in health-care

demiology of AIDS: Current status and future prospects. *Science* **229**, 1352–1357.

DUBOIS, R.M., BRAITHWAITE, M.A., MIKHAIL, J.R. *et al.* (1981). Primary *Pneumocystis carinii* and *Cytomegalovirus* infections. *Lancet* **ii**, 1339.

GALLO, R.C., SALAHUDDIN, S.Z., POPOVIC, M. *et al.* (1984). Human-T lymphotropic retrovirus, HTLVIII isolated from AIDS patients and donors at risk for AIDS. *Science* **224**, 500–503.

JESSON, W.J., THORP, R.W., MORTIMER, P.P. AND OATES, J.K. (1986). Prevalence of anti-HTLVIII in UK risk groups 1984–85. *Lancet* **i**, 155.

JONES, P., HAMILTON, P.J., BIRD, G. *et al.* (1985). AIDS and haemophilia: morbidity and mortality in a well-defined population. *British Medical Journal* **291**, 695–699.

MCEVOY, M. AND TILLETT, H.E. (1985a). AIDS for all by the year 2000? *British Medical Journal* **290**, 463–464.

MCEVOY, M. AND TILLETT, H.E. (1985b). Some problems in the prediction of future numbers of AIDS cases in the UK. *Lancet*, **ii**, 541–542.

MORTIMER, P., JESSON, W.J., VANDERVELDE, E.M. AND PEREIRA, M.S. (1985). Prevalence of antibody to human T lymphotropic virus type III by risk group and area, United Kingdom 1978–84. *British Medical Journal* **290**, 1176–1178.

ROBERTSON, R., BUCKNALL, A.V., WELSBY, P.D. *et al.* (1986). Epidemic of AIDS-related virus (HTLVIII/LAV) infection among intravenous drug users. *British Medical Journal* **i**, 527–529.

7

Second Question Session

Mrs Fearns (Newcastle): If a positive finding has been made, is there any point in repeating it? Secondly, if a negative finding has been made on an individual whom the clinical staff feel perhaps may be positive, how many further times and at what intervals should that individual be tested before a negative result is taken at its face value?

Dr Mortimer: In answer to the first point, my laboratory colleagues and I are fairly cautious people. Because we have seen specimens being mixed up in transit and, indeed, within our own laboratories, we feel that it is important to repeat a positive test on at least one occasion on a separate and independent sample. When this has been done twice I cannot see much point in repeating it.

The other question is, of course, very much more difficult to answer. The time that it takes for someone to seroconvert does vary a great deal and my impression — which is not based on any hard facts — is that those individuals infected sexually will mostly seroconvert in a matter of two months. Those who have been exposed in other ways, perhaps through blood products or inoculation injury, may take a great deal longer to seroconvert. Therefore, it would certainly be proper to test at an interval of 6 months and perhaps even a year, depending on the particular circumstances. Does that answer your question?

Mrs Fearns: Not entirely, because on the answer to the second part of the question may hang the decision of an individual and his partner about whether or not it is safe to have a child.

Dr Mortimer: Every situation has to be looked at on its own merits but, given negative results for a year and assuming that exposure was not continuing (which of course it might be in lots of situations, perhaps with blood products), if it were just a single exposure or past exposure I do think that it would be unreasonable to delay pregnancy beyond that year.

Dr David Miller (St Mary's Hospital): One of the arguments commonly put forward in favour of routine screening for anti-HTLV III is for the protection of staff from patients who are identified seropositives.

from your assessment of the kits available, how much confidence do you have in the ability of the test to identify *all* seropositives? What percentage are *false* negatives?

Dr Mortimer: I am not confident, and I hope that I did not give the impression that I was confident, that in all circumstances these antibody tests will detect people who are infected, or potentially infectious. Indeed, in broad terms I do not think that antibody screening in the context you mentioned is the way to go. We ought to know that certain virological fluids, and certain operative procedures and so on, represent potential hazards to staff no matter who they come from, and people should take precautions accordingly. I am sure that in every laboratory in this country there are specimens collected from 'infected individuals' — specimens which are going in several different directions for several different reasons, and which are being handled in entirely different ways by different members of staff who foresee different risks! I challenge anyone to swear that that is not happening within laboratories. The moral is that we must *all* be careful how we deal with *all* patients and how we handle *all* specimens.

Dr Gunson: I would reinforce what Dr Mortimer has said with the example of a virus that we cannot test for, and that is non-A, non-B hepatitis, where every laboratory worker is at potential risk and, therefore, great care must be taken with every sample. The same is true of HTLV III/LAV: great care must, again, be taken with every sample, whether it comes from a patient suffering from AIDS or not.

Kay Carpenter (Social Worker): The first speakers have talked about the importance of education. Could they tell us more about the information that is available from the UK Health Education Council?

Dr Sibellas (DHSS): The Health Education Council have already produced a leaflet and are now preparing another, as part of the Government's public health information initiative. There are difficulties in educating without separating or bringing attention to risk groups and causing a backlash, and without creating alarm. The message is a difficult one to achieve but money has been set aside and we are working on an education campaign.

Delegate from the Blood Transfusion Service, Newcastle: It has been said repeatedly that this is an 'epidemic'. Bearing in mind that there have been only 287 cases of AIDS in the UK, do you really think that 'epidemic' is the right word? The public associate that with diseases like measles or chicken pox and expect many children to be affected. In a population of 54 million, do 287 cases really constitute an epidemic?

Dr McEvoy: An epidemic is strictly defined by epidemiological means and I can speak as an epidemiologist. There are two ways of defining it. An epidemic is an increase in the incidence of a particular

look at cases of AIDS in the United Kingdom, they fulfil those criteria. The other definition is 'an outbreak of two or more related cases': that definition is more usually employed for foodborne outbreaks but, because it applies to any communicable disease, AIDS certainly fulfils that criterion too.

Delegate from Newcastle: If you have a case of a homosexual who is also a drug user, what category is he put in?

Dr McEvoy: They are classified hierarchically in some countries. We would put them into the homosexual group. Of the homosexual men with AIDS who have been reported in this country, there are two who are also intravenous drug users. A recent paper from Curran *et al.* (1985) of the Centers for Disease Control described a 12% overlap in United States cases reported in homosexual men and intravenous drug users.

Dr Volberding: Yes, the CDC uses the same hierarchical system so that an i.v. drug user who is also a homosexual will be classified as a homosexual risk group member. The overlap is, as you say, about 10% of gay men who report the use of i.v. drugs. Although we do not know, we suspect that these cases represent transmission by i.v. drug use.

Dr Tedder: To revert to the question of anti-HTLV III testing, it seems that a decision may be taken that HTLV III antibody testing cannot and should not be used in an infection control situation. I personally disagree with that. I think that there are situations, for instance in a busy metropolitan hospital, where a surgeon obviously should avoid self-contamination with blood or materials from a patient. However, we all know that surgery invariably makes a patient bleed, and an orthopaedic surgeon reaming out a femur is bound to scatter material everywhere. Now, is it practical to make that surgeon take all the more extensive and expensive precautions which he would if he was dealing with a known positive patient, if you could demonstrate that the patient was seronegative? I think that we have to look carefully at the question of risk and that there are situations where the use of anti-HTLV III screening can help the medical profession as a whole to come to terms with caring for patients who are seropositive and therefore infectious, and those patients who are not infectious. I say this in order to redress the balance slightly as I do not agree that there is no value in testing.

Dr Gunson: I did not think that there would necessarily be no value in testing. However, if you have a negative anti-HTLV III test it does not mean that you can go ahead without proper care; I would have thought that *that* was the important message.

Dr John Green (St Mary's Hospital): I think that there are a number

that there is no risk. All we can say is that up to 1983 it was not known that AIDS was caused by an infectious agent, and surgeons in America were investigating and operating on patients without taking any special precautions whatsoever — yet there has not been one single case of any of these surgeons either seroconverting or getting AIDS as a result of their work. Secondly, the premise that precautions should be taken when the surgeon knows that someone is possibly in a high-risk group, would, in itself be enough for those precautions, without the need to test. However, I do not actually agree with that premise because I think that it is necessary to assume that *anyone* is potentially infected with this virus. I have seen patients of 17 to 70 years and some of them did not even know that they were in high-risk groups, and one certainly would not have expected them to be. For instance, the female sexual partners of bisexual men often do not know what their husbands are doing in the evenings. My conclusion is that it is necessary to take the view that anybody may be potentially infected with this virus and what we must do is tighten up clinical procedures in hospitals generally.

Unidentified delegate: I was struck with the question about whether, in lay terms, we are dealing with an epidemic. It appears that even the UK projected figures are relatively small, made on the basis of mortality figures. These cover a very short period, from about 1979 to 1986. What is thought about the morbidity projections? To the public and the Press, the issue that has to be understood is seropositivity. Articles appearing in *Science* magazine last year likened HTLV III to a slow virus and we know that kuru and Creutzfeldt–Jacob disease and Alzheimer's disease may take 25 or 30 years to produce dementias and other problems. Could it be, speculatively, that there are a lot more problems related to the HTLV III virus that have yet to surface in terms of morbidity and perhaps, eventually, mortality?

Dr McEvoy: That is a very valid comment. Our predictions were not drawn up on mortality figures but on individual cases. The reason that we used cases is that they provide hard data. We think that we have 90% or more accuracy of case reporting in the UK and we know that there is a pattern. To do projections on seropositives would be very difficult although some excellent cohort studies have been carried out. The difficulty is that we do not know denominating populations in this country with any degree of certainty, particularly the population of those who currently may be most at risk. We can estimate it from data by Kinsey, who said, for instance, that 10% of the male population were homosexuals, or we can look at the absolute numbers of unmarried men between 16 and 65: this may give us some indication, but many of these will be heterosexual while, on the other hand, there will be many married men who are homosexual. It is difficult to find a reliable denominator [illegible]

why we have not made any projections on seropositives: we just do not know with any degree of certainty how many there are. I very much agree with what you said about the possible natural history of the condition.

Dr Bird (Newcastle): Dr McEvoy's figures are obviously going to be increasingly important for health care planning. How accurate does she feel that these figures are at present, and how accurate are they likely to be in the future? In particular, it is my own feeling that there are problems about the case definition of AIDS at present. In our own local experience we have seen three patients who died of HTLV III-associated disease — of a wasting illness where, even at autopsy, we were unable to identify any opportunistic agents which would have allowed us to apply the case definition to the mortality.

Dr McEvoy: In the United Kingdom we are fortunate in having a number of sources of data. In itself, the clinical reporting scheme does not provide a means of validating the data. So we have the laboratory reporting scheme, which gives us reports of opportunistic infections and we have mortality data from death certificates on all possible HTLV III-related conditions, including opportunistic infections as well as AIDS. We use all the morphology codes and International Classification of Disease codes that could possibly be AIDS-associated, and co-ordinate this work with a medical statistician on a strictly confidential basis. In addition, we now have the antibody reports. By using a number of sources of data like this, it is possible to apply means of validation and I believe that we do have very full reporting. There will always be a few cases which are not picked up, but the routine national surveillance system is meant to monitor trends and not to define incidence: this is done by a specific study.

Reference

CURRAN, J.W., MEADE MORGAN, W. AND HARDY, A.M. (1985). The epidemiology of AIDS: Current status and future prospects. *Science* **229**, 1352–1357.

Part III

The Effects

8

Immunology

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Introduction

Immunology, no less than any other area of medicine, is ultimately concerned with people: with that in mind, in this chapter I would like to provide a perspective on the way in which clinical immunologists look at this very remarkable new immunodeficiency disease. We determine whether people are immunodeficient or not by observing how they behave in their microbiological environment, by studying the organisms that they meet or (more often) carry around with them from previous encounters and by noting how they respond to them. People, rather than laboratory tests, provide the ultimate bioassay and patients with AIDS have taught us much about what we really mean by immunosuppression. Although AIDS is a terrible and tragic disease, one small benefit is the enormous amount of scientific knowledge that has accrued from its study. Perhaps even more important is the amount that we have learned (and, I hope, will continue to learn) about the community in which we live and, indeed, about ourselves. The knowledge thus gleaned has therefore gone beyond AIDS itself and extends into many other areas of science and society.

The properties of HTLV III/LAV

The *physical* properties which govern the modes of transmission of HTLV III/LAV, the AIDS-related virus, are determined by its lipid envelope. Within its genetic structure and the nucleoid is the information that gives rise to its particular *biological* properties, which are quite distinct from those physical properties. Thus, while HTLV III/LAV can cause severe disease, this must not be taken to mean that it is readily transmitted from person to person.

It was apparent from a very early stage, from observations on

cells of the immune system. In particular, cells known as 'T4' or 'T helper' lymphocytes appear to be the main target for the virus. Elegant work at the Chester Beatty Institute and elsewhere has shown that the T4 antigen, a surface molecule carried by these T helper lymphocytes, is the receptor which the virus uses to enter the cell. Thus the virus has adapted itself, not only to infect cells of the immune system, but also to make use of what is, in effect, one of the communication signals that the immune system uses for its own function of helping to defend the body.

Other cells, termed antigen-presenting cells, also appear to be targets of this virus. Such cells include other white cells concerned with defence — monocytes and macrophages. The fact that these and other antigen-presenting cells are directly infected may prove to be a very important aspect of this infection. In addition, the microglia of the nervous system are a possible target, in view of the encephalopathy that we see in some patients with AIDS. All of these cells bear small amounts of the T4 antigen, which thus is not specific to the T4 lymphocytes.

The question of whether the B cells (the antibody-producing part of the immune system) are directly infected has been much debated, but most of the evidence now seems to indicate that they probably are not directly infected *in vivo*, although they may be indirectly affected. The same may be true for 'natural killer cells'.

The consequences of exposure to HTLV III/LAV

What is the sequence of events that follows exposure to the virus in a normal subject who meets it in one of the three settings in which it is transmitted: by sexual intercourse, by blood-to-blood contact, or by materno-fetal transmission? There are several possible consequences. First, the person may not be infected by the virus, despite exposure (sometimes repeated exposure) and current estimates indicate that 40–50% are not infected in the risk groups examined. Second, those who do become infected (virtually all of whom will be anti-HTLV III positive) may remain asymptomatic for long periods. Some develop minor disorders such as persistent generalized lymphadenopathy (PGL), or they may develop moderately severe (prodromal AIDS) or severe (AIDS) immunodeficiency disease. The latter are certainly very closely interrelated and most patients with prodromal AIDS (or ARC) go on to develop full-blown AIDS. It is quite apparent that people in the less severely affected groups do not necessarily develop the full-blown disease: the term 'pre-AIDS' is therefore inappropriate in this

DEVELOPMENT OF DISEASE: CO-FACTORS

What factors determine who subsequently develops AIDS? Although we have more information about this disease than about many other diseases that have been known for centuries, our perspective is necessarily limited by the fact that we have observed AIDS for only five or six years; any predictions that we make therefore must relate to those years. Although some people talk as though they can foresee the course of events (and it is sensible to be aware of what *may* happen), we should nevertheless recognize that this is speculation and that we should try to stick to the known facts.

At present, several different studies indicate that perhaps 1–10% of people infected by the virus actually develop AIDS over a follow-up period of 4–5 years. That figure may rise with time; those who are infected may take longer to develop the disease. On the other hand, those who develop infection at an early stage may be the ones most likely to develop AIDS and ultimately the natural history of the infection may be seen to be less severe. There is increasing evidence that co-factors play a part, after the acquisition of the infection, in enhancing the development of the disease. One such co-factor is intercurrent infection, in particular, sexually transmitted infection in sexually active gay men; another may be severe infections of the type seen in tropical Africa. Both of these seem to increase the risk of developing disease: thus, a person who frequently develops sexually transmitted disease or severe major systemic infections is more likely to progress from being symptomless to developing lymphadenopathy or AIDS itself. Other important co-factors include pregnancy and the neonatal period; early estimates are that about 50% of infected infants may develop disease within the first 2 years of life. These co-factors may operate by switching on latently infected T cells, leading to increased viral replication and hence infection of more cells of the immune system; such a process may eventually damage so many cells that the threshold for developing disease is reached. It is probable that those people who contract the infection early in the epidemic will be those in whom the co-factors which enhance the development of disease are most common; it is possible that, as HTLV III/LAV infection disseminates more widely, we will see a more benign natural history. The separate question as to whether people are more susceptible to HTLV III/LAV infection if their T cells are switched on before an encounter with the virus, remains to be answered.

Early clinical features

What are the clinical manifestations of early infection? An acute retroviral illness occurs in only a proportion of patients. What effect this has on the prognosis is not yet known, but it is important to emphasize that not everybody gets this glandular-fever-like illness. Persistent generalized lymphadenopathy may be divided into two groups, Type A and Type B: patients with Type A have no systemic symptoms; patients with Type B do have such symptoms. Lymphadenopathy may be minimal or absent in patients with prodromal disease, but the key issue is that it is Type B patients who are most at risk of developing progressive disease; Type A patients seem to have a very much more benign prognosis.

Most of the prodromal features are clinical and their presence should alert one to the possibility that the patient will develop more severe disease (*Table 8.1*). There are also a number of laboratory features which form part of pattern recognition. None of them are diagnostic in themselves; they are simply part of the pattern recognition that we use in clinical diagnosis generally. There is no pathognomic test — diagnosis of these disorders and of AIDS is a question of taking the history, doing an examination, performing a few judicious tests and then exercising clinical judgement.

Table 8.1 Prodromal features

Weight loss	Leucopenia
Oral candidiasis	Anaemia
Unexplained diarrhoea	Raised erythrocyte sedimentation rate
Dermatitis	T4 lymphocyte depletion
Shingles	Anergy
Hairy oral leukoplakia?	Follicular involution in lymph nodes
	Follicular dendritic cell destruction in lymph nodes

IMMUNOHISTOLOGY

It may be possible to separate Type A and Type B patients by looking at the immunohistology of lymph nodes. The work described here was performed with Dr Janossy at the Royal Free Hospital, London (Janossy *et al.*, 1985). The normal node contains germinal centres, which are where the B cells are mainly situated, and also T-cell areas. The germinal centre also contains follicular dendritic cells (FDR cells):

the germinal centre with normal FDR cells: these people are type A, as judged by clinical features. Type B people show patchy destruction of FDR cells in the germinal centres: this has a very clear association with progressive disease. This association may become of even more interest since it has been shown by George Janossy, together with a Hamburg group, that the HTLV III/LAV virus is actually concentrated in the FDR cells and may, indeed, replicate in them: this, therefore, may be the main reservoir of the virus (Tenner-Racz *et al.*, 1986). There is no difference in the expression of HTLV III or LAV antigens between types A and B: the virus is present in both but, clearly, is behaving in a different manner in each.

AIDS

THE IMMUNE DEFECT

The patterns of infection seen in full-blown AIDS are determined by a number of factors. First, the *nature* of the cellular-immune defect is important. As mentioned earlier, it is predominantly a defect of T4 cells and of macrophages and related cells, with secondary effects on other parts of the immune system: it is the primary defect that determines the pattern of infection in this predominantly cellular immune deficiency. The *severity* of the defect is also important because, within patients or between patients, the type of infection that is seen gives a 'bioassay' of the severity of the immune deficiency; thus, the infections that occur can serve as a crude marker of the stage of immune deficiency — a guide that is very important in assessing prognosis and in managing patients, as well as in evaluating clinical trials of a variety of different agents. The *presenting features* are determined also by the severity of the immune defect, often being much more insidious because of the defective host defences. Thus, many of the criteria on which we would normally make a diagnosis, even in another sort of immunocompromised host such as a transplant recipient, clearly have to be modified for this very different situation.

OPPORTUNISTIC INFECTIONS

It is often forgotten that one cannot contract an opportunistic infection unless the relevant micro-organism has been encountered. The pattern of opportunistic infection — in which the organism takes advantage of

would not do so — depends on actual exposure to that organism. Previous microbiological exposure is important because many of the infections contracted by these patients are caused by organisms that they, like the rest of us, have been carrying around with them for years. They are usually kept in check by a normal immune system and only reveal themselves when these defences are impaired. Current exposure is also important for some organisms, for instance *Salmonella*. The effects will be determined by where patients have been, by their age (children will have a rather different profile) and by what they have done, and it is clear that we have to recognize these differences. People have been surprised to find that Haitians showed a different pattern of disease to North Americans, or Europeans to North Americans, or Africans to non-Africans. This simply reflects the fact that each of these peoples has been exposed to a different range of opportunistic infections and that these will emerge accordingly.

THE EPISODIC NATURE OF ILLNESS IN AIDS

The 'shape' of this disease must be recognized. It is often thought that, once patients have developed AIDS, they are admitted to hospital and gradually succumb to a progressive wasting illness. The much-publicized 'horror' pictures of patients in the terminal stages of AIDS are not representative, and neither is the idea that patients progressively decline. Although the function of the immune system may, indeed, be progressively impaired, there is an *episodic* shape to this illness. A patient who has AIDS is simply *susceptible*: AIDS itself does not make people ill, illness results from the secondary infections or the secondary tumours that occur as a consequence of the susceptibility; when such events are absent, the patient is not ill.

As many of these infections, particularly early in the course, are eminently treatable, early diagnosis and early treatment are of crucial importance. Patients may be restored thereby to a normal appearance and feeling of well-being, which may persist for some time until they develop another opportunistic infection which, again, may be treated successfully. People with AIDS should be helped to return to the community where they belong, and it is the job of all health care workers to keep them there as long as is humanly possible, by recognizing that the disease is episodic. At a later stage of the disease, when it is more difficult to overcome the opportunistic infection(s), or where the immune system is inadequate to act in conjunction with antibiotics to eradicate the infection, there may well be a progressive decline. Nevertheless, in the early stages patients may benefit greatly

SPECIFIC OPPORTUNISTIC EVENTS IN AIDS

Table 8.2 indicates, in a rough rank order, the opportunistic infections which will emerge as immune deficiency becomes progressively more severe. The tumours are shown separately. Early signs are oral and oesophageal candidiasis (thrush), herpes simplex ulceration, pneumocystis, and *Mycobacterium* tuberculosis (which is more common in the United Kingdom than in the United States because the pathogen is more prevalent in the UK). Atypical mycobacterial infections occur later in the course of the disease because these are low-grade pathogens that will cause disease only when the immune system is severely damaged. Cytomegalovirus (CMV) is an important cause of disease because it is very widely prevalent among what is currently the highest risk group in the United Kingdom — sexually active gay men, virtually all of whom are seropositive and have latent infection; when they become immunodeficient this infection emerges. CMV is also important because it is itself immunosuppressive and so will add insult to the injury already caused by HTLV III. Treatment of CMV is now possible — an illustration of the fact that treatment of the secondary infections may alter the natural history of AIDS. Certainly, patients who previously would have been expected to die within a matter of months, are now surviving longer.

Although Kaposi's sarcoma is generally at the benign end of the AIDS spectrum, in Africa it is much more aggressive, often affecting

Table 8.2 List of opportunistic infections in AIDS in rough order of occurrence in progressively severe immune deficiency. Separate list of AIDS-associated tumours, of which Kaposi's sarcoma, if occurring alone, generally reflects less severe immune deficiency than the opportunistic infections

Oral and oesophageal candidiasis	
Mucocutaneous herpes simplex ulceration	
Pneumocystis carinii pneumonia	
Mycobacterium tuberculosis infection	
Salmonellosis (septicaemia)	
Cryptococcal meningitis (disseminated)	
Toxoplasma encephalitis	
Cytomegalovirus disease:	
Pneumonitis, oesophagitis, colitis, adrenalitis, retinitis, encephalitis	
Cryptosporidiosis	
Atypical mycobacterial infection	
Kaposi's sarcoma	?CMV
B cell lymphoma	?EBV

the viscera; this, again, reflects the different manifestations of immune deficiency in different hosts.

In *Pneumocystis* pneumonia it is very important to know that the radiograph *may* be normal. If a patient has a persistent dry cough and breathlessness, and is suspected of immunodeficiency, bronchoscopy must be performed. This is not only to confirm *Pneumocystis* (and, indeed, a diagnosis of AIDS) but also to seek other organisms occurring alone or in combination, such as CMV, *Mycobacterium tuberculosis* and cryptococci. We must make every effort to identify all the organisms in any patient in order to give rational, prompt and effective treatment. A similar approach is used in diagnosis and treatment of opportunistic infections of the gut and the central nervous system.

IMMUNOLOGICAL PROFILE

The diagnosis of AIDS is clinical and depends on demonstrating an opportunistic infection in a patient who is not otherwise known to be immunosuppressed. AIDS patients have a characteristic pattern immunologically, with reduced numbers of T lymphocytes (particularly T4 lymphocytes), anergy on skin testing, raised immunoglobulins and abnormal function of natural killer cells and macrophages. However, it must be emphasized that some of these defects, either alone or in association, may be seen in other diseases; furthermore, some patients with early AIDS may not show them: for example, 25% of patients presenting with AIDS to our unit, whether with opportunistic infections or with Kaposi's sarcoma, had normal T4 counts. We have to recognize the limitations of laboratory tests; they merely provide a profile which must be seen in the context of the clinical features. This is rather like the role of antinuclear antibodies in the diagnosis of systemic lupus erythematosus. Tests have no independent meaning outside a relevant clinical context.

Although the majority of problems that we see in our patients are due to the familiar opportunistic infections indicating defective cell-mediated immunity, a few patients are infected by more common pyogenic organisms, in particular the capsulated organisms *Pneumococcus* and *Haemophilus*. These may cause pneumonia or chronic cough with purulent sputum. It might seem strange that such infections should occur in patients with raised levels of immunoglobulins, which are the major defence against such organisms. However, not only are such people unable to make a *new* antibody response to organisms that have not been met before, but there is also a reduction in the level of immunoglobulin subclass 2 (IgG2); the total rise in im[illegible]

Because IgG2 is the major antibody involved in eliminating capsulated organisms, its deficiency makes patients susceptible to such infections as well. Immunoglobulin therapy can replenish IgG2. For example, one of our patients was producing a cupful of sputum a day and had a greatly reduced exercise tolerance. Regular intravenous immunoglobulin therapy not only eliminated sputum production but also abolished his cough; he is now able to run up five flights of stairs. This is yet another illustration of the importance of concentrating on the positive aspects of what we can achieve by active therapy.

We have also seen a recrudescence of atopic disease in some AIDS patients and this has led to new ideas about atopy in general. The atopic features are typical: asthma, hay fever, rhinitis, atopic eczema and urticaria, often with defined allergens. These complaints occur only in patients who have been affected previously by atopy, for instance if they were affected as children and 'grew out of it'. When these people have developed AIDS, their allergic symptoms returned although not necessarily with the same feature: they may have had eczema in childhood and developed asthma with AIDS. One patient developed acute sensitivity to milk, with marked swelling of her tongue and urticaria on contact even with small amounts of milk, such as in tea or coffee. These patients have increased skin prick-test reactivity but their IgE levels are not different to those of non-atopic AIDS patients. During a trial of recombinant gamma interferon, used in an attempt to reconstitute the cellular immune system, two atopic patients improved, and relapsed when therapy was stopped: for example, the patient mentioned above could tolerate undiluted milk. While it would be wrong to suggest that everyone with atopic disease should be treated with gamma interferon, here again our experience with AIDS has given us an insight into yet another disease.

The T helper cell is the central figure in the immune system: it is involved with macrophages in recognizing antigen and also exerts a controlling influence on cytotoxic T cells, on the B cells (which produce antibodies) and in particular on the activation of macrophages which are important in the elimination of several important organisms. AIDS is *not* the total breakdown of the body's immune system: it is the breakdown of some very key elements, especially the helper cells and the macrophages, other cells remaining broadly intact, although without T-cell control.

HTLV III ENCEPHALOPATHY

[illegible]

This progressive neurological disease, estimated to occur in 25–50% of AIDS patients, also occurs to some extent (yet to be determined) in people who do not have full-blown immunodeficiency; this observation has an important bearing on our perception of the long-term effects of HTLV III infection. Once again, it is probable that the target cells in the brain are T4 antigen-bearing cells, possibly microglia.

Conclusions

Laboratory studies, for instance in mice, can provide much basic information about the immune system. Nevertheless, it is only by the study of man that we can determine the true function of the immune system and how it behaves both when it is impaired and when it is not. Ultimately we have to remember that what happens in mice is interesting, but what happens in man is vital.

References

AUCOUTURIER, P., COUDERC, L.J., GOUET, D. *et al.* (1986). Serum immunoglobulin G subclass dysbalances in the lymphadenopathy syndrome and acquired immune deficiency syndrome. *Clinical and Experimental Immunology* **63**, 234–240.

JANOSSY, G., PINCHING, A.J., BOFILL, M. *et al.* (1985). An immunohistological approach to persistent lymphadenopathy and its relevance to AIDS. *Clinical and Experimental Immunology* **59**, 257–266.

TENNER-RACZ, K., RACZ, P., BOFILL, M. *et al.* (1986). HTLV-III/LAV viral antigens in lymph nodes of homosexual men with persistent generalised lymphadenopathy and AIDS. *American Journal of Pathology*, in press.

Further reading

PINCHING, A.J. (1986). The immunology of AIDS: immunological profile, pathogenesis and the role of diagnostic tests. In *The Management of the AIDS Patient* (D. Miller, J. Weber and J. Green, Eds), pp. 35–52. Macmillan, London.

PINCHING, A.J. AND WEISS, R.A. (1985). AIDS and the spectrum of HTLV-III/LAV infection. *International Review of Experimental Pathology* **28**, 1–44.

WEBER, J.N. AND PINCHING, A.J. (1986). Clinical manifestations of AIDS and related disorders. In *The Management of the AIDS Patient* (D. Miller, J. Weber and J. Green, Eds), pp. 1–33. Macmillan, London.

9

Sexually Transmitted Disease: Clinical Perspectives and Control

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Introduction

In the previous chapter (Chapter 8) Dr Pinching mentioned the spectrum of infection that we see in people with HTLV III disease. At one end of this spectrum there is acute infection with HTLV III, from which a proportion of patients recover while the rest develop chronic infection. Again, a proportion of the latter recover and the remainder develop end-stage disease, which can manifest itself in tumours, opportunistic infections or possibly other severe phenomena that we will begin to recognize as we watch the natural history of the disease for a longer period.

The seroconversion illness

First, we should consider the acute phenomenon — the 'seroconversion illness' — and how one may encounter it in an outpatient environment. An Australian group (Cooper *et al.*, 1985) suggested that a seroconversion illness resembling acute glandular fever occurred very frequently, with manifestations of fever, sweats, myalgia, arthralgia, malaise, lethargy, lymphadenopathy and sore throat. Many physicians in the United Kingdom would feel that this is not a common phenomenon, but nevertheless, if a patient who is in the high-risk group presents with this sort of illness, then a seroconversion illness should be considered. The other seroconversion illness that has been described more recently, both in the United Kingdom and in the United States, is acute encephalitis. The four cases that we described with Dr Tedder and with colleagues working with haemophiliacs (Carne *et al.*, 1985)

tability, loss of consciousness and grand mal fits. Serial observations suggested that all these were associated with seroconversion; all these patients recovered completely. Thus, although it is uncommon, acute seroconversion illness can occur and is something that one should be aware of, especially in the context of a sexually transmitted disease clinic/department of genitourinary medicine.

Patients can be chronically infected with HTLV III virus and yet be totally asymptomatic. Others have cytopenia (low blood cell counts), constitutional symptoms, minor opportunistic infections, lymphadenopathy and the so-called AIDS-related complex (ARC). Lymphadenopathy in particular is being seen increasingly in the STD environment.

Persistent generalized lymphadenopathy

The working definition of persistent generalized lymphadenopathy (PGL) is as follows: enlarged lymph nodes of at least 1 cm diameter, found in two or more non-contiguous extrainguinal sites, present for at least 3 months and not attributable to any current illness or medication known to cause enlarged lymph nodes. The sites that are usually involved are the anterior and posterior cervical, the submandibular, the axillary, the supratrochlear and (although excluded by definition) the inguinal nodes. Other sites also may be affected and about one-third of patients with PGL also have associated splenomegaly.

The first problem is that, when one sees a homosexual man in a department of genitourinary medicine, it is only too easy to assume that he has PGL, and to forget basic medicine. In dealing with young people, one must remember that there is a substantial differential diagnosis in relation to lymphadenopathy. Diagnoses as diverse as Epstein–Barr Virus (EBV) or cytomegalovirus (CMV) infection, syphilis and malignancy must be considered. Any young person may present with a lymphoma and must be examined and investigated in exactly the same way as anyone else who is not in a high-risk group; lymph node biopsy therefore may be required.

The natural history of PGL is still unfolding and a number of prospective studies are being undertaken (*Table 9.1*). In Mathur-Wagh's series (Mathur-Wagh *et al.*, 1984) the median follow-up of patients with PGL was 22 months; 19% of these patients subsequently developed AIDS. In another American study (Metroka), this figure was 17%; in Abrams' group, initially of 70 and subsequently of 200 patients, the figure was 8%; our own cohort of initially 88 patients showed that 8% developed AIDS. The range is therefore 8–19%, but the proportion of

Table 9.1 Persistent generalized lymphadenopathy: prospective studies

No. of patients	Follow up (months)	AIDS		Investigators	
		(N)	(%)		
42	Median 22	8	(19)	Mathur Wagh	1983
90	8 – 19	15	(17)	Metroka	1983
70	Longest 16	0	(0)	Abrams	1983
200	Longest 61	16	(8)	Abrams	1985
88	15 (3 – 30)	7	(8)	Middlesex	1985

patients subsequently developing the end-stage disease of AIDS may increase as the cohorts are watched for longer periods.

What are the prognostic features of progression from PGL to AIDS? As discussed in Chapter 8, they include oral candidiasis, raised ESR, cytopenia, development of herpes zoster and, paradoxically, either an increase or a decrease in lymph node size. The latter requires explanation; many have found that just before PGL patients develop AIDS, the lymph nodes undergo an involution, i.e. they become smaller. However, non-Hodgkin's lymphoma has also been described as an end-stage phenomenon of HTLV III infection, so an increase in size may reflect the former disease.

End-stage disease

Let us now consider end-stage disease, particularly Kaposi's sarcoma (KS). The lesions of KS can be extremely small and are therefore easily missed. The lesions can occur in sites that many general physicians would not normally examine, but that those working in genitourinary medicine always look at, namely the mouth and the feet. In some out-patients the first lesions have been on the hard palate, so it is very important to look in the mouth. In one patient, with lesions on the feet, the initial diagnosis was of tinea, but more careful inspection revealed KS on the sole.

Moving from Kaposi's sarcoma to the opportunistic infections, as mentioned in Chapter 8, the lung may be involved by a number of such infections, e.g. *Pneumocystis carinii*, CMV and mycobacteria — as well as fungal infections such as candidiasis and aspergillosis. It is important to realize that patients with *Pneumocystis carinii* pneumonia (PCP) may present as out-patients without appearing to be very ill. They may present with an insidious illness and with a normal chest

Table 9.2 Clinical and laboratory features at presentation – patients with *Pneumocystis carinii* pneumonia (PCP) (from Kovacs *et al.*, 1984)

Symptoms	Patients with AIDS (N = 46) (%)	Patients with opportunistic infectious diseases (N = 39) (%)
Fever, chills, dyspnoea, cough, sputum, chest pain	No difference	
Median duration (days)	28	5
Percentage with temperatures ⩾ 38·0°C	76	92
Median respiratory rate/min	24	26
Chest radiographs (bilateral, unilateral, no infiltrations)	No difference	
Blood gas values (mmHg)		
Room air arterial O_2 tension	69	52
Alveolar arterial O_2 gradient	41	59

radiograph. *Table 9.2* shows an American series which compares patients with PCP who did have AIDS, with those with PCP and other immune deficiency disorders. The median duration of symptoms before diagnosis was established in patients with PCP and AIDS was one month, compared with 5 days in the other patients. It should be emphasized that PCP can be a very insidious illness which is easily missed in a busy out-patient clinic when it occurs without acute dyspnoea and without signs of decompensation.

The central nervous system may be involved, with viral infections such as CMV giving rise to a meningitis-like picture. In addition, an encephalitis may be associated with herpes or fungal infections. Finally, patients in the high-risk groups may present with focal signs such as a hemiplegia, a monoplegia or a grand mal fit, all of which could be due to cerebral toxoplasmosis.

In the gut, the most frequently seen organisms are *Cryptosporidium* and *Candida*. Cryptosporidiosis is manifest as a high-volume diarrhoea which is extremely difficult to control. Candidiasis may involve the entire gastrointestinal tract and, in particular, cause retrosternal pain and dysphagia. Many who work in departments of genitourinary medicine see herpes proctitis in homosexual men. Unlike the insidious PCP, recurrent herpes in patients with AIDS is very virulent indeed and similar to that of a primary attack. In this situation, treatment with acyclovir for the recurrence, or even prophylactic treatment, is indicated.

Patients may present in the out-patient department with a pyrexia of

be considered. Finally, a word of warning: the central nervous system, the respiratory system and the gut have been mentioned, and a patient may therefore present with headache, shortness of breath and diarrhoea. These are the classic symptoms of anxiety: we see more patients presenting with these symptoms who do *not* have AIDS but who are anxious about AIDS, than we see patients that really do have true end-stage disease.

PREMATURE MORTALITY

Those working in genitourinary medicine have had to orientate themselves to the fact that patients are dying. Until recently, every Appointments Committee when interviewing junior staff would always ask the traditional question 'Why do you want to do genitourinary medicine?'. The stock answer was 'I would like to work with young people who get better'. That, of course, is changing. The median survival from the time of the initial diagnosis of Kaposi's sarcoma in one New York series was 31 months, for PCP, 9 months, and for any other opportunistic infection, survival was half that time. Thus, AIDS is a potent factor in causing premature death in young people — years of potential life lost. In New York there has been an increase of 500% in AIDS as a cause of premature mortality between 1982 and 1984 (*Table 9.3*). The second largest increase in premature mortality was caused by pneumonia and influenza and hidden in that statistic may be people who have died from PCP and who have not been recognized as having AIDS.

Table 9.3 Years of potential life lost (YPLL) before age 65 years, and changes in YPLL. New York City, 1984. *MMWR* (1985) **34**, 669–671

Cause of death	YPLL	Change in YPLL from 1982 (%)
Homicide and suicide	47 900	−14
Heart disease	41 600	−2
Malignant neoplasm	33 900	+5
AIDS	24 400	+510
Chronic liver disease and cirrhosis	18 700	−3
Accidents	11 600	−19
Pneumonia and influenza	8 900	+86
Cerebrovascular disease	5 800	+14

Prevention and control of HTLV III infection

SURVEILLANCE

The first element of prevention and control is to have good surveillance. Unless one has this, one has very little idea of how the disease progresses in the community, and whether the control measures are having any effect. However, the surveillance and monitoring that is carried out in the United Kingdom is currently far too passive and what is required is a much more aggressive form of surveillance that allows us to go into the community and to sample both high-risk and low-risk groups of the population at regular intervals. Thus we would sample people coming to departments of genitourinary medicine, to antenatal clinics and to general practices, as well as intravenous drug abusers and prostitutes. In this way we would know more about the prevalence of the virus and its spread. It is only through such 'outreach' monitoring that we will be able to control this disease and will have an accurate measure of the epidemic and its control.

In common with other groups, we have monitored what is happening in our (albeit atypical) population at the Middlesex Hospital in London. In March 1982 for one week we assessed the prevalence rate in a random sample of homosexual men coming to the Department of Genito-Urinary Medicine; the prevalence of anti-HTLV III was 3·7%. Two years later, in March 1984, we had shown a fivefold increase in that antibody prevalence, to about 21%. This rise is similar to, but slower than, that in San Francisco where, in 1978, there was a prevalence of about 1% which had increased by 1980 to over 20% and in 1984 was virtually 70%. In London, therefore, we are 2–3 years behind San Francisco in terms of prevalence in this particular high-risk group. The prevalence is also increasing in other high-risk groups. The high prevalence in Edinburgh drug addicts is reflected in high prevalence rates among drug addicts in the rest of Europe. For example, there are very high rates in drug addicts in Switzerland (about 40%), in Spain (about 40%), and there is a report from Southern Italy that in the last four years the prevalence has increased in drug addicts from 6% to 75%.

COUNSELLING AND HEALTH EDUCATION

The second element of control must be through counselling and health education. Given that we are discussing a disease for which at present there is no cure, it is quite clear that this element is going to form the cornerstone of control. If one is going to control the disease, one

has to address both high-risk and low-risk populations, and also high-risk populations that currently are in low-risk areas. It could be argued that to spend vast amounts of money on health education in San Francisco or London, where there may be virtual saturation of a high-risk group, is inappropriate and that money might better be spent in Newcastle, or in Sheffield, or in Scotland, where the prevalence among high-risk groups may now be very low but is expected to rise. To this end, the media must be encouraged to help. Already they have made a significant contribution to the control of AIDS by disseminating information about the disease, thus encouraging those in the gay community to alter their life-style. For example, the rate of gonorrhoea in patients at the Middlesex Hospital was about 16% at the beginning of 1982, but fell significantly throughout 1982 and the first three quarters of 1983, as the media became interested in AIDS. Perhaps there was no true causal relationship but it is interesting that, as information is disseminated — through the media or through health education — there is a fall in the rate of surrogate measures of sexual activity (such as rates of gonorrhoea and syphilis). Gay men, in particular, have tried to be very responsible in altering their life-style.

SCREENING

The next element of control is screening. Screening of individuals who donate blood is now universal in the United Kingdom (*see* Chapter 10). Screening of other individuals is very hotly debated by virologists, clinicians and epidemiologists. People who have not fully considered the consequences of screening for HTLV III see it as the panacea, the way to control everything. Certainly, there are advantages to screening: it allows people to know what their anti-HTLV III status is, and on that basis to have a very positive commitment to health, and, possibly, to alter their behaviour. The cons, however, must be considered. The first relates to the basic epidemiological tenet, that one screens only for a disease of which one understands the natural history and in which one can intervene. Screening for carcinoma of the cervix is a good example of effective screening because we understand the natural history of this disease and can stop it progressing if we act early enough. With HTLV III disease we do not yet have any therapy, so that we cannot alter the possible progression of an antibody-positive patient through the spectrum of infection and development of AIDS. There is very considerable psychological and social morbidity associated with knowing that one is antibody positive (*see* Chapters 16 and 17). It is becoming increasingly difficult for anti-HTLV III-positive people to

houses, not because they have AIDS but because they are antibody positive. Not only have they been ostracized, but some have lost their jobs, again, not because they have AIDS but because of the result of a laboratory test. There is a move by certain groups in the medical profession to screen everyone, for instance, who needs a surgical operation, as part of the routine investigation. It is my view that it is not ethical to screen anyone for anti-HTLV III without first seeking their permission, because the implications of a positive test are so considerable.

PROTECTION OF HEALTH CARE STAFF

The final aspect of control is that health care staff must be protected. The original United Kingdom guidelines devised by the Advisory Committee on Dangerous Pathogens were very unrealistic, but I am sure that good sense will now prevail in their revision.

Cost of implementation of control measures

How do we actually manage to put all those arms of control into effect? We can succeed only if resources are available for the following needs. On an in-patient basis one needs dedicated staff working with dedicated equipment. On an out-patient basis one obviously needs additional staff and equipment for diagnosis and follow-up, and for counselling and education. It should not be forgotten that on an out-patient basis we are still working with the backdrop of an increasing workload *before* the advent of AIDS. In the last 15 years there has been a fourfold increase in the number of cases coming to departments of genitourinary medicine in the United Kingdom.

Table 9.4 shows the cost of such treatment at the Middlesex Hospital. Just under £0·5 million revenue and £360 000 for capital equipment are

Table 9.4 Total revenue and capital costs for HTLV III infection

Service	Revenue (£'000s)	Capital (£'000s)
In-patient services	113·5	41·3
Out-patient services	141·4	175·0
Pathology laboratory services	169·8	120·3
Dental hospital services	40·0	25·0

needed in our area of London to care for people with AIDS and HTLV III positivity in one year. It is only through these additional resources that we will be able to control HTLV III infection. This costing is based on hospital services and has not taken into account the additional costs involved in community care, in extensive monitoring, and in health education and public information. It is only when all of these elements come together that we can hope to get reasonable control of this disease.

References

CARNE, C.A., TEDDER, R.S., SMITH, A. *et al.* (1985). Acute encephalopathy coincident with seroconversion for anti-HTLV-III. *Lancet* **ii**, 1206–1208.

COOPER, D.A., GOLD, J., MACLEAN, P. *et al.* (1985). Acute AIDS retrovirus infection: definition of a clinical illness associated with seroconversion. *Lancet* **i**, 537–540.

KOVACS, J.A., HIEMENZ, J.W., MACHER, A.M. *et al.* (1984). *Pneumocystis carinii* pneumonia: a comparison between patients with the acquired immunodeficiency syndrome and patients with other immunodeficiencies. *Annals of Internal Medicine* **100**, 663–671.

MATHUR-WAGH, U., ENLOW, R.W., SPIGLAND, I. *et al.* (1984). Longitudinal study of persistent generalized lymphadenopathy in homosexual men: relation to acquired immunodeficiency syndrome. *Lancet* **i**, 1033–1038.

10

The Blood Transfusion Service in the UK

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Introduction

There is convincing evidence from studies involving donor–recipient pairs that the HTLV III/LAV virus can be transmitted by the transfusion of infected blood and blood products (Feorino *et al.*, 1984, 1985; Jaffe *et al.*, 1985). The first case of transfusion-associated AIDS was reported in an infant transfused in 1982 (Ammann *et al.*, 1983) and up to August 1985, 194 cases had been reported to the Centers for Disease Control in Atlanta, USA (Peterman *et al.*, 1985). In the USA approximately three million transfusions are performed each year so that the incidence of disease following transfusion is low; however, the transmission of the virus may be much higher and with the long incubation period for AIDS it may still present a significant problem for the future.

Although the comparable figure for the UK is five cases, two of whom have received their transfusions abroad, the Blood Transfusion Service (BTS) in the United Kingdom can not be complacent with respect to the transmission of the AIDS virus from the transfusion of red cells, and products manufactured at Regional Transfusion Centres (RTCs). Such products, of course, cannot be heat-treated in the manner found to be satisfactory for fractionated coagulation factor products and albumin.

Discouragement of unsuitable donors

An immediate priority for the BTS was to discourage those donors who belonged to groups of people who were particularly susceptible to

have many different partners, drug addicts (male and female) using injections, and sexual contacts of persons suffering from AIDS. At this time, of course, there was no screening test to detect persons who had been exposed to the causative virus.

In September 1983, the Department of Health and Social Security issued a pamphlet which was distributed to potential blood donors and, coincidentally, a health education campaign was undertaken which stressed the dangers of the transmission of disease.

During 1984, the causative virus for AIDS was recognized as the retrovirus termed 'human T-cell lymphotropic virus, Type III, (HTLV III)' or 'lymphadenopathy-associated virus (LAV)' (Barre-Sinoussi *et al.*, 1983; Popovic *et al.*, 1984) and a significant correlation between the antibody developed to HTLV III/LAV with patients suffering from AIDS was found (Sarngadharan *et al.*, 1984). Various commercial companies began the process of developing a suitable screening test for anti-HTLV III/LAV and the first test systems became available in March 1985.

As further information became available about AIDS, it was necessary in January 1985 to issue a second leaflet to blood donors with a widened range of persons at risk from AIDS, including practising homosexual and bisexual men, both male and female drug abusers who inject drugs, and sexual contacts of people in these groups. It was stated that AIDS had also occurred in a number of haemophilic patients treated with blood products, and that there was evidence that those people who had lived in Haiti or Central Africa, particularly Zaire and Chad, may be at risk.

Persons in these risk groups were requested not to donate blood. Positive action was taken by ensuring that each potential donor received a copy of the second leaflet; they were asked before donation whether they had read this leaflet. By 1985 there was evidence that certain donors were under the impression that they might develop AIDS by giving blood and, in order to counter this potential for reduction in donor recruitment, a statement that infection of donors in this way was not possible was included within the leaflet.

Screening tests — preliminary considerations

It would have been reasonable to expect that when the test for the detection of anti-HTLV III/LAV was available, problems for the BTS throughout the world would be greatly reduced, as the elimination of potentially infectious donations could be achieved. In the event, the advent of ELISA screening tests for anti-HTLV III/LAV on blood

Several aspects of the use of the screening tests had to be considered. These included (1) the specificity, sensitivity and reproducibility of the test; (2) the possibility of false negative tests, and (3) information given to blood donors.

SPECIFICITY, SENSITIVITY AND REPRODUCIBILITY OF THE TEST

Development of the ELISA test for anti-HTLV III/LAV was carried out in the USA initially, and the first tests licensed by the Food and Drug Administration had impressive sensitivity and specificity. Sensitivity was between 93% and 99% and specificity was greater than 99%. It must be stressed that at this time the prevalence of anti-HTLV III/LAV in the donor population was unknown but previous theoretical estimates, based on a prevalence of 1 in 1000, indicated that 68–89% of all repeatedly positive donations were likely to be false positives (Osterholm *et al.*, 1985).

Concern was expressed on two counts by several major blood centres in the USA: first, that the withdrawal of the positive anti-HTLV III/LAV-reactive donations would actually lead to blood shortages and how, under such circumstances, donors could be advised properly with respect to their future life-style. Secondly, it was felt that the effect on donor recruitment could be serious; if potential donors were aware of a significant false-positive rate in the tests, some might be reluctant to come forward to donate their blood.

It was important, therefore, that highly specific confirmatory tests should be available within a relatively short time after routine screening of blood donations was undertaken, so that false positive reactive tests on donors could be identified and the donor recalled for a further donation. Critics of this policy who argued that, at least, positive reacting donations could be eliminated, did not recognize the practical problems involved in the avoidance of further blood collections from donors, without advising them of the reasons for not requiring their blood donations in the future.

THE POSSIBILITY OF FALSE NEGATIVE ANTI-HTLV III/LAV TESTS

Despite the publicity by the BTS to discourage persons in high-risk groups from presenting as donors, it was feared that some persons in

forming the screening tests, there was the danger that a false negative result could be obtained from an infectious donor. Obviously, this would have made the safety of blood donations less secure. It was important, therefore, to ensure that alternative test venues were made available for persons, other than blood donors, who wished to know their anti-HTLV III/LAV status.

INFORMATION GIVEN TO BLOOD DONORS

Many tests are carried out on blood donations: these include blood grouping, antibody investigations and tests for hepatitis B surface antigen and syphilis. These tests have been recognized by the profession as necessary and donors have been aware, before donation, that tests were carried out on their blood, although they were not informed of the exact nature of such tests. However, the significance for the donor of a positive anti-HTLV III/LAV result was such that it was agreed that it was essential that the donor should be informed that this particular test was to be performed on their donation, and that their agreement should be sought before their donation. This has been achieved in the UK by issuing a third leaflet in September 1985. In addition to the previous requests to donors in high-risk groups to refrain from donating blood, donors were informed that their blood would be tested for the antibody to AIDS and that they would be asked at sessions to agree to this test being performed; permission subsequently is obtained by asking the donor to sign a statement indicating his or her consent.

It was recognized that concern that the test was to be performed might discourage some persons from donating, and that the effect on recruitment would have to be observed closely.

Prerequisites for introduction of tests

During the period March–October 1985, successive events took place which were considered to be essential prerequisites for the introduction of the screening tests into the Blood Transfusion Services of the UK. Thus:

1. An evaluation of the available test systems for anti-HTLV III screening was undertaken by the Public Health Service Central Laboratory. From this, three tests emerged as the most suitable for

2. Of these three, two test systems — Organon Teknika and Burroughs-Wellcome — were subjected to an evaluation within the BTS at the Manchester and Edgware RTCs. This study gave several interesting results but is still in progress, so detailed data cannot yet be presented. However, it was found that both tests were suitable for use in RTCs.
3. Arrangements were made with the Public Health Laboratory Service (PHLS) for the performance of confirmatory tests on repeatable positive reactors found by anti-HTLV III/LAV screening of blood donations (*see also* Chapter 5).
4. It was agreed that the initial counselling of blood donors whose confirmatory test was positive would be carried out by senior medical staff in RTCs and these persons attended training courses at St Mary's Hospital, Paddington, London.
5. Alternative testing venues were established by Regional Health Authorities so that tests were available for members of the public other than blood donors.
6. A training programme for the scientific and technical staff in RTCs was started, so that on the nominated day (14 October 1985) all Centres began routine testing of all blood donations.

Experience with the Organon Teknika test

Of the 21 Centres where anti-HTLV III/LAV screening of blood donations was being performed, initially 16 elected to use the Burroughs-Wellcome test and five the Organon Teknika test. Before presenting a summary of the results for the UK from the first 3 months of testing, it is useful to review briefly the experiences obtained using the Organon Teknika test at the Manchester Centre during this period.

The manufacturer provides control antisera which are used to calculate the cut-off value for each micro-titre plate of 90 test sera. Although most donor sera give optical density (OD) values significantly below the cut-off value, with an occasional result clearly above, others may give OD values below the cut-off but clearly higher than the values of the majority of negative results. A 'low positive' control supplied by the Central Laboratory of the PHLS gave OD values close to the manufacturer's cut-off value; on some plates this was above and on others below the cut-off.

Because it was known that this serum contained anti-HTLV III, it seemed prudent to regard certain results — where the OD was less than that of the cut-off value — as equivocal, as on repeat testing a proportion of these were found to be positive, i.e. giving an OD value

Table 10.1 Analysis of equivocal results* obtained using the Organon Teknika test† at Manchester Regional Transfusion Centre

Percentage of the optical density value of the cut-off	Initial equivocal results		Repeat test results					
			Equivocal		Positive		Negative	
	(No.)	(%)‡	(No.)	(%)§	(No.)	(%)§	(No.)	(%)§
50	198	50	45	23	14	7	139	70
51–60	66	17	24	36	8	12	34	52
61–70	53	13	15	28	4	8	34	64
71–80	42	11	16	38	6	14	20	48
81–90	23	6	8	34	5	22	10	43
91–100	14	4	6	43	0		8	57

* Total no. of equivocal results = 396 (1·18%)
† Total no. of tests = 33 608
‡ Percentage of total initial equivocals (396)
§ Percentage of total initial equivocals at this cut-off level

results obtained in the performance of 33608 tests, divided into 10% steps to an OD value of 50% below that of the cut-off. It can be seen that the number of equivocal results increases, the further the OD values are from the cut-off; nevertheless, even at the 50% level, on repeat tests 7% of the results were found to be positive. The percentage of tests which were either positive or equivocal on repeat testing tends to rise, the nearer the initial result was to the cut-off value.

If one accepted that confirmatory tests should be performed on those 151 of the 396 units of blood that were found to be either positive or equivocal on repeat tests, this would mean that almost 0·5% of the total blood collected would have to be quarantined. This is in addition to those units found to be positive on the initial screen and subsequently repeatably positive. Not only does this create a considerable workload, but wastage is caused with short-dated products such as platelet concentrates. Dr J. Craske of the Manchester PHLS carried out confirmatory tests on over 300 of these equivocal results and found them to be uniformly negative. It was concluded, therefore, that these were not true positives and a value of less than 20% of the cut-off was chosen to define an equivocal result, as this covered the majority of the results obtained with the PHLS 'low positive' control serum.

There was a batch variation in the finding of positive and equivocal results, as shown in *Table 10.2* where the number of tests found to be

Table 10.2 Positive and equivocal results of initial screening at Manchester Regional Transfusion Centre, using the Organon Teknika test

Batch no.	No. tested	Positive		Equivocal*	
		(No.)	(%)	(No.)	(%)
239	7509	3	0·04	3	0·04
260	7201	15	0·21	10	0·14
272	5728	22	0·38	6	0·10
268	7246	14	0·19	7	0·10
306	5924	34	0·57	11	0·19
298	563	2	0·36	1	0·18
Total	34171	90†	0·26	38	0·11

* Defined as within 20% of the cut-off value
† One subsequently confirmed positive

six batches used. A smaller variation in the equivocal results was observed. Of the 90 initial positives, only one was confirmed.

THE BURROUGHS-WELLCOME TEST

Experience with the Burroughs-Wellcome test has been more limited at the Manchester RTC and comments on possible differences between batches cannot be made. However, using a value of 10% above the cut-off value to define an equivocal result, a proportion of repeat tests have proved to be positive. The findings described with respect to the Organon Teknika test, therefore, are not confined to it alone, and a degree of variation has to be expected with the current ELISA tests for anti-HTLV III/LAV.

Routine testing in the UK: the first 3 months

An analysis of the anti-HTLV III/LAV tests carried out on blood donations throughout the UK to the end of December 1985 is shown in *Table 10.3*. This has been compiled with the co-operation of the Regional Transfusion Directors who have sent their results to the Manchester RTC for collation. It can be seen that many more tests have been carried out using the Burroughs-Wellcome kit than using the Organon Teknika kit and, with this test, on initial screening the total number of positive and equivocal results decreased during the

Table 10.3 Analysis of anti-HTLV III test results for the UK, 14 October–31 December 1985

Test kit	Results	Month		
		October	November	December
Burroughs–Wellcome	Total tests	140 351	162 279	147 031
	Positive/equivocal	1 878 (1·3%)	925 (0·57%)	355 (0·24%)
	Repeatable positive/equivocal	20 (0·014%)	20 (0·012%)	18 (0·01%)
Organon Teknika	Total tests	50 207	48 816	45 830
	Positive/equivocal	221 (0·44%)	336 (0·69%)	204 (0·44%)
	Repeatable positive/equivocal	54 (0·1%)	81 (0·16%)	26 (0·06%)
	Combined total tests	190 558	211 095	192 861
	Confirmed positives*	3	3	7

* 13 confirmed positives in 594 514 tests, i.e. 0·002% (1 in 45 731)

for this: it may be that, with time, experience in performing the test has increased, leading to better definition of results; alternatively, the difference may be related to batch number although this could not be proved as a large number of batches are involved. In addition, changes in the cut-off value were made by the manufacturer during this period.

With the Organon Teknika test, the percentage of positive and equivocal results did not change markedly during the 3-month period.

Despite the changes in the percentage of initial positive or equivocal results with the Burroughs-Wellcome test, the percentage of *repeatable* positive/equivocal results has remained similar in the 3 months. The number of repeatable positive/equivocal results with the Organon test is more variable and consistently higher than with the Wellcome test. This may be explained, at least in part, by the fact that the Organon Teknika test will give repeatable positives with anti-lymphocytic antibodies which are not detected by the Wellcome test.

Thirteen positive results have been confirmed, giving an *overall incidence in the UK of 0·002% or 1 in 45 731*, although there are regional differences. Three of the 13 confirmed positives (i.e. 23%) were detected by the Organon Teknika test, which correlates reasonably well with the proportion of the total donations tested with this system (i.e. 32%). At the initial interview, at least 10 of the 13 donors with confirmed positive tests were found to fall into recognized high-risk groups and one was a donor from sub-Saharan Africa. The frequency of positive results is much lower than that reported from the USA; Schorr *et al.* (1985) reported that in screening 1·028 million American Red Cross blood donors [illegible]

was 1·0%, repeat positives 0·17% and the projected prevalence of confirmed positives by Western blot was 0·038% (1 in 2600). Thirty-six of the first 41 donors interviewed were in high-risk groups. It may be that the prevalence of HTLV III infectivity is higher in the USA than in the UK; a recent report estimates that there may be 1·7 million adults in the USA who have been exposed to the virus, including 64 000 not belonging to an identified risk group (Sivak and Wormser, 1985). Perhaps, also, our publicity designed to discourage donors in high-risk groups has been particularly effective, as well as the availability of alternative test sites so that people can obtain anti-HTLV III/LAV tests without having to donate blood.

I am sure that now anti-HTLV III/LAV testing is included as one of our routine screening tests for blood donations, everyone is relieved in that we recognize that we are doing our utmost to secure a supply of blood and products from RTCs with the maximum safety with respect to the transmission of the AIDS-related virus. The introduction of testing has not, apparently, had a significant effect on the number of donors coming forward to give blood. Donors can be assured that if a positive result is found on their blood donation they will be treated in a confidential and sympathetic manner, and will be given as much help as possible by the Senior Medical Staff in the Blood Transfusion Service.

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References

AMMANN, A.J., COWAN, M.W., WARA, D.W. *et al.* (1983). Acquired immunodeficiency in an infant: Possible transmission by means of blood products. *Lancet* **i**, 956–958.

BARRE-SINOUSSI, F., CHERMANN, J.C., REY, F. *et al.* (1983). Isolation of a T-lymphotropic retrovirus from a patient at risk for acquired immune deficiency syndrome (A.I.D.S.). *Science* **220**, 868–870.

FEORINO, P.M., KALYANARAMAN, V.S., HAVERKOS, H.W. *et al.* (1984). Lymphadenopathy associated virus infection of a blood donor–recipient pair with acquired immuno-deficiency syndrome. *Science* **225**, 69–72.

FEORINO, P.M., JAFFE, H.W., PALMER, E. *et al.* (1985). Transfusion-associated acquired immuno-deficiency syndrome: Evidence for persistent infection

JAFFE, H.W., SARNGADHARAN, M.G., DEVICO, A.L. *et al.* (1985). Infection with HTLV III/LAV and transfusion-associated acquired immuno-deficiency syndrome: Serologic evidence of an association, *Journal of the American Medical Association* **254**, 770–773.

OSTERHOLM, M.T., BOWMAN, R.J., CHOPER, M.W. *et al.* (1985). Screening donated blood and plasma for HTLV III antibody: Facing more than one crisis. *New England Journal* **312**, 1185–1188.

PETERMAN, T.A., JAFFE, H.W., FEORINO, P.M. *et al.* (1985). Transfusion-associated acquired immuno-deficiency syndrome in the United States. *Journal of the American Medical Association* **24**, 2913–2917.

POPOVIC, M., SARNGADHARAN, M.G., READ, E. *et al.* (1984). Detection, isolation and continuous production of cytopathic retroviruses (HTLV III) from patients with A.I.D.S. and pre-A.I.D.S. *Science* **224**, 497–500.

SARNGADHARAN, M.G., POPOVIC, M., BRUCH, L. *et al.* (1984). Antibodies reactive with a human T-lymphotropic retrovirus (HTLV III) in the serum of patients with A.I.D.S. *Science* **224**, 506–508.

SCHORR, J.B., BERKOWITZ, A., CUMMING, P.D. *et al.* (1985). Prevalence of HTLV III antibody in American Blood Donors. *New England Journal of Medicine* **313**, 384–385.

SIVAK, S.L. AND WORMSER, G.P. (1985). How common is HTLV III infection in the United States? *New England Journal of Medicine* **313**, 1352.

11

Haemophilia

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Introduction

In 1974, in a book for the families of my patients, I wrote about the pleasures and pains of living with haemophilia. To the uninitiated the choice of the word 'pleasures' may have seemed strange then; with the advent of AIDS it probably seems even stranger now. Yet haemophilia still carries with it many of the attributes most highly prized by mankind. Among them are courage, gentleness and determination, three qualities that help people face and overcome an ever-present threat of disablement and death.

The disorder

Haemophilia is an inherited disorder in which one of the clotting ingredients is either deficient or absent from the blood. In classical haemophilia or haemophilia A this ingredient is called factor VIII. In haemophilia B or Christmas disease, named after the first patient described, factor IX is affected. The severity of these two forms of haemophilia is variable, so that while within the United Kingdom there are some 5000 people with haemophilia, only 2000 have the condition in its severest form.

Both factor VIII and factor IX are normally produced in the liver through genetic instructions inherited from the parents. Because these instructions are found on the X chromosome, females (with two X chromosomes and therefore duplicate sets) do not suffer from haemophilia: it is a disorder of males.

People with haemophilia bleed no faster than anybody else; the hallmark of their disorder is prolonged oozing, often from trivial injury.

especially in childhood, are internal into joints and muscles and the result is a very painful and crippling arthritis. Contrary to popular belief, haemophiliacs do not bleed uncontrollably from scratches, small cuts or pin-pricks: the body's protective mechanisms for these insults are intact. Nor do they bleed externally any more than other people, nose bleeds or blood in the urine being the most usual manifestations. These observations are of fundamental importance when we come to look at risk from spread of a blood-borne disease. The chances of contamination of the environment and therefore of other people from someone with haemophilia are negligible.

The treatment

Haemophilia has recently been cured, but only by liver transplant — not a procedure to be undertaken lightly. There is, however, considerable hope for more appropriate cures, perhaps with easier transplant techniques or with genetic manipulation. However, these are goals for the future. At present, haemophilia may be treated very simply and very effectively. All that is required is the replacement of the missing factor, either when a bleed is occurring or in anticipation of bleeding — the practice of prophylaxis. Recurrent treatment is necessary because the life of the clotting factor in the bloodstream, and therefore its usefulness, is finite. About half the activity disappears within 12 hours and this loss is speeded up during bleeding.

Thirty years ago the only treatment available to most patients was freshly donated blood or plasma, or fresh frozen plasma (*Table 11.1*), but in 1964 a way of concentrating the factor VIII in human blood was discovered near San Francisco, and the resulting product, cryoprecipitate, revolutionized the lives of people with haemophilia.

Table 11.1 Blood products for treatment of haemophilia

Product	When available
Fresh whole blood	Before 1964
Fresh plasma	1964 onwards
Fresh frozen plasma	1973
Cryoprecipitate	1985
Lyophilized concentrates	(1955)
Heat-treated concentrates	(?)
(Animal concentrates)*	
(Recombinant DNA concentrates)†	

* Not a generally viable alternative
† Not yet available

Because cryoprecipitate is a small-volume product it can easily be given on an out-patient basis and its introduction freed people from the need to be admitted to hospital for most of their treatment. In the 1950s and 1960s, small quantities of even more potent concentrated blood products which had been developed in Oxford and Scandinavia were available. In 1955 a factor VIII concentrate made from pigs' blood was developed. Unfortunately this product has so far not proved to be effective over a long period, although it is of great value in the treatment of some of the complications of haemophilia. In this country, as a result of a government decision to allow importation of human blood products for the first time in 1973, freeze-dried (or lyophilized) concentrate became readily available, the products coming principally from manufacturers in the United States. Within the last two years the genetic structures of both factor VIII and factor IX have been discovered, and there is hope that within the next five years genetically engineered or recombinant DNA factor VIII and IX concentrates will be available to the haemophilic population. Until they are, the health and life of this population is still dependent entirely on the donation of human plasma. Without the help of donors, haemophiliacs are lost. It is vital to them, and of course to countless others, that healthy donors continue to come forward from the community. Donors must be continually reassured, beyond question, that there is no risk of contracting *any* disease, let alone AIDS, by donating their blood or plasma.

Viral contamination of donated blood

In order to make clotting factor concentrate, up to 30000 donations of plasma may be used. The more refined the product, the greater the loss of biological activity occurring during manufacture, and thus the more source material needed and the greater the likelihood of viral contamination. The commonest complication of this massive exposure is viral hepatitis, and abnormal liver function tests and cases of cirrhosis are seen in every haemophilic population studied. However, when in July 1982 the Centers for Disease Control reported unusual opportunistic infections in three men with haemophilia, the possibility of a viral aetiology was thought less likely than an immune response to the constant barrage of extraneous denatured protein involved in treatment. However, in December 1982 the first case that linked AIDS and blood transfusion directly was reported and this, together with further reports of AIDS in haemophiliacs, proved without doubt that the disease appearing in haemophilia was essentially the same as that affecting the other risk groups.

Table 11.2 Anti-HTLV III status of haemophiliacs in the UK (courtesy of UK Haemophilia Centre Directors)

Haemophilia type and severity	No. tested	Anti-HTLV III positive (No.)	(%)
Haemophilia A, all severities	2025	896	44
Haemophilia A, severe	1268	752	59
Haemophilia B	324	20	6
von Willebrand's disease	215	11	5

tested a substantial proportion of the haemophilic population of the UK. Their results show that overall 44% of the people with haemophilia A are anti-HTLV III positive (*Table 11.2*); this figure rises to 59% in the severely affected population. The percentage of infected people remains low in those with haemophilia B, or von Willebrand's disease, another (usually mild) bleeding disorder. In these disorders the percentage affected lies between 5% and 6%.

In this country it is usual to treat small children with cryoprecipitate collected from volunteer donors in the National Blood Transfusion Service. As families learn when and how to treat bleeds, freeze-dried concentrates are introduced so that children can be put on to home therapy and do not have to come to hospital. This practice is reflected in *Table 11.3*. The anti-HTLV III status of the children examined by the Haemophilia Centre Directors is low in children below the age of 5 years (12%) and then rises through 35% for the 5–9-year-old group to a peak of 68% in those entering their teens.

The reason for this increase is apparent in *Table 11.4*. Only 1% of the anti-HTLV III positive people examined by the Directors had received only cryoprecipitate. Ten per cent had received only National Health Service concentrate, indicating that before individual donor

Table 11.3 Anti-HTLV III status of children with severe haemophilia A (courtesy of UK Haemophilia Centre Directors)

Age (years)	No. tested	Anti-HTLV III positive (No.)	(%)
<5	40	5	12
5–9	91	32	35
10–14	104	71	68
15–19	163	106	65

Table 11.4 Type of factor VIII therapy and anti-HTLV III status in UK haemophiliacs (courtesy of UK Haemophilia Centre Directors)

Type of factor VIII therapy	Anti-HTLV III positive (%)
Cryoprecipitate	1
NHS concentrate only	10
Commercial concentrate only	45

testing the AIDS-related virus was a contaminant of our volunteer blood donation system. Sixty per cent of the factor VIII used within the United Kingdom is imported from the United States, and the evidence that this was the principal vehicle for the transmission of AIDS to our haemophilic population is overwhelming.

AIDS in haemophiliacs

We still do not know with precision what the future holds for our antibody-positive haemophiliacs. Present figures suggest that the chances of developing overt AIDS lie between 1% and 5%. To date, 135 cases have been reported to CDC in the United States and 11 to CDSC in the United Kingdom (*Table 11.5*). Although no child in the United Kingdom has developed AIDS we will undoubtedly see this happen in the near future. Within the Northern region in our population of 143 multi-transfused patients we have reported three cases fulfilling the CDC definition of AIDS. In retrospect, and with HTLV III testing, a further two haemophilic men have died with AIDS. We now have to report a further two cases, diagnosed within the past month. To date, the majority of haemophiliacs who have developed AIDS have contracted, and died from, opportunistic infections. These latest cases, however, are of lymphomas, one of the lower jaw, and one of the gastrointestinal tract. Thus, we are now seeing malignancy in haemophiliacs, as well as in the other risk groups. In addition, my colleague

Table 11.5 Cases of AIDS and haemophilia known to CDC/CDSC, January 1986

	USA	UK
Adult	124 (1%)	11 (4%)
Child	11 (5%)	0

Dr Dietrich in Los Angeles tells me that three cases of Kaposi's sarcoma are now known in haemophiliacs without other risk factors in the United States — one of the liver, one of the gastrointestinal tract and one presenting as a small skin lesion in the axilla.

Although the average incubation period from infection to development of the fully developed syndrome is generally accepted as about 29 months, recent evidence from patients infected by blood transfusion in the United States suggests that it may be longer. For these cases, the 'best guess' is currently 4 years, with a long 'tail-off' during which activation of the disease by unknown co-factors may occur. Given that a cohort of 15 of our patients have proved to be negative for anti-HTLV III on blood samples put into store in 1982, and have subsequently seroconverted to positive, we are, at best, at peak prevalence only now.

The efficacy of heat treatment

If we take a 60% prevalence rate from the Haemophilia Centre Directors' survey, we can expect about 5000 severely affected haemophiliacs in the United States and 1200 in the United Kingdom to be anti-HTLV III positive (*Table 11.6*). These people cannot stop treating their haemophilia, because bleeding and its complications is still the major cause of morbidity and mortality. In the United States the appearance of AIDS did initially cause a fall of about 20% in the amount of factor VIII and factor IX concentrate used, and a similar phenomenon is now occurring in this country. However, in the United States the use of these concentrates has now returned to previous levels. In part, this is due to confidence in the sensitivity of testing of individual blood donations for anti-HTLV III and the exclusion of donors in the high-risk groups, and in part it is due to the introduction of concentrates

Table 11.6 Haemophilia A: estimated numbers of patients at risk in the United States and United Kingdom

	Total population	Haemophilic population	Severe	Anti HTLV III positive*	AIDS	% of +†
USA	218 M	20000	8000	4800	135	3
UK	54 M	5000	2000	1200	11	1

*Taking 60% prevalence

which have been subjected to heat during manufacture. It has been known for many years that heating destroys viruses in blood products: indeed, albumin, which is pasteurized and which is used principally for the treatment of shock and burns, transmits neither hepatitis nor AIDS. Heating was not applied to the factor concentrates before 1984 because it results in a further loss of activity and therefore the need for more plasma and more donors, with a subsequent increase in both exposure to extraneous material and cost.

Laboratory experiments show that the AIDS-related virus does not like heat and is readily destroyed. Most manufacturers now use heat during the preparation of the concentrates, although chemical methods of viral inactivation are also being studied. Whatever method is used, complete AIDS inactivation cannot yet be guaranteed; hence the enormous importance of discouraging people in high-risk groups from donating, and of continuing to check individual donations by the most sensitive test available. Only time and careful follow-up will tell us how effective introduction of the more expensive heat-treated materials has been. To date I know of four possible failures: three are known to CDC and have been described to me by Dr Peter Levine as being probable seroconversion to anti-HTLV III positivity in one case and possible seroconversion in two others; the fourth case is about to be reported by Dr Breederveld from the Netherlands and is perhaps the most convincing. This patient is known to be in no other risk group, and was seronegative when started on heat-treated material, becoming positive after almost a year's treatment. This takes him well past the known incubation period between infection and seroconversion.

Given that haemophilia has to be treated, the alternatives now available lie between a reliance on heat-treated concentrate, perhaps with adjustments in terms of type and length of heating, and tested cryoprecipitate for haemophilia A, or fresh frozen plasma for minor bleeds in haemophilia B. In the case of mildly or moderately affected patients with haemophilia A, or those with von Willebrand's disease, the alternative to blood product is DDAVP, or Desmopressin, which carries no risk whatsoever from either hepatitis or AIDS, but is useless in severe haemophilia.

The effects of HTLV III infection on haemophiliacs

The impact of AIDS on the haemophilic population is enormous. Within the past 20 years, people with haemophilia have learnt to lead almost normal lives: they hold down normal jobs, go to normal schools, follow normal careers and participate in most sporting activities. Fam-

affected children and the children have grown and thrived in healthy competition with their non-haemophilic peers.

AIDS has changed all that. Haemophiliacs now demand a response from the medical and para-medical professions, like that forthcoming 20 years ago when concentrates first became generally available. They need formal medical, dental, nursing and social care of the highest quality. They need facilities for repeated and confidential counselling. They require information and advice about topics as diverse as prognosis, heterosexual spread, their relationship with other risk groups and the increasing claims of alternative medicine. And in helping them, their carers also need help. Our nurses, social workers, physiotherapists and laboratory workers must be protected as they mourn the loss of patients well known to them for years.

Public health considerations

At present, the most important and positive help we can give is to emphasize that AIDS is *not* spread by casual contact. People caring for those with haemophilia, whether it be in the hospital, in the home, in the school, in the place of work, in the swimming pool, on the sports field or on holiday, have nothing to fear. In the many studies made of casual medical, household and environmental contact there have been no cases of transmission. To emphasize this we have tested 79 hospital staff, most of them working every day with blood and many of them working with patients with overt AIDS, and all these staff are anti-HTLV III negative.

This, and other incontrovertible scientific evidence, has allowed the health and education authorities in both the United States and this country to issue guidelines about the schooling of infected children. The draft document recently referred for discussion in the United Kingdom by the DHSS and DES is particularly welcome because it addresses itself both to the privacy and integrity of the individual child and his or her family, and to all the vagaries of a boisterous and healthy school life where parents and teachers may have questions of concern. It is worth quoting parts of these documents, because upon them depends in part the future of the 500 or so haemophilic children likely to be anti-HTLV III positive in the United Kingdom, as well as their peers born to mothers infected for other reasons:

'Infected children should be allowed to attend school freely and be treated in the same way as other pupils' (UK).

'These children should be allowed to attend school and after-school day-care and to be placed in a foster home in an unrestricted setting' (USA).

'Persons involved in the care and education of infected children should respect the child's right to privacy, including maintaining confidential records' (USA).

'The basis of any teaching (about AIDS) offered should be the presentation of straightforward, factual information about the virus and about modes of transmission of infection in order to balance the incomplete and inaccurate impression which pupils may have gained from other sources' (UK).

It cannot be pretended that the question of confidentiality is always an easy one. School and clinic doctors need to know the antibody status of children because live vaccines, including polio and BCG, may be dangerous to them and are contra-indicated, and those children with symptoms of immunodeficiency are at especial risk from contact with the common infectious fevers of childhood, including measles.

Sexual transmission and counselling

One of the most distasteful aspects of the work of those of us working with people at risk is having to counsel that there is a risk of transmitting the virus sexually to loved ones. In the context of haemophilia this usually means heterosexual spread. In our cohort of patients reported in the *British Medical Journal* (Jones *et al.*, 1985), we noted that three female sexual partners of haemophiliacs were also anti-HTLV III positive. *Table 11.7* shows that these three women were the partners of three seropositive men. We have also tested a further 33 sexual partners who have proved to be negative although the males are positive. Nine partners of seronegative males have also proved to be negative. Detailed investigation has shown no risk factors other than normal vaginal intercourse in two of the three positive cases, all of

Table 11.7 Anti-HTLV III status of sexual partners of haemophiliacs in Northern England, February 1986

Male	Female	No. of repeat tests
3+	3+	3
33+	33−	10
9−	9−	1

whom have voluntarily allowed repeated testing. One of the cases fulfils the CDC criteria for AIDS and has had *Pneumocystis carinii* pneumonia. She had previously received blood transfusions and until we have cleared all the donors we cannot be certain of a sexual cause for her infection. Another lady has delivered a child who is also seropositive, demonstrating both the horizontal and vertical transmission of the virus. These figures, although small, are in keeping with other studies outside Africa which suggest that there is a 10% risk of heterosexual transmission. Because of them we have no option but to advise those at risk that sexual intercourse should be protected by sheath, together with a lubricant. Until we know more about the disease and also have a vaccine for their partners, those at risk have to think carefully about having children. Such advice obviously has a very sad and profound effect, which depends in part on the age of the patient. I am particularly concerned about our youngsters and their psychosexual development during adolescence, both because of the bleak future of so-called 'safe', but not perhaps so enjoyable, sex and because of the knowledge that at present both marriage and parenthood might be at stake because of the result of a laboratory test. Not unexpectedly, our advice will not always be heeded, indeed it would be inhuman if it was. It is of great importance that we ensure that people who decide not to heed it are not made to feel wrong or guilty by their decision; censure will only add another burden to their disrupted lives.

Psychosexual aspects

Distortions that may occur in psychosexual development may be echoed in distorted body image in these patients. Certainly, in the days before there was effective treatment for haemophilia, severely affected patients frequently grew to regard themselves as handicapped and, in some cases adopted a sick role, becoming chronic invalids. Once again the haemophiliac is in danger of falling prey to the many facets of a single disease. He has been referred to as 'the innocent victim', a term I do not personally like because the adjective 'innocent' implies that somebody else is guilty, and I cannot condone differentiation by sexuality any more than I can differentiation by race, or class, or colour, or creed. However, there are major differences between the perception of AIDS in the haemophilic and the gay populations. The haemophiliac has to have a diagnostic label in order to receive treatment should he be injured or need surgery. Because of this need for treatment, coupled with the need to ensure the safety of staff dealing with blood and body fluids, the haemophiliac's anti-HTLV III status must be known. The gay's decisions to be [illegible]

unless of course he elects to try to donate blood. Because both patient and doctors know the result of the haemophiliac's test, so will insurance companies, and people with a positive test now find that decisions about insurance are postponed; in other words, their chances of obtaining life insurance or mortgage endowment have been lost. A haemophiliac's sexual partner will, in most cases, know that he has haemophilia and will therefore also know the results of the test; indeed, there is a medical reason for the partner to know. Although this reason is as necessary in the gay population, the decision to tell remains purely voluntary. Children with haemophilia are affected and the attitudes of those who work in schools and places of employment may also be affected, and the public now equate the diagnosis of haemophilia with the diagnosis of AIDS. The final vestige of confidentiality and — because of an insensitive response by the media — the privacy and dignity of affected haemophilic families, is stripped away shortly after death by the decision of the Coroner's Society to submit all cases to public inquest. While I cannot, especially as the prescribing doctor, argue against the fact that death from AIDS contracted via haemophilia treatment is misadventure, I do question the concurrent need for personal publicity. Because they are identified so readily, those with haemophilia already perceive themselves as guinea-pigs for the study of the epidemiology and treatment of AIDS. We must try to find some way both to protect them and their families and to compensate them for our failure as a society to deliver safe therapeutic material. Watching the advent and unfolding of AIDS in the haemophilic population is like watching a slow Aberfan — the engulfing of a generation because we, as a country, did not act in time.

References

JONES, P., HAMILTON, P.J., BIRD, G. *et al.* (1985). AIDS and haemophilia: morbidity and mortality in a well-defined population. *British Medical Journal* **291**, 695–699.

12
Third Question Session

Dr Alex Mills, Terrence Higgins Trust: I would like to comment first of all on Professor Adler's remarks about health education and screening, which the Terrence Higgins Trust would like to endorse fully. The one point I wish to question is the prevalence of HTLV III infection in London. The figures that Professor Adler quoted were from his clinic: would he not agree that the overall prevalence in London is probably much lower and that therefore there is still a case for health education in London as well as in peripheral cities such as Newcastle?

Professor Adler: I take all those points. I was quoting from my own Unit and was not suggesting that one should give up health education in London. For example, even if someone is infected with the virus one wants to do everything that one can to stop that person going on to develop AIDS. So, for example, co-factors such as sexually transmitted diseases may be important, and it is vital that patients are given advice about how they might alter their life-styles and protect themselves. It is also important to give individuals advice on how modifications in their life-style can protect other people from infection.

Dr Volberding: I realize that the question of screening for anti-HTLV III is controversial. However, because my own feeling about screening has changed somewhat, I would like to make one or two points.

The initial reaction in San Francisco was very strongly against screening. However, as I thought more about that reaction I wondered if we could not benefit by screening in some situations. By concentrating on the social problems that arise when a test is positive, we ignore the great reassurance provided to someone who can be told that he or she is, in fact, negative. We find that people, including myself, are very reassured to find out that they are antibody negative. I also think that by merely looking at the individual consequences instead of thinking of society as a whole, we may be missing opportunities. By focusing on the individual test we may miss the opportunity to curtail the spread of the disease. I am thinking especially of the problem in intravenous

Professor Adler: I agree, in London, where we have been debating the question a lot, we are coming across to that way of thinking. This is an evolving process of education which depends in part on the prevalence rates in different places.

Dr Pinching: I would like to add a few comments. I hope that by getting this discussion out into the open we recognize that the question of screening is not as simple as many think.

One immediate reaction is that, because this is an infectious disease, we must isolate the source. That clearly is illogical because it does not take account of the way in which this disease is spread. The key is that somebody who performs an antibody test should think in advance about the implications of the test for the person concerned, and of what he is trying to achieve for that individual patient. Ultimately we have a responsibility to the patient in front of us. Of course we have a broader public health responsibility as well and, in general, this responsibility is in accord with the needs of the individual. Nevertheless, what may seem superficially attractive as a public health measure may prove devastating for a patient. We have seen too many casualties of indiscriminate screening. Too many people have been tested without their consent — without a full appreciation, either by them or by their doctors, of the implications of a positive result. The position is different for somebody who *does* understand the implications and who is psychologically prepared, before testing, for either a positive or a negative result. In that case anybody who wishes to have the test, should have it. Nobody is saying that we should not test: the issue is whether we should *screen* in an indiscriminate fashion. I suspect that there is actually much less disagreement than there seems to be in this debate. Some of us, however, are reacting to those very painful tragedies that have occurred as a result of a thoughtless approach.

Marilyn Barker, Health Visitor, Newcastle upon Tyne: Professor Adler, could you explain further your comment about the years of potential life lost in the USA? You said that the influenza and pneumonia deaths had risen, as well as those from cerebrovascular disease. Could not there be other explanations than this, for instance in an increasing incidence of cardiovascular disease?

Professor Adler: Of course you are correct in saying that there may be alternative reasons. I was suggesting that one of the alternatives was that hidden in the figures for pneumonia and influenza may be patients with opportunistic infections as a result of AIDS, and one could say the same about CNS disease as well.

Dr Crawford, Blood Transfusion Service, Glasgow: I wonder if I could induce Professor Adler to make some comments about the ethics of 'aggressive' epidemiological screening? This would involve taking,

patients that they were going to be screened — but at the same time making absolutely sure that, even if a positive was found, the clinician would never be told the result. Such a study would be purely for epidemiological purposes and might apply equally well to addicts or police officers, or to other groups in the community.

Professor Adler: I think that it depends on what the purpose of the test is and what you do with the result. I feel now that it is ethical to monitor disease in this way provided that it is done anonymously, that codes are used, and that no identifying data are available. Not to do this form of monitoring removes an important aspect of our ability to follow this epidemic in society. I think that this is ethical. However, I do not think that it is ethical to perform the anti-HTLV III test on a patient sitting in a bed simply because a surgeon wishes not to be 'at risk' from that patient. The ethics of these two examples, one of surveillance, the other clinical and individual, are different and I would accept that the answers are debatable.

Part IV

Management

13
Clinical Care

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Introduction

Previous chapters have dealt with aspects of the clinical spectrum of AIDS viral infection, especially the AIDS-related complex (ARC) and persistent generalized lymphadenopathy (PGL), and have introduced the subject of the associated opportunistic infections. In this chapter, I want to concentrate almost exclusively on Kaposi's sarcoma (KS). Although this is not a topic of direct interest to everyone, I will try to show why it has been important in the development of therapeutics for AIDS.

Experimental drugs have often been tested on KS patients, for valid reasons. KS is one of the only aspects of AIDS that is *visible* to other people, and is therefore associated with social reactions to the patients more than any other manifestation of the disease. Before the AIDS epidemic we saw few, if any, cases of KS in young, otherwise healthy people. In fact I finished my training programme in cancer medicine without having seen a single case of KS, and without having read much about it either. The same is true of many of the opportunistic infections for most specialists in infectious disease. Until recently, therefore, we had a substantial background in neither the malignancies nor the infections that we now consider routine in the management of patients with AIDS. This presents us with the problem that we have to learn what we should perhaps have known before we began seeing patients with AIDS. Everyone caring for people with the disease is, in a sense, a student of it.

Opportunistic infections

a number of different infectious diseases. In a patient with AIDS, opportunistic disease often follows reactivation of a latent infection that had become established previously in youth or adolescence. Such infections are not generally spread from person to person, even if the other person is also immunosuppressed. This means that, despite a lot of concern initially, we do not think that it is necessary to follow rigid infection control measures when looking after patients with AIDS. The infections are endogenous and not transmissible between patients, or between patients and healthy people. A possible exception to this is pulmonary tuberculosis, which is increasing in incidence both in the USA and Europe.

The infectious diseases span nearly all the major groups of pathogenic organisms, including viruses, bacteria and protozoa. Many of the infectious diseases that are associated with AIDS are very difficult to diagnose, especially when one is not on the alert for them. They are also often difficult diseases to treat. There are numerous problems. For example, patients with AIDS are frequently more susceptible to drug toxicities than are other patients, and, because of the persisting, underlying immunodeficiency, successful therapy is often followed by reinfection, either with the same organism, or with another opportunistic infection. The patient's condition is not characterized by a gradual, continuous decline, but by a stepwise decline, with one problem following another, even after previous problems have been dealt with successfully. A similar progression applies to AIDS-related malignancies which are, in many clinical respects, handled in similar ways to the opportunistic infectious diseases.

AIDS-related malignancies

We believe that KS patients are relatively immunocompetent compared with those with AIDS-related infections. As we have gained experience we have realized that, to be successful, we must begin therapy very early in the course of the disease, possibly at, or shortly after, seroconversion. This approach would suggest that, when a really effective therapy is finally discovered, populations must be screened on a large scale for the presence of HTLV III in order to identify suitable candidates for therapy.

In Chapter 11 Dr Jones has already drawn attention to the fact that lymphomas are beginning to appear in haemophiliacs. What we are seeing now is an increasing spectrum of AIDS-associated malignancies, including not only KS, but also Hodgkin's and non-Hodgkin's lymphomas (*Table 13.1*). I am convinced that, within the next 10–20 ...

Table 13.1 AIDS: association with cancers

Definite
Kaposi's sarcoma
Primary CNS lymphoma
Large-cell lymphoma
Probable
Hodgkin's disease
Squamous cell carcinomas (oral, anal, others)
Expected
Hepatocellular

nosuppression that is not severe enough to cause AIDS, and who survive longer, we will see an increase in the incidence of other cancers. The diseases that we see already which, in addition to KS, are part of the original CDC surveillance definition, are primary lymphomas of the central nervous system. Not included in the CDC definition of AIDS are diffuse, aggressive large-cell, non-Hodgkin's lymphomas. In our opinion Hodgkin's disease itself is part of the AIDS spectrum, when it occurs in somebody who is in a high-risk group and who is seropositive for HTLV III.

Clinical research

It has been stressed that the care of AIDS patients requires unique resources. In addition to the additional resources needed for the care of the patients themselves, AIDS clinical research has its own set of special requirements, which are difficult to obtain. The need for professional staff is obvious, but the scope of the work is often unknown. Clinical trials are frequently very complex, partly because we often do not know the end point of the study. Sometimes we do not even know how to decide whether or not a drug is working, so we have to adopt a 'shotgun' approach to the trials, monitoring many different aspects of the disease; this requires a large full-time medical and nursing staff, and numerous other staff to cope with the data and the associated laboratory investigations.

In our own clinical research programme at San Francisco General Hospital, we have tried to allocate specific problems with AIDS to individual principal investigators; this limits competition within groups studying patients, and simplifies the whole operation. I am mainly involved with the malignancies of AIDS, especially KS, whereas Dr W... the Co-Director of the Clinic, is responsible for the clinical

Abrams is responsible for the very comprehensive and important studies of the AIDS-related complex (ARC).

Kaposi's sarcoma

Kaposi's sarcoma is not a new disease, having been described first by Dr Moriz Kaposi, an Austrian dermatologist, in 1872. Kaposi described the tumour as multiple idiopathic haemorrhagic sarcomas, which we now recognize commonly in patients with AIDS. The tumour that was originally described is now called 'classical' or 'traditional' Kaposi's sarcoma and affects men in their seventies or eighties, following typically a very indolent disease course. It rarely requires therapy, and this is one reason why even oncologists seldom encounter cases. In 1960 it was realized that KS occurred in a very high incidence in black Africans; indeed, in some parts of Africa, KS was the most common malignancy in humans, but the disease was not related to AIDS. Retrospective studies show that before 1975 there was no evidence that immunodeficiency was involved, in spite of the fact that the same areas of Africa are now very seriously affected by AIDS.

The most important group of KS patients before AIDS became prevalent comprised people who developed the tumour following renal transplantation (*Table 13.2*). It is a curious but important observation, that people who are iatrogenically immunocompromised develop malignancies, the most common of which is KS. However, such tumours, which are often very aggressive, have often regressed completely following withdrawal of immunosuppressive medication; this contrasts with the situation in patients with AIDS, where regression rarely occurs. In renal transplant patients, if the prednisone and azothiaprim treatments were discontinued, and dialysis reinstituted, KS would often regress; this suggested KS as an indirect marker of immunocompetence in our AIDS patients. So if we tried therapy with, for example, an immune stimulator or an antiviral drug, the return of immunocompetence should be marked by a regression of KS. This hypothesis has formed the basis of much of our work, particularly in developing therapy for our patients. The KS tumour was among the first reported manifestations of AIDS, and the fact that it was normally so rare was one of the main reasons for our early recognition of this new disease. I am confident that we did not miss patients with AIDS before, because KS is such an unusual cancer that it cannot be ignored when it affects a young person.

Table 13.2 'Traditional' Kaposi's sarcoma: clinical features

Group	Disease features	Response to therapy
1. Elderly men, especially Jewish	Indolent, skin of legs, feet	Local radiation, good control
2. Black Africans	Variable: children – aggressive adults – indolent No underlying immune deficiency	Systematic chemotherapy → poor → excellent
3. Renal transplant recipients	Aggressive, visceral involvement	Controlled by stopping immunosuppressive

FEATURES OF KAPOSI'S SARCOMA

The distinguishing features of KS are numerous (*Table 13.3; Frontispiece*). AIDS-related KS, unlike that in elderly patients, is often a very aggressive disease with rapid dissemination. There is also frequent visceral involvement, even during the early stages of the disease, which again is not the case in non-AIDS-related KS. A major problem in designing treatments is that patients with AIDS-related KS always have a high incidence of associated opportunistic infections. This presents us with a major dilemma in our approach to the treatment because we would normally use aggressive chemotherapy to treat an aggressive tumour, such as AIDS-associated KS. Because such chemotherapy is obviously itself immunosuppressive, we have been forced to move quickly to experimental therapies. The other major problem with KS is that it marks the patients with AIDS and, given the fear that surrounds AIDS, these people often bear the brunt of the social stigma attached to the disease, even in their own communities.

Table 13.3 AIDS/KS: distinguishing characteristics

Extent of disease:
  Unlike 'traditional' KS, AIDS/KS is *rarely* limited to single anatomical region
Site of involvement:
  Head and neck primary sites common (including face, oral cavity)
Visceral involvement:
  Common. Rarely symptomatic except pulmonary KS which is *rapidly* fatal
Opportunistic infections:
  Almost uniform, usual cause of death
Social problems:

The earliest lesions of KS are subtle, and are similar to the naevi that all of us have somewhere on our bodies. They are brownish discolorations which are not pruritic and not painful in the early stages of the disease. In its advanced stages KS is characterized by rapid dissemination and severe cachexia leading to death six months after diagnosis. My first patient had three simultaneous opportunistic infections and KS in every organ of his body, with the exception of his brain, when he died; the autopsy revealed a lymphoma in the central nervous system that had not previously been suspected.

There are some important biological points to be made about KS. First, it is not a conventional cancer; it is a multicentred process, not a tumour with a primary site with metastases. In fact there has been much discussion about whether or not KS is a true malignancy. It has not been successfully transplanted into immunodeficient animal models, and I have found studies in which KS has been cultured in the laboratory unconvincing. However, whether KS is a true malignancy or not matters very little because it is an aggressive process that kills.

Second, this tumour often follows cutaneous lymphatic distributions, and the linearity of the lesions can be striking. They follow skin folds and, for example, we often see necklace-like lesions surrounding a patient's collar line. When KS follows cutaneous lymphatic drainage, what we see pathologically is a tumour that originates from the lymphatic endothelium. This has obvious clinical relevance, because one of the common problems that we see in KS patients is lymphoedema, especially of the lower extremities and of the face. This is a horrible problem for those people with advanced KS who develop a disfiguring lymphoedema of the face. Such patients are sometimes literally unrecognizable, even to friends and clinic staff who have known them very closely over the course of their disease.

Third, KS in the elderly usually affects the feet, whereas it is one of the tragedies of AIDS-related KS that it primarily affects the head and neck in most patients. Lesions of the conjunctiva can, in some cases, erode into the eye and are not uncommon. As the facial lesions become more advanced, the attendant psychosocial problems worsen for the person himself, who is daily reminded of the disease by looking in the mirror. He is further reminded of the progression of the disease as more and more lesions appear.

THE COURSE OF KAPOSI'S SARCOMA

With AIDS-related KS we are grappling with a new disease. We cannot rely on previous descriptions of this tumour in order to know what to do, or what to expect in the course of the illness. All KS

is bad, but there is a spectrum of disease ranging from relatively better to relatively worse. Patients that present with multiple lesions that have appeared rapidly have a predictable course — the disease will progress rapidly and, in our experience, they will die quickly. On the other hand, we see a smaller number of patients with a few lesions that have not progressed for six months or more; some of these patients are living in an apparently healthy state four or more years after AIDS has been diagnosed. So when we see a new patient it is very important to hold out what hope we can, without being false to our patients, that perhaps the course of the disease will be mild, and that they will live long enough for us to develop more effective therapies for treating the underlying disease process. It is important to realize that when we refer to the treatment of AIDS-associated malignancies or infections we mean palliative therapy for the symptoms of the underlying disease: the immunodeficiency caused by infection with the HTLV III retrovirus. As we become more sophisticated in our approach to AIDS-related diseases, we must recognize that no matter how successful are our therapies, we are not going to change the ultimate mortality, because that is dictated by the persisting immunodeficiency.

Approaches to the treatment of Kaposi's sarcoma

In the treatment of KS, we have to recognize that there are therapeutic problems, because it is a new disease with an unknown natural history (or at least a very variable natural history), and one which occurs in the setting of immunodeficiency. One of our immediate reactions to KS as oncologists was to use chemotherapy, and undoubtedly some mistakes were made, especially in the early use of combination chemotherapy, before we knew the disease process we were dealing with. Nevertheless some attempts have been made at developing therapy that has sometimes been successful, at least in slowing the progression of the tumour. For patients with this visible tumour, even a temporary regression of the disease is often enough to enable a patient to live a relatively normal life for a limited period. Our therapeutic approach is summarized in *Table 13.4*. At present we are using vinblastine one week and vincristine (or bleomycin) the next, in an alternating regimen. We think that this is more effective in causing regression, because it spares the immune system and causes fewer toxic effects than either drug used alone. Vinblastine is a useful drug because it has minimal toxicity and does not cause hair loss. This latter advantage is important for the patient who is concerned about the cosmetic and social problems associated with KS. In other cancer patients, hair loss is a relatively

Table 13.4 Guidelines for chemotherapy in Kaposi's sarcoma

Group	Recommendations
Minimal KS No infections or B-symptoms	Experimental immune modulators and/or antiviral drugs
	Vinblastine or other single-agent chemotherapy
	Expectant observation
Minimal KS History of infections and/or B-symptoms	Vinblastine or other single-agent chemotherapy
Advanced cutaneous KS or pulmonary KS	VP–16–213 or other single-agent chemotherapy
KS with severe neutropenia or thrombocytopenia	Vincristine or bleomycin

The patient with minimal KS is an ideal candidate for experimental therapy. He has a serious disease, and yet has a fairly intact immune system and a relatively good prognosis. Mild chemotherapy can be of benefit in more advanced stages of the disease and, increasingly, we recommend chemotherapy at an early stage. For patients with very advanced visceral disease, particularly in the lungs, we recommend more aggressive chemotherapy.

As was previously mentioned, KS in the elderly often occurs on the feet or lower extremities; it is also sometimes seen at these sites in patients with AIDS. Lesions on the feet can be painful and can cause considerable difficulty in walking. Although radiotherapy is not generally employed in the treatment of AIDS-related KS, it can be successful in treating those localized lesions that cause symptoms, especially those on the feet, or those of advanced disease in the oral cavity which can sometimes erode other tissue.

Although chemotherapy is a very necessary part of patient management, it is of little interest scientifically because it is not treating the underlying disease. A more rational approach might be to use immune stimulators, but there are problems with this approach. We first tried alpha interferon, a drug which appeared to have potential as an immune stimulator and which looked like the ideal AIDS drug. It has antiviral, antiproliferative and immune-stimulating activities in some

III. The antiproliferative activity was present, but this drug was no more successful in this respect than conventional chemotherapy. Alpha interferon had no detectable immune modulating activity.

With AIDS it is often possible to convince oneself that a drug is going to be effective, before a test is carried out. This raises political and social problems, because with AIDS we have a large group of informed people who know about the disease and realize that they are infected, and who are truly desperate for some hope. When we talk about the next untested drug as 'potentially interesting', or say 'We are very excited about testing this new drug', we should remember that even very bland statements can be interpreted by people with AIDS as a cause for great optimism. Such optimism is often unfounded because, as we have seen with alpha interferon, drugs that sound first-rate on paper do not necessarily work against AIDS. I am afraid that, even in our testing of antiviral drugs, we are often more optimistic ourselves than we should be. Although I consider it important not to be pessimistic with this group of patients, we must be very honest with them.

Recombinant interleukin-2 was another drug which seemed to be ideal for the treatment of AIDS, particularly because it is an essential requirement for growing T cells in the laboratory. Patients with AIDS are known to be deficient in their production of interleukin-2, and many of the normal cellular functions of lymphocytes from AIDS patients are restored when those cells are cultured with this drug. Dose-finding trials were therefore set up but the drug had no beneficial effects in AIDS patients. In the course of these trials we realized that the HTLV III virus was in the same cells that we were trying to stimulate. There seems to be a very real risk of stimulating virus-infected cells, perhaps when they are at a latent stage of infection, thus possibly stimulating more virus production in attempting to treat the underlying immunodeficiency. This will be a problem with any therapy that is simply immunostimulatory.

What can we do that may be more rational? We approach any other infectious disease by treating the causative organism or agent, and the same must be true with AIDS. We have not been very successful in developing antiviral drugs, although the situation is improving and we are beginning now to use drugs that are effective against other viral diseases. However, HTLV III has a unique enzyme, reverse transcriptase, which is probably not used anywhere in the body other than in infected cells. Thus for the first time with antiviral therapy we have a potential target, that might allow us to inhibit the production of the virus in the patient without damaging other body functions: in other words, we may be able to block the enzyme reverse transcriptase by

In discussing antiviral therapy, it is important to remember that HTLVIII infection is chronic and probably lifelong. We are therefore not considering curative drugs, but rather those which will stop the replication of the virus. There is no way that I can think of whereby we could rid anybody of the virus once they are infected, because the virus is integrated into the DNA of the cells of the host. Because infection with HTLV III is lifelong, therapy will probably also need to be lifelong: we therefore need a therapy which has neither subjective nor cumulative toxicity. Because the virus is in the central nervous system, the therapy needs to penetrate the blood–brain barrier. This is asking a lot of any potential drug, and I am not optimistic about finding such a magic agent (*Table 13.5*). However, there are already several drugs that are capable of inhibiting the virus in the laboratory and which have not yet reached the stage of clinical testing, including the agents suramin, HPA-23 and ribavirin. New potential antiviral compounds are being developed all the time. One of these, a Burroughs-Wellcome agent, azidothymidine (AZT509), is about to undergo clinical trials.

Table 13.5 AIDS/antiviral drugs

Pros	Unique virus enzyme (reverse transcriptase) may provide therapeutic 'target'
Cons	Need to treat early infection (asymptomatic seropositives?) Need for chronic (lifelong?) treatment Problem of CNS infection as reservoir Drug must itself be non-toxic to T-lymphocytes

Conclusions

Where do we stand in the treatment of AIDS at present? *Table 13.6* summarizes our approaches. The most important sector of the population in which we should be attempting to stop the AIDS epidemic is that of seronegative people in high-risk groups. We must consider what we should do to keep such people healthy. While we try to develop vaccines and improved methods of therapy, we must concentrate heavily on educational programmes — although we must admit that, for some groups, such programmes will be very difficult to implement. For seropositive asymptomatic people there are several possibilities, including anti-retroviral and co-factor therapies designed to interrupt the process by stopping exposure to infective diseases. We need to

Table 13.6 Clinical trials in AIDS virus subgroups

Group	Approach
Seronegative	Vaccine trials Education/prevention
Seropositive asymptomatic	Anti-retroviral Co-factor therapy Education
ARC	Anti-retroviral Co-factor therapy Education
AIDS	KS: antineoplastics, anti-retroviral + interleukin 2, bone marrow transplant Opportunistic infections: Anti-infectives

that a high percentage of them will develop fatal disease. The virus has already shown immunosuppressant properties in people with ARC, and the same approaches that we might consider appropriate for patients with established AIDS may prove necessary for this group also. I am not optimistic that anti-retroviral therapy alone will be very successful once the immunodeficiency is truly established, and certainly once the person has developed AIDS. In such cases, combinations of anti-retroviral drugs, together with immune stimulators, such as interleukin-2, or possibly even bone marrow transplantation might be employed. These are extreme measures for what we hope will become a progressively smaller group of patients, as other approaches become more successful.

I have tried in this chapter to summarize our approach to the therapy of the disease, using one aspect of AIDS, namely Kaposi's sarcoma, as a model on which to focus. I think that it is a valid model because, although KS patients have a fatal disease, they are less ill than patients with opportunistic infections and are therefore ideal candidates for experimental therapy that will, we hope, lead us to develop ways in which we may more effectively combat AIDS and its related disorders.

14

Nursing

GAYLING GEE

AIDS/Kaposi's Sarcoma Clinic, San Francisco General Hospital, California, USA

Introduction

Ward 86 of the San Francisco General Hospital is an out-patient medical clinic specializing in the care of AIDS and oncology patients. The clinic has evolved to provide a spectrum of services for its patients: we provide comprehensive medical evaluation, diagnosis, treatment and follow-up care to AIDS and ARC patients; we provide a comprehensive psychosocial support system; we participate very heavily in clinical research. In addition to all this, we provide comprehensive medical and psychosocial support services to people with cancer. The organization required to do all this did not spring up overnight. In four years of development we have made our share of mistakes. There have been times when we have wrung our hands or torn our hair because we knew that we were not doing it quite right! Overall, however, we have a great deal of experience to share with people, who perhaps can learn from it.

Professor Adler's talk provided a general outline of what is needed for AIDS medical care. This chapter is an elaboration of one model developed to provide that care.

Evolving the timetable

When we started in June 1981 there were just Dr Paul Volberding and myself doing one oncology clinic a week on a Wednesday morning. In 1981 we saw our very first Kaposi's sarcoma (KS) patient. His disease progressed rapidly and he died that autumn. His case was the first of what was then known as GRID or Gay Related Immune Deficiency, later changed, of course, to Acquired Immune Deficiency Syndrome. In January 1982 we saw three KS patients to whom I gave weekly

his first clinical trials of alpha interferon and we rapidly accrued ten more patients. In December 1982, Dr Constance Wofsy joined us in giving care to AIDS patients. She needed a clinic where her *Pneumocystis* pneumonia patients who had been discharged from the hospital could be followed in a primary care setting. She did not feel that her routine infectious disease (ID) clinic was the appropriate place to give long-term follow-up AIDS care. In December 1982 we were averaging 20–25 out-patients weekly. In January 1983 we moved to our present location on Ward 86.

Table 14.1 shows our clinic timetable in November 1985; it remains essentially the same today. We hold a general AIDS clinic on Monday morning and afternoon, with both ID and oncology physicians attending. On Tuesday morning, our AIDS clinic with an ARC focus is run by Dr Donald Abrams. We also have a small oncology clinic on that morning, but our larger, general oncology clinic takes place on Wednesday morning. Also on Wednesday, nurse practitioners on our staff continue to see AIDS patients for physicals required for the clinical trials in which we are involved. Thursday morning is our nurse screening clinic, an innovative programme that we have developed for screening patients for AIDS (run by nurses). Nurse practitioners are registered nurses who have had extra training in how to do physical assessments. We have developed process protocols for this clinic that are specific for AIDS screening. These protocols are diagnostic algorithms that allow the nurse practitioner to do the first-line assessment of new patients, most of whom have never had to seek comprehensive medical care before. For the most part, theirs has been a healthy population and, when they show symptoms that they feel are AIDS-related, they are not sure where to go. We find very often that their attendance at our screening clinic is the first occasion that they have been to see a medical care provider for a long time. If the history and physical examination are suggestive of AIDS, then the patient returns for a second AIDS clinic appointment, for physician consultation. The Thursday afternoon clinic is set aside for patients with opportunistic infections (OI). This AIDS/OI clinic is run by specialists in infectious diseases;

Table 14.1 Ward 86 Clinic Schedule, November 1985

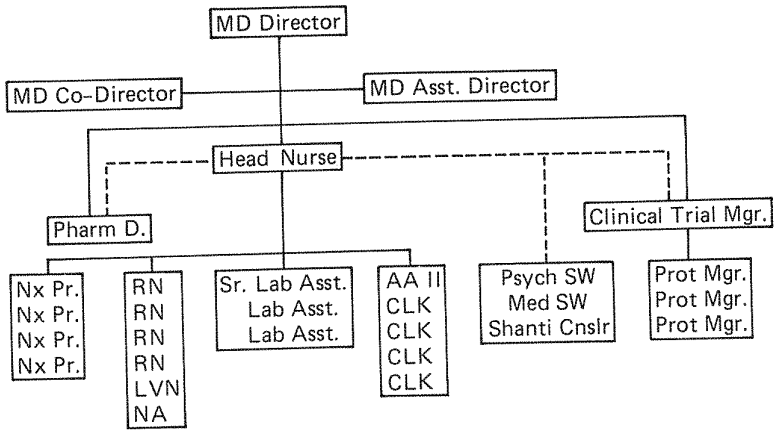
	Monday	Tuesday	Wednesday	Thursday	Friday
AM	AIDS	AIDS/ARC Oncology	Oncology AIDS/NX clinic	AIDS/NX screening	AIDS/KS
PM	AIDS				

the focus of this clinic is dealing with the opportunistic infections, if that is what constitutes the patient's primary problem. The Friday morning AIDS/KS clinic is run by our oncology staff; its primary focus is to manage KS or other AIDS/related malignancies. Above and beyond the clinics described above, throughout the week the nursing staff are administering treatment: some of the protocols call for daily intravenous medication; others call for weekly chemotherapy.

In 1983 we had 3500 AIDS-related encounters; in 1984 we had 7900 AIDS-related encounters; in 1985 we had 11600 AIDS-related encounters: our clinic census has expanded exponentially as the epidemic has grown.

The clinic staff

The clinic staff also has grown rapidly with the epidemic, from Dr Volberding and myself to the staff shown in *Figure 14.1*. The Figure relates simply to the out-patient clinic staff, that is, the staff of Ward 86. To accomodate the staff we have had to expand our administrative office space to include another floor of the building, Ward 84. This Ward now includes all the offices for attending physicians, staff physicians, data managers, epidemiologists, the Women and AIDS Research Programmes, as well as infectious diseases and oncology services. In addition to the medical staff there are four nurse practitioners, four registered nurses, one licensed vocational nurse and one nurses' aide. They are backed by a senior laboratory assistant and two phlebotomists trained to draw blood, to collect specimens and to bank them. There



is a clerical support staff of five, and an extremely good social support service that includes the psychiatric social worker, a medical social worker, a Shanti counsellor and other practical support volunteer staff of the Shanti project, who provide practical back-up; this includes the running of errands, the escorting of patients to other parts of the hospital, the collecting of prescriptions or the calling of cabs. We now have three research protocol managers and one clinical trials supervisor. We are due to expand that staff, with two more protocol managers, reflecting the amount of clinical research undertaken. Finally, our clinical pharmacist has a major commitment to clinical services for patients as well as to research implementation.

The physicians on the AIDS team not only provide out-patient care but also have consultative in-patient duties. They also participate in research and do their share of teaching. They have to take their share of general medical attending duties, as well as providing the supervision of at least two AIDS clinics during the week, in addition to their AIDS research work.

In order to expand the primary care capabilities of the clinic and appointment times to be given to the patients, we have developed nurse practitioner protocols that allow our nurses to provide that care. The nurse practitioners have worked in the AIDS clinics for over two years now and function at about the level of intern or possibly first-year resident. They work very closely with the physicians and must seek a physician's advice before any treatment decision is made; this use of practitioners and close teamwork does allow for more active participation of nurses than is usual in most clinics. The protocols include a very specific AIDS history form and physical examination check list. Nurses can order specimens for chemical investigation; they can order radiographs; they can refer patients to special clinics, for instance dermatological or oral surgery clinics, for a suspicious KS lesion. Nurse practitioners also participate directly in research by doing physical examinations and monitoring patient response to drug therapy.

Using process protocols, nurse practitioners can perform about 80–90% of the work-up required in the investigation of out-patients with *Pneumocystis carinii* pneumonia. Out-patient evaluation includes chest X-rays, pulmonary function tests, gallium scans and sputum induction. In-patient management would then include bronchoscopy and the giving of intravenous trimethoprim (sulphamethoxazole/trimethoprim) or pentamidine and, if the patient was severely compromised, admission to the intensive care unit. Some of the nurses on our clinic are certified to do skin-punch biopsies for Kaposi's sarcoma and, as previously mentioned, we are able to refer patients directly to oral surgery. As far as possible, we try to keep patients out of hospital; however, when

or dementia, or need for radiation, it is necessary to hospitalize them. Other illnesses that we see and that require careful nursing are the problems of gastrointestinal tract involvement that many cases of AIDS present at some stage. We have many problems with nutrition and hydration. We also have problems with skin care because of the profound weight loss in our patients: they are admitted in what looks like a catabolic state and we have to worry about bed sores, in addition to the problems of herpetic ulcers and candidiasis.

The nursing staff are responsible for clinic co-ordination—a difficult job when one considers the nature of AIDS-related disease and the need for some of our patients to treat us as emergency (or casualty) room as well as an out-patient clinic. Our case load is invariably heavy and, because each case is so complicated, there is an inevitable tendency to overrun the time allotted: it is difficult to take lunch breaks! Nurses are responsible for triaging many of the patient telephone calls to the clinic and for looking after drop-in patients or those who fail to attend on time but who have acute problems that require immediate attention. As already mentioned, nurses administer chemotherapy, drugs under investigation and blood products, and they also do their own share of patient referrals. When patients need hospitalization to our dedicated in-patient AIDS unit, the paperwork required is the nurses' responsibility. We always try to give a nurse report on each patient admitted because, of course, we know them so well already.

We are greatly helped by the role of our clinical pharmacist. She is available to all the staff for consultation on the many investigational drugs that are being used in the unit. She helps to prepare information, both for patients and for staff, about the various drugs on trial; this helps in the obtaining of informed consent from patients. The clinical pharmacist is also able to write prescriptions for most drugs except controlled narcotics, and therefore can provide repeat prescriptions for clinically stable patients without bothering other physician members of staff; these prescriptions are honoured by the hospital pharmacy. The clinical pharmacist also participates in research, especially pharmacokinetic studies.

In order to try to streamline the system for putting research protocols into operation, each study comes under the direct supervision of a clinical trials manager. The patient is given a study encounter sheet and then goes from station to station within the clinic: history, together with physical examination, is taken at one station, vital signs are recorded at another, laboratory tests are carried out at another, and treatment is given at yet another. The flow sheet facilitates the enormous amount of data gathering and protocol management that takes place within Ward 86.

Social work—the role of Shanti

A full-time psychiatric social worker has been assigned to us from the AIDS Health Project. Her function is primarily to perform crisis intervention, and to become involved in more in-depth psychological counselling. She is a licensed clinical social worker and her role is to counsel people who have greater emotional problems than just the normal grief and anxiety reactions to the diagnosis of AIDS or AIDs-related disease.

The medical social worker is the person primarily responsible for the concrete needs of people with AIDS or ARC; she helps to sort out their financial and health-regulatory problems (in San Francisco there are public health benefits for people diagnosed as having AIDS). The medical social worker also helps with such diverse needs as emergency food and housing, and with legal problems.

A third resource is the lay counsellor from the Shanti project: Shanti is a Sanskrit work meaning 'inner peace'. The project was started in Berkeley in order to help people with life-threatening illnesses; in 1983, AIDS patients were included in this project. With funding from the City of San Francisco as well as the voluntary sector, Shanti provides a great deal of the psychosocial support needed by patients and their families, and Ward 86 has been one of the beneficiaries of that support. Shanti counsellors provide community care as well as out-patient care. They perform the initial psychosocial assessment of individual patients, by introducing themselves to new patients and relaying the various forms of psychosocial support available. Their primary focus is to help people cope with the anxiety that accompanies any diagnosis of life-threatening illness.

Shanti also has developed to include many other services: (1) support groups have been established for individual patients as well as families and lovers, to help people to cope with death and dying, grief and bereavement; (2) they have developed a practical support staff who work in the community, doing such things as going to people's homes to do the shopping or laundry, or just sitting and being a friendly visitor, or transporting patients to clinics, to hospitals or to their homes; (3) a Shanti housing project provides low-income housing or subsidized housing to people with AIDS who have been displaced from their usual residences because of their primary diagnosis. All these functions are carried out in strict confidence.

With Shanti's help, many psychosocial needs are met and access to clinic and other community services are facilitated.

Clinic services

Chemotherapy and investigational drug administration are among the many procedures carried out in the clinic. In any one month, we start 400–500 i.v. treatments: some of these are rapid 5-minute infusions, whereas others may take 1–3 hours. In addition, we average about 12–15 out-patient blood transfusions per month. Services will be greatly relieved as treatment moves from intravenous administration to oral medication. Bone marrow biopsies, lumbar punctures and skin-punch biopsies are other procedures performed in clinic.

Community-based agencies and organizations

Figure 14.2 shows the elements of optimal AIDS care. Possibly what makes Ward 86 unique and successful, and why we are a good model for the delivery of AIDS care, is the encouragement given to multi-disciplinary input. This involves teamwork and team meetings, both among those concerned with hospital care and those concerned with community care. There is good liaison with community-based agencies. Services not located on the San Francisco General Hospital campus include the Shanti Project and AIDS Hospice Home Care programme. Within the city there is no hospital or designated unit for hospice beds: instead, there are hospice nurses who go out to take care of terminally

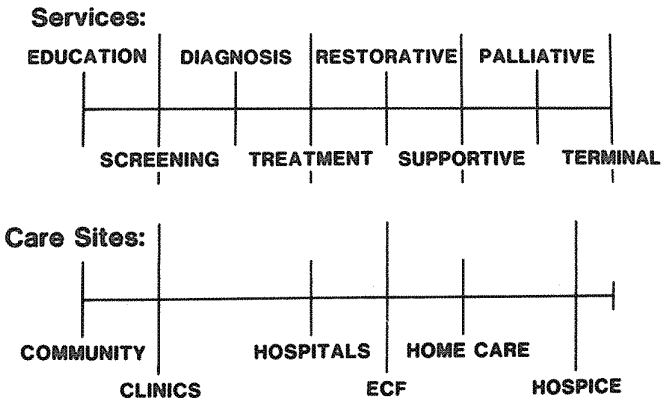


Figure 14.2 The spectrum of care in AIDS

ill patients in the home. At present, they are responsible for a case load of 50–55 AIDS home care patients.

The hospital also works closely with public health nurses in the five different health districts of San Francisco. Each district has a health centre, two of which are located in a catchment area with a high population of gay men. These centres run AIDS screening clinics, and clinics for AIDS-related disease. Like us, they have expanded their resources and (thank goodness!) they use the same forms that we have developed in our nurse screening clinics: this means that the databases are the same and that, when patients with AIDS are referred to us, the background information fits ours. Physicians and nurses in the peripheral city clinics have been to our Centre and have worked with out staff, so that there is a real consensus and continuity in terms of referral and clinical care.

The primary responsibility for professional and public education in San Francisco lies with the AIDS Foundation. This Foundation is very open to the needs of the community and it arranges talks to any community agency. On a personal note, I was asked to speak to the Chinatown YWCA Group recently: my parents heard about the talk and decided to come along — so there I was, standing in front of them, talking about safe sex! It is through the work of the AIDS Foundation that there has been a reduction in the rates of venereal disease and, indirectly, in the plateauing of the AIDS cases within the city.

Another organization — the People with AIDS Alliance — is, as the name suggests, made up of people with AIDS. Patients themselves have always objected to being called 'victims' of AIDS: I have heard many of them say 'I am not a victim, I am a person', and the AIDS Alliance reflects this feeling. We have found that patients do not want even to be called 'patients' any more: they are *people* with AIDS. We should not see AIDS as a disease entity and, indeed, no patient really should be thought of in this way. In the case of AIDS there is, of course, a great deal of sociopolitical background: it has been very important for people at risk to identify themselves as individuals, rather than as part of an amorphous group with a strange new disease. The people in this organization, and especially those chairing or directing it, have been our patients, and they have open access to me or to any other member of staff to talk about their concerns, their needs and their worries. They know that they can approach us to provide them with speakers, or with help if there is something that they need to complain about.

This, then, is the spectrum of care for AIDS: it starts in the community with education and, unfortunately, ends with terminal care. Along the spectrum is the need for screening and medical treatment, as well as palliative and supportive care. Extended hospital care is

provided within the San Francisco General Hospital on Ward 5A. Community care and a very extensive home care system are embodied in the voluntary organizations and in the professional AIDS Hospice Nursing programme and the Visiting Nurses' Association.

Dedicated hospital units

There are very great benefits in dedicated units. They have certainly allowed us to concentrate much of our nursing expertise in two areas—the out-patient and the in-patient clinics of the San Francisco General Hospital. Because of this concentration we have been able rapidly to identify the medical and emotional needs of patients. We know the patients who rely heavily on the hospital and we know how to react rapidly and appropriately. We can recognize people who are stable and can wait, and we can recognize emergencies which, of course, have to be dealt with straight away. Our constant exposure to AIDS care issues allows us up-to-date knowledge, which otherwise it would be difficult to keep abreast of in those units where only a few patients are seen. Education is helped by team meetings and team efforts and these, in their turn, allow for more efficient planning of patient management. Discharge planning begins on the day of admission, and I think in nursing that is a very important thing to remember. The dedicated unit means that counselling staff are right on site: if a nurse sees somebody in crisis, for instance somebody sitting in the clinic crying, then we do not have to wait for a social worker to come from another part of the hospital. Patients' needs are met more immediately in this way. In addition, patients can choose their counsellors much more easily: they are not reliant on one person. The philosophy of care in a dedicated unit therefore becomes much more comprehensive and co-ordinated. I think that we deliver a more sensitive and holistic type of care because of this.

San Francisco has a large gay community, and many of the men within this community are remote from their families and places of origin. This, too, is reflected in the system of care. The AIDS Clinic, the AIDS Unit, Shanti, AIDS Hospice, and Public Health Nursing, are all systems that have developed to provide support to individuals whose families are geographically distant. I look on it, in a way, as the development of an extended family — an idea that I like because it is more sensitive and more caring, not just a concrete model or a room or building, that we have built to deliver AIDS care. It is really a sense of family, which is also reflected in the staff themselves. Just like any other family, we have tremendous fights and feuds, but that is only because there is a very good 'family' feeling within our organization.

Infection control precautions

With regard to general infection control precautions, the Association for Practitioners of Infection Control in San Francisco has put together a package costing US$25, which is available from the AIDS Foundation. It contains a compilation of all kinds of infection control guidelines, including recommendations by the American Hospital Association and the University of California, and recommendations for the emergency services: for instance the policemen, firemen and ambulance drivers. It also includes infection control precautions for the non-professional staff: for instance, dieticians, or plumbing, housekeeping, buildings and grounds staff. Without guidance of this sort, silly things can happen: for instance, plumbers are sometimes afraid to come and change a water fixture if they know that they will be working in an AIDS Unit.

The information given in this particular packet has been complemented by further information, including the Safe Sex Guidelines and general information about AIDS, put out by the San Franciso AIDS Foundation (the address of which is given in Appendix A).

PRECAUTIONS IN CLINICS

We know that AIDS is caused by a transmissible infectious agent: I will refer to this as the AIDS virus in the context of this chapter. We know that this virus is transmitted by intimate sexual contact or by inoculation with blood or blood products. There is no evidence for casual contact spread, and, with one exception, no cases of the transmission of the AIDS virus among health care laboratory personnel. That one case involved a nurse in Britain who seroconverted after being inoculated with some blood.

As far as protective wear is concerned in the clinics, we use gloves for direct contact with body secretions including drawing blood or when emptying bedpans, urinals or changing dressings. We use gowns when our clothes themselves may become contaminated and, when necessary, these gowns are waterproof. We do not use gowns routinely in the clinics, although we do use them for mixing or giving chemotherapy medication. Within the laboratory personnel wear gloves and waterproof aprons when they are working with specimens; they also use goggles if they feel that there is going to be any splatter. Masks are used only when in direct sustained contact with an actively coughing patient. Masks are, of course, always available in the clinic but are very rarely used: it is also rare to see staff wearing them on the in-patient unit. It is, of course, appropriate in some cases for the patient to wear a mask: when this is suggested, patients should be treated with

privacy and not be expected to sit in waiting rooms or clinics with this additional 'label'. Protective goggles are available to all staff but are rarely needed. There is no need for full barrier nursing of AIDS patients: for instance bringing in the meal tray does not require any protection at all and, even when taking a patient's temperature or blood pressure, we do not glove in the clinic. Infection control with AIDS is much more a matter of common sense than a list of special procedures to follow.

IN-PATIENT PRECAUTIONS

With regard to in-patient infection control guidelines, most of the precautions that we use are consistent with hepatitis B practice. Strict isolation is not necessary: however, in our hospital, most of our patients are put into single rooms with their own bathroom; if sharing, the immunocompetence of both patients must be taken into account. Once again, masks are not needed unless people are actively coughing. If I, for instance, were giving a bed bath to a patient who was coughing and I was going to be there for 20 minutes or so, or if I was doing a procedure that would require me to be in the room for a long time and my face would be close to the patient's face, then I might consider a mask. I would always talk to the patient and tell them why I had made that particular decision. In many cases I forget and I have had many patients asking me why I am not wearing gloves, for instance, when I am starting their intravenous infusion.

Specimens taken from patients must all be labelled. Rather than labelling them as AIDS specimens we have special labels bearing the letters H/A for hepatitis/AIDS; these labels are green and are in two parts: one that can be stuck to the request form and one to go on the specimen. Very careful precautions are necessary when disposing of sharps, for instance needles or scalpel blades, or excreta, but really the most effective precaution of all is handwashing — scrupulous handwashing with ordinary soap and water before and after examining the patients. All equipment for disposal must be treated as infectious waste. All our examination rooms and patient care areas contain red biohazard bags so that all waste is regarded as very infectious. Needles and other sharps and syringes should be placed in puncture-proof containers preferably made of stout plastic. It is of crucial importance to ensure that needles are never resheathed. The only time that I have ever had a needle-stick injury was when I was resheathing: the needle bent a little, went through the cover and pricked my skin. I spent a couple of sleepless nights worrying about it. Never resheath needles:

Linen contaminated with body fluids (urine, stools or blood) should be double-bagged; other linen can be treated in the routine way. Contaminated environmental surfaces should be wiped down with dilute bleach solution (1 in 10 dilution), although alcohol is used primarily in our clinics to clean examination tables, desks and chairs.

Out-patient policies are also in accordance with guidelines for control of hepatitis B cross-infection; for instance, we minimize direct contact with other immunocompromised patients. We have had no problems at all in terms of the use of common waiting areas or bathroom facilities.

HEALTH AND SAFETY OF EMPLOYEES

On the question of employee health, I feel very strongly that health care personnel should not be excused on their own request from delivering care to AIDS patients. This implies two things for the hospital administration. First, they have to provide a very active and aggressive employee in-service training programme which gives information about AIDS, what it is, how it is caused, how it is transmitted, and what are the special needs of AIDS patients. Secondly, the employer must look at the work setting and must ensure that his institution provides a safe environment for the employee. If an employee is asked to work with AIDS blood specimens but is not provided with gloves, or is asked to work with patients with respiratory problems but is not provided with a mask, then there may be a legitimate cause for concern and the employee has a right to ask not to work with these particular people. I feel that, as long as these requirements are satisfied, there is no excuse whatsoever for employees opting out: employers should insist that AIDS patients deserve quality care just like that given to any other patient in the particular hospital facility.

Employees with AIDS-related disease require individual consideration. Their work should be tailored according to their responsibilities and the stage of their infection. Pregnant staff should not be given direct care responsibility: this is because of the possible transmission of cytomegalovirus infection and possible harm to the fetus. As far as cardiopulmonary resuscitation (CPR) is concerned, that has always been an issue since we realized that AIDS was infectious and, in most cases, a terminal illness. Ambu bags are readily available throughout our clinic, as is other emergency equipment. We think that direct mouth-to-mouth resuscitation should be avoided. Employees with documented AIDS should be restricted from doing mouth-to-mouth resuscitation or two-man CPR training. However, one-man CPR certification

Psychological problems

It should be very obvious to everyone that denial, anger, grief and grieving are almost always the initial feelings of people when they are given a diagnosis of AIDS. Very often their self image and feelings of guilt really come into play: 'how much in terms of my life-style am I responsible for getting this disease; what is it about my life-style and why do gay people seem to be getting AIDS?' All the doubts and all the 'old issues' that patients may have felt that they had resolved, come to the surface again. Family problems that may have been festering and perhaps had been pushed down, resurface because children are faced with the prospect of telling their parents that they have AIDS. They wonder what their parents' reaction will be, particularly if those parents have never been in sympathy with their children's life-style.

We see many problems of body image. There is a dramatic change, with AIDS, in how people look: I have seen people change from a strapping 190 lb to a very thin 130 lb with bones sticking out and no fat. It is particularly difficult to come to terms with this, because of the short time taken to go from a picture of health to someone looking as though they have just emerged from a concentration camp.

The patients that we have seen in the clinic are mostly in their twenties, thirties or early forties: thus, we are looking at people who are dealing with developmental tasks such as establishment of their careers and partner relationships, and solidification of their own sense of identity. All this becomes totally disrupted because of the diagnosis of AIDS. Their occupation becomes 'a patient in the AIDS clinic'. There are tremendous issues of control: 'how can I control my life; if I can't keep my job, how am I going to pay my bills; how am I going to pay my rent; where am I going to live; where am I going to buy food?'

These are examples of the issues that come up time and time again. In San Francisco, we have tried to meet many of the needs. I cannot pretend that we have answered them any better than anyone else, but I think that we have been able to co-ordinate care in a way that might not have been possible four years ago. At that time, I thought that the epidemic would not last long, that everything would soon be resolved and that I would soon be the only nurse (or perhaps one of two nurses) in a small oncology service again. However, I know now that the epidemic is not going to go away tomorrow. I think that, perhaps, in the United Kingdom you are beginning to realize that and are beginning to reverse the initial denial of 'it is not going to happen here'.

The need to be prepared

As the epidemic unfolds, so the disease evolves. Very few people who were diagnosed four years ago are left, although there are some who are active and healthy enough still to come to the clinic on their own; these people have minimal and seemingly stable disease. We still see people with multiple opportunistic infections and multiple lesions of Kaposi's sarcoma. The neurological manifestations of AIDS are becoming a more frequent finding. The message is really that staff and programmes for health should be identified *now* rather than later, while people wait for their first patient with AIDS to be admitted. This means that hospitals where an AIDS patient has not yet been seen should start planning now to include crucial staff education. If this happens with firm administrative support, the first patient to be admitted will be treated sensitively and well.

I would also like to emphasize the very important role that conferences such as this have in establishing contacts between people in the multi-disciplinary team. We can all, in our countries, probably define and identify agencies like those that serve the people of San Francisco. The more communication there is in identifying these agencies and strengthening them, the easier it is to cope with the disease.

CONFIDENTIALITY

A word about confidentiality. Despite the fact that we are all involved in education, and most of us from the clinic go out to talk to various groups, confidentiality remains the golden rule. In our clinic, despite the fact that hundreds of media people have come through, we have managed to do a very good job of protecting confidentiality, and our reputation in the community (as not giving out lists of names or details to anybody who comes through the clinic, and as identifying very carefully people who want to visit us) remains good. We are trusted by our community and, in particular, by the gay community. I think that as we go to the next group of people, the intravenous drug abusers, that this confidentiality — this sense that people can trust the clinic — will serve us well.

Conclusions — the difficulties and the rewards

Finally, I want to draw attention to what should be done for staff, and what you can do for yourself, to avoid burn-out. Administratively

want staff members who want to be on an AIDS clinic or an AIDS in-patient unit. I think that it is wrong, despite what I have said before about opting out, to work off a list and randomly to assign somebody to work on such a specialist unit. In San Francisco we have had no problems at all in recruiting nurses for either the in-patient or the out-patient unit. Nobody is paid hazard pay because we do not consider that to be necessary, but we do recognize the stress and difficulty in working with a disease that has a lot of hysteria surrounding it and many issues concerning infection control, death and dying. Everybody on the staff knows that they are supported, that my door and many other doors are always open, and that people can come in and talk to me about whatever is bothering them at any time. The last three years have enabled me to separate an administrative issue and an emotional issue very quickly, and if the emotional issue overlaps into an administrative issue I always let the emotional issue out first and *then* (if ever) can deal with the administrative issue. I also let newcomers know that there is a 6-month 'breaking-in' period: I tell them that, no matter how prepared they feel that they may be, no-one can really be fully prepared for the enormity and impact of working daily with dying AIDS patients.

Nevertheless, I think that working with AIDS patients has probably been the most professionally (and personally) rewarding job that I have ever done. I have found out, with the patients that I have worked with, that I get as much as I give. As we think about our early, groundbreaking involvement with AIDS, we often compare it to making a film or writing a book. We think that we have written several very moving and meaningful chapters in the past four years and I hope that, as you in the United Kingdom begin to write your book, it will have as many good chapters as we have been able to identify.

15
Fourth Question Session

Dr David Miller (St Mary's Hospital, London): Is it not confusing for the patients to have so many people caring for them on so many different levels? How do you cope with that and yet maintain the kind of quality control that you regard as very important in the counselling services?

Gayling Gee: Although we provide all these services, patients rapidly identify with someone with whom they feel comfortable. That person can be a nurse, a social worker or a physician. Of course, we occasionally step on each other's toes. But the fact that we encourage a lot of communication among the staff is the important point. We discuss cases all the time in confidence between ourselves. We can respond to problems either individually or as a team.

Quality control is an ongoing problem, because we have expanded so rapidly. I think that my being there at the clinic, and working closely with the physicians and nurses, watching for things that I think are issues, helps all those who work at the clinic to have a personal and not just a professional commitment. Our staff is perhaps 60% gay and 40% straight, and we certainly have a lot of feedback about their feelings on good and bad care. That is really one of the advantages of having a voluntary staff.

Dr Volberding: One of the problems we have had with the size of the clinic and how fast we have grown is that quality control must be addressed repeatedly; it is not something that you can settle once and for all. One of the things we have tried to do is to develop job descriptions that are concrete enough to eliminate overlap as much as possible.

Dr Pattman (Newcastle upon Tyne): In a recent paper from the Communicable Diseases Surveillance Centre, somebody who was labelled as a 'good Samaritan' nursed a neighbour, who subsequently died of AIDS. This lady has developed HTLV III infection. The only known risk factor was eczema on her hands. In view of this, would you as a nurse take any special precautions in attending to patients with AIDS or HTLV III, if you had eczema?

stand by the infection control guidelines which have been drawn up. If there was seroconversion, it might well have been because the neighbour did not wear gloves or take proper hygiene precautions.

Professor Michael Adler (Middlesex Hospital Medical School): The questioner quoted a fairly unusual case, the epidemiology of which is uncertain and very unusual. I suggest that everyone should read the *New England Journal of Medicine* for the week beginning 2 February 1986, which reports an extremely good study of the risk of acquiring HTLV III by casual contact, which is nil.

Delegate from Dartford: I was impressed by Gayling's talk on the control of infection and by her enthusiasm for her living patients. I wonder if she would like to say how the dead are managed. For example, are post mortems allowed? Is cleaning of the body permitted? How is the body disposed of — by cremation or burial?

Gayling Gee: The CDC has issued control guidelines for morticians. In general they are the same as for any other infectious disease, such as hepatitis B.

Dr Volberding: There has been a lot of concern among pathologists about performing autopsies on AIDS patients. There is a need to design facilities that really ensure protection for the pathologists.

Unnamed Delegate: What do you do about patients as they approach critical events in the development of their disease, for example when the patients require mechanical ventilation or admission to an intensive care unit?

Dr Volberding: We have never had a policy against ventilation, or against intensive care unit admission, for any patient. However, we have found that more and more patients are declining mechanical ventilation, once they understand the issues about their chances of survival. This has meant that, although the number of in-patients in our hospital has increased, our use of the intensive care unit is almost nil; this is not at all what we expected.

Dr Pinching (St Mary's Hospital Medical School): The first point I would like to make is that clearly you did not develop this extensive staffing overnight; I know that you worked very hard to obtain it. The key issue seems to be to have enough staff available to avoid 'burn-out'. What do you think is an appropriate strategy for ensuring adequate staffing through the medico-political process? My second point is that this disease is now emerging as a much bigger problem, in Africa and certain other countries with limited resources, than any of us are yet facing in North America or Europe. How would you adapt your experience to places without either medical or economic resources? How are we going to adapt your very good model to situations that are clearly very different from your own? I know there is no easy answer, but what are the key issues you would pick out to tell the leaders in those countries?

Dr Volberding: There are no easy answers. I think that how you ensure adequate staffing depends totally on your own local situation. For us it was relatively easy because the problem in San Francisco was relatively simple. The fact that we have only one university medical school in the city and a gay community which was, until recently, the only group at risk for AIDS, and was so open and well organized even before AIDS, made our job comparatively easy. The situation was much more complex in other places, for example New York City. In addition, the gay community's relationship to the city government in San Francisco, and the political power that this community wields there, were very effective in requesting and obtaining support for the required staffing. Our situation is probably unique, and it is not going to be as easy in most other cities, even in the United States.

Concerning the export of our model to other situations, you will appreciate that it is difficult enough to export our model to other hospitals in the United States, let alone to the Third World. This is an area of real concern. We get so self-centred about our own local problems, that it is important for us to hear about Africa, and the problems with AIDS that face the rest of the world. The most important component of our programme, as Gayling said, is its multidisciplinary nature, and this aspect should be applicable everywhere. Programmes everywhere will benefit if a team approach can be developed, both to prevent burn-out and to get other opinions on difficult cases. That is easy to say, but I doubt if such thoughts mean much in Africa, where people are lucky to have a drug, let alone a doctor.

Gayling Gee: One way to help is to encourage the formation of AIDS task forces, both within hospitals and within communities. Such task forces might be a good way of really determining what the local needs are, and then finding the easiest ways of meeting those needs.

Part V
Counselling

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Counselling (1)

JOHN GREEN

St Mary's Hospital, London, UK

Introduction

This chapter, which describes the counselling of those who are HTLV III seropositive, and those in high-risk groups, has three main parts. First, I explain how we, at St Mary's Hospital, deal with our patients in high-risk groups, and I concentrate particularly on the giving of information. David Miller's chapter on AIDS patients (Chapter 17) discusses the reactions, not only of AIDS patients, but also of seropositive patients, so that our chapters overlap and should be read as a whole, in order to get the full flavour of our work. Secondly, I consider the high-risk groups and what we must do to help them. Finally, there is a brief overview of the whole issue of health education and what must be achieved in order to stop the spread of the HTLV III virus.

TESTING

Before discussing counselling, however, I must mention antibody testing. My view is that any testing should be for the benefit of the *patient*. There is a case for encouraging some people to be tested, for instance those women in high-risk groups who are pregnant, or who wish to become pregnant. It is also my view that, once patients have heard all the issues relating to testing, it is ultimately *their* decision whether they should be tested or not — and that includes the example above. Testing should always be the patient's choice, and should always be for the patient's benefit. Furthermore, I believe that testing should also be done on the basis of *fully informed* consent: patients must know the implications of the test, they must know what it means, and they must be informed before they agree to it.

Where tests are of little value

There are two purposes for which I think that testing should not be used as it is of little value in those situations. First, testing should not be done simply to protect clinical staff. There have been no cases of AIDS among hospital staff *as a result of their duties*. Similarly, there have been no cases of HTLV III infection contracted by hospital staff in the course of their duties, except for needle-stick injuries, where people have inadvertently microinoculated themselves with infected blood. Even here, there has been only one case of confirmed HTLV III transmission, with a further two 'possibles'. This must be contrasted with at least 650 known needle-stick injuries in which absolutely no ill effects have resulted — and we can be fairly confident that there have probably been hundreds, or even thousands, of unreported needle-stick injuries as well. The HTLV III virus is really not very infectious: we know, for instance, that it is much less infectious than the hepatitis B virus, because there have been a number of cases in which needle-stick injuries occurred involving blood from patients who were infected with both hepatitis B and HTLV III. In those cases only hepatitis B was passed on.

In terms of the safety of clinical staff, the answer lies not in HTLV III testing but in the improvement of all clinical procedures and in the assumption that all patients are a potential source of infection. In our clinic at St Mary's we see patients aged from 17 to 70 years, both men and women; it is hard to believe that many of them are in high-risk groups. In fact, many of them do not realize that they *are* in high-risk groups — for instance, the female sexual partners of bisexual men may not know what their husbands are doing in the evening. We cannot rely on the test to protect health staff, nor should we aim to do so.

There are two areas in which safety measures could be improved immediately: it is vital that dentists should wear gloves, masks and eye protection, not to protect themselves from HTLV III infection alone, but also to protect themselves against other blood-borne infections; in addition, anyone who takes blood should wear gloves.

The second purpose for which the test is probably of little or no use is source isolation: i.e. by testing people, we cannot actually prevent the spread of the HTLV III virus. Few people in high-risk groups will come forward for testing, even if encouraged to do so. This is known from the experience of other countries, where only a tiny fraction have come forward. It has repeatedly been suggested that the situation would be different in a small town, and that if everyone in that town were tested, then they could be kept free from infection as they are confined to such a small geographical area. In my opinion, this would work only

if we surrounded it with barbed wire and cut all road and rail links into the town. However, as most people, including those in high-risk groups, occasionally travel outside their home town, this approach is unlikely to prove successful. AIDS is spreading nationally and will continue to do so. It cannot be handled on the 'potato patch' concept of ignoring everything except the immediate environment. The same advice should be offered to everyone, whether they are antibody positive or not, and whether they have or have not been tested: the same advice that will keep them well and that will prevent them from passing on the virus if they are seropositive, will prevent them from catching it if they are seronegative and, at the same time, will prevent them catching other sexually transmitted diseases.

It has been suggested to me that it is easier to counsel someone who knows their antibody status. While this is probably true, lack of that knowledge does not prevent any difficulties from being overcome. With time and care, exactly the same results are achieved, whether the patient knows his antibody status or not. We cannot adjust our methods to suit ourselves — we *must* put the patient first.

Patient counselling

PRECOUNSELLING

What happens when someone comes to our clinic at St Mary's Hospital? First, anyone who asks for the test will be precounselled; that is absolutely essential. At present only about 20–25 people a week are asking us for the test: this is partly because, in London, people are very sophisticated about the test and understand the issues. Some are in very low-risk groups, for example those women who think that they might possibly have slept with a bisexual man sometime in the past. When people have heard the issues about this test discussed, probably only about half will go on to be tested. The situation was rather different just after testing was introduced, when there was a sudden rush of people to be tested. Because we do not believe that the test can be used simply as a basis for counselling, we consider it necessary to counsel *all* those people coming to clinics who are in high-risk groups — they must all be reached, regardless of whether they want to be tested or not. In doing this our aim is to maintain a friendly, personal and caring approach. To get people to accept change — major change — in their lives, they have to believe that we are interested in them personally and that our interests are in their well-being, and we must back up any advice with reasons for that advice. It is no use

their whole sex lives: if we hope to persuade people not to have anal intercourse, we must explain why we are making those suggestions.

There are two specific issues which it is vital to convey to patients at the precounselling stage. First, we need to explain what the test actually means — many people believe that this is a test for AIDS. *It is not a test for AIDS: it is a test for the antibody*. In other words, it is a test to see whether someone has been infected with the HTLV III/LAV virus. Secondly, it must be made clear that anyone who knows themselves to be seropositive will find it almost impossible to obtain life insurance. Life insurance companies stipulate that an applicant must disclose anything which is material to getting life insurance: this means that such applicants must tell them if they are antibody positive; if they do not, and the company finds out, the policy will be null and void. Because of this, anything that is linked to life insurance is similarly affected — endowment mortgages for example. Getting a job can also be difficult, if it involves filling in a health questionnaire; those who, on being asked if they know of any health problem, write 'I am HTLV III positive' on their forms, are unlikely to be successful candidates. In addition, there are personal consequences. In my experience, most people who are tested are delighted to be told that they are sero-negative, but most people who are told that they are seropositive are far from happy: they often become depressed and anxious and they need a lot of time and care to help them to adjust. The patient must be told: 'It would be very nice if you were negative, but have you thought through the implications for you if you turn out to be positive?' In other words, we *must* make them think about the consequences of testing.

COUNSELLING — AFTER THE TEST

We do not merely precounsel, we also counsel people *regardless* of whether they have been subsequently tested or not. Regardless of the outcome of the test, the same rules apply. However, I will describe here the counselling of those people who turn out to be seropositive.

They are there in front of us; they are very upset about their test result; they are very anxious and worried, and they are going to have a battery of questions for us. Of course they must be given time to ventilate their feelings about being seropositive, but then there is some information which we must impart to them. First, we must help them to understand that being seropositive is *not* the same as having AIDS — we *must* get that point across. Although about 10% of infected gay

situation will be in the future. In the longer term, more may get AIDS. On the other hand, those who were infected early on may have had more co-factors and hence their risk of AIDS may have been higher. Nevertheless, we can tell patients that, according to our current knowledge, only a small minority of infected people will subsequently develop AIDS. However, even though they are well, *they are still infectious*. This is something that people do not understand at all well but it is a vitally important point that we must get across to them. (Incidentally, counsellors tend to have their own 'pet' ways of handling this particular problem: they usually explain it using an analogy, such as a typhoid carrier, or a hepatitis B carrier. However, I personally feel that such analogies should be avoided because it is very time-consuming to explain the transmission of, for example, hepatitis B, and at the end of a conversation when employing this analogy, a patient may be very unsure about what they are infected with — hepatitis B or HTLV III!) It is crucially important to explain that there are things that patients can do to keep themselves well: in particular, they must avoid getting other sexually transmitted diseases because we believe that these diseases will push someone who is HTLV III-positive into a worse state of health.

Another issue is that of live vaccines. Vaccines are of two types — live and killed. We do not think that killed vaccines present any problem. However, live vaccines may present two problems: first, many people who are seropositive will be immunocompromised to some extent, even though they may not be symptomatic, and there is a risk that the vaccine, which would cause no problem in someone with an intact immune system, may cause problems in someone who is immunocompromised. The second point is that the antigenic challenge from a live replicating virus is probably much stronger than that from a killed vaccine and therefore is a potential co-factor for the development of AIDS, although it remains a theoretical risk for which we have no clear experimental support at present. The live vaccine problem is a real one for people who have to travel abroad as part of their work. Patients who think that they may be infected should tell whoever is giving them a vaccination that they should have *killed vaccines only*, if at all possible.

It is important that people who may be infected should take care of themselves: they should have plenty of rest; they should take plenty of exercise; they should eat well. There is no special AIDS diet: if there were, I would have written a book about it and made a fortune in America as such a book would combine the two best-selling factors — diets and AIDS. Sensible eating is, as always, the rule. Patients need not live exclusively on brown rice and nuts, but should not live entirely

as possible: although a little stress is good for us, and we should not advise our patients to wrap themselves in cotton wool, nevertheless we must convey to them that most people can reduce *some* of their stress. They should also cut down on recreational drug use, particularly nitrites or 'poppers'. While we are not sure which of these pieces of advice — exercise, rest, good diet, stress reduction — are important in HTLV III infection, they all allow patients to do something to help themselves, thus giving them a feeling of being in control; in addition, we believe that any or all of these factors *may* be important.

The next vital issue is that of telling patients that they can actually pass this virus on to other people. The only way in which this can be tackled is to explain about the transmission of the virus directly to the patient (which means that the counsellor also must understand it in order to give the patients a convincing explanation). A mere list of 'dos and don'ts' is pointless because if patients do not understand the principles, then they will not know how to act in an unfamiliar situation. If we are asking a man to change his entire sex life, we must have some valid reasons for our advice.

With regard to the transmission of HTLV III, we know of three methods by which this is done. First, we know that the virus is infectious in semen: we know from Australia, where women were found to be infected from artificial insemination by donor, that semen alone is sufficient for transmission. Second, we know that the virus is transmissible in blood: it is transmitted in transfusions, in needle-stick injuries and in blood products (or at least, it has been in the past). The third method of transmission also involves blood: the virus is passed in contaminated needles and syringes between intravenous drug abusers.

At this stage it should be stressed that there are no known cases of transmission from someone who is bleeding, to another person. We do not know of any cases of someone cutting themselves in the street and then infecting other people. Provided that one's own skin is intact, I do not think that there is any risk of being infected in this way. However, breast milk, even that from which cellular material has been removed, *is* infectious if the mother is seropositive. On the other hand, there are no known risks of transmission (and no known cases of transmission) from saliva: the virus is of low titre (i.e. it is extremely dilute) in saliva. Similarly, although the virus is present in urine, a small amount of virus in half a litre of urine does not appear to present a particular problem. In the same way, tears (which have caused panic among some opticians) are not hazardous. There is a great difference between being able to grow the virus in the laboratory, and it being infectious in real life.

What advice are we, at St Mary's, giving to people who come to our clinic, about safer sex? First, we are advising people to avoid unprotected anal intercourse: in fact, we are advising them to *avoid* anal intercourse altogether. For someone who cannot, or will not, give up anal intercourse, the use of condoms is a possibility. We know that it should prevent viral transmission, and also should prevent the acquisition of other sexually transmitted diseases — or should at least reduce it. The problem with condoms is that those designed for vaginal intercourse tear, break or slip off when used for anal intercourse. Female prostitutes having anal sex have reported a 50% failure rate on condoms designed for vaginal use. During anal intercourse, the anal sphincter goes into spasm and causes far more pulling and tearing than occurs during vaginal intercourse. We cannot, therefore, completely recommend condoms. However, there are some coming on to the market at the moment which are specifically designed for anal intercourse. They are difficult to obtain outside major cities and we do not know yet whether they are really safer. At the moment we are telling our patients that they are *not* safe — that is probably the only thing that you can do. However, if they are to be used, it should be with a lubricant. We believe that a spermicidal lubricant is best, such as those used with a contraceptive diaphragm or cap, because there is some evidence that the spermicide itself may inactivate the virus, although how much extra protection it will offer in real life is hard to establish.

Unprotected vaginal intercourse should be avoided. Do not forget that many men are bisexual. If people are going to continue to have casual vaginal intercourse, they must understand the risks: they must use a condom and the woman must use back-up contraceptive precautions, because the risks accompanying pregnancy are so great in this disease. We are advising people to avoid oral sex — at least until more is known: we know that the virus is present in semen but we do not know whether getting ejaculate into one's mouth can be infective. Such evidence as we have, would suggest not, but we cannot be certain as yet. Avoiding oral/anal sex — often called rimming — is also vital.

Safer sex is easier with fewer partners. Provided that people keep to totally safe sex, they can have as many partners as they like. However, the fewer partners, the easier it is to keep to safe sex. We must help our patients not to get into compromising situations: if they get drunk, for example, they are less likely to be able to put safe sex into practice. We know that mutual masturbation and body rubbing are perfectly safe activities, and that these can be engaged in without the risk of transmission. Nevertheless, when we discuss this with our patients it is vital to relate it to the real-life activities, i.e. how will they introduce the topic of safe sex with the people that they meet and have intercourse

with. How, for example, will they get the message across over the noise of a disco, or in a club. These considerations *must* be thought through, with each patient.

It is fairly straightforward to tell our patients not to give organs, blood, semen or breast milk, if they are in a high-risk group. Tattooing, ear piercing and acupuncture should be avoided. We advise patients to tell their doctors and dentists of the situation, so that they can monitor patients' health. Anyone who thinks that their doctor or dentist is not sympathetic, should change them — I personally have a list of other (sympathetic) doctors and dentists for anyone who does not have a good relationship with their medical adviser, and who does not feel that any information will remain totally confidential. Patients should not share blood-contaminated items, such as razors or toothbrushes, with other people: we have read nine sets of infection control guidelines and found that the single most consistent piece of advice was to avoid sharing a toothbrush. Looked at in this way, the toothbrush is clearly a major health risk of our time! I personally do not think that HTLV III can be caught from a toothbrush, but there *is* a theoretical risk, so the answer is to buy your own toothbrush. Patients should also know what to do if they bleed — they should stop the bleeding, mop up the blood with a paper towel, flush it down the lavatory and wash any surfaces down with diluted bleach (one part of bleach to ten parts of water). With clothing, if it is heavily contaminated with blood, it can be boil-washed or discarded, but just for the odd spot of blood or for clothes which are not contaminated in any way, a hot wash should be sufficient. Vital, too, is caution about whom patients should confide in — we have had many examples of people telling employers or other people about their HTLV III infection and being surprised at the appalling reaction that they get from them. We *must* discuss with the patients just whom they propose to tell, and we must ensure that they have thought it through before telling anyone else.

What is *not* a risk is everyday casual contact: there is *no* risk from the bathroom or lavatory; there is no risk from cups, plates, knives or forks. This is not an airborne virus, and kissing and cuddling are quite safe.

CONFIDENTIALITY

If we are to test people, we must guarantee confidentiality. The Sexually Transmitted Disease Regulations mean that Health Service employees must not pass on information to anyone else about a person infected with a sexually transmitted disease, except for the purpose of treatment or to prevent the spread of infection. This is not only

but is also a matter of common sense and a duty we owe to our patients. We, ourselves, are very careful about confidentiality, and I believe that local authorities have a similar duty to their clients.

The main risk groups

What are the implications for the main risk groups? First, this is a virus which incorporates itself into the chromosome of the host to produce a lasting infection. We believe that people may be infectious for life. Second, this is a highly variable virus. Different isolates of the virus vary by up to 10% (which is a lot for a virus), more even than for influenza which is, itself, a highly variable virus. It cannot be assumed, therefore, that just because two people are seropositive, that it is 'safe' for them to sleep together — they may be carrying different strains of the virus.

HOMOSEXUAL MEN

The first of the main risk groups to be considered is that of gay men. Numerous men in the population are homosexual, or have had homosexual experience at one time or another. Kinsey showed that, throughout their sexual careers, 5% of men were exclusively homosexual; 12% of men have been homosexual for at least 3 years (between the ages of 15 and 59); 17% of men have had at least one experience of orgasm with another man (this means physical contact, but not necessarily anal intercourse); so that, overall, 34% of men have had some homosexual experience. Many people start out their sexual careers as homosexuals but then change: others start as heterosexuals and move to being homosexual.

Kinsey said that people could not be separated into homosexuals, heterosexuals and bisexuals because there was a continuum and many people moved through this continuum during the course of their lives, from being exclusively heterosexual to being exclusively homosexual, but with many stages in between, and with many people having both hetero- and homosexual experiences. Relatively few gay men are — or were in 1978 in California — in close-coupled monogamous relationships, and this was one of the reasons why they were the first risk group to be struck by AIDS. Gay men tended to have more sexual partners than heterosexuals: for instance, Saghir and Robbins (1973) found that 94% of the homosexuals but only 21% of the heterosexuals sampled had had more than 15 partners during their lifetime; 75% of

30 partners. The preferred sexual behaviours of gay men at that time were high-transmission risk behaviours, particularly anal intercourse, which was practised by 80% of men in one survey. Those practices which we consider to be totally safe, such as mutual masturbation and body rubbing, were preferred much less.

In a study of gay men attending the STD clinic at St Mary's, of 158 homosexual men, 10% were, or had been, married at the time they were seen; 50% had a steady partner but not necessarily a stable monogamous relationship. Again we see the pattern of high-risk sexual activities being preferred. In the 6 months before interview, 10% had been monogamous; 70% had both regular and casual partners; and 13% of our sample had had sex with a woman, again showing the overlap between the heterosexual and homosexual populations. This group had a very high rate of sexually transmitted diseases, which is one of the reasons why gay men show a particularly high rate of development of AIDS: they have many co-factors.

To what extent is the behaviour of gay men changing in the United States? We cannot rely on data from other sexually transmitted diseases to indicate transformation. Evidence suggests that highly sexually active gay men in San Francisco in 1982 had 40 partners a year; today the rate is 10 partners a year. So men are cutting the number of their partners and the rectal gonorrhoea rates are falling. However, in the same period, the level of HTLV III infection in San Francisco has quadrupled. The numbers of *infected* partners that a gay man will meet today in San Francisco with ten partners a year, is exactly the same as he would have met in 1982 with 40 partners: it has not made any real difference at all; the issue of rectal gonorrhoea is a 'red herring'. We believe that the same thing is happening in the UK: it is not cutting the number of partners, but the adoption of safer sex that matters; we *must* get that across.

We believe that gay men have a very high level of knowledge about HTLV III and AIDS. The problem is not the lack of knowledge but the difficulty of putting safe sex into practice. A set of guidelines is not sufficient: support, help and practical advice are needed. That is why voluntary groups such as the Terrence Higgins Trust (*see* pages 223–231) and Body Positive are so important; that is why counselling is so important; and that is why I have doubts about the ability of a Government-sponsored information-only campaign to modify sexual behaviour by itself.

INTRAVENOUS DRUG ABUSERS

The second group is the intravenous drug abusers. They are causing

Scotland show that we are in for a major epidemic among intravenous drug abusers, up to 50% of some samples studied being anti-HTLV III positive. Intravenous drug abusers get the disease because they share syringes with other people — that is the only reason. Some work by Geraldine Mulleady and myself (Mulleady and Green, 1985) showed that 50% of i.v. drug abusers in London shared needles, and probably we would find that all i.v. drug abusers have shared them at one time or another. The answer is straightforward: we must make clean syringes and needles available (possibly on an exchange basis); we must make them available *easily*; we must make them available *now*. The difficulties that we have in putting those simple steps into practice are, first, that it is sometimes seen as conflicting with the aim of society to reduce intravenous drug abuse, although I do not accept the argument as valid, and second, that at the moment the main arm of treatment in drug-dependency clinics is through *oral* methadone. There is a conflict between, on the one hand, prescribing methadone and on the other, telling people to use clean syringes: however, we *must* overcome this difficulty; we *must* stop the spread of the infection, and we *must* get the clean syringes to the users and persuade them to stop sharing them.

HETEROSEXUALS

Will this virus spread to heterosexuals? I believe that it will: it will spread slowly, but it *will* spread.

First, as Dr Tony Pinching and Dr Jane Wadsworth have pointed out (personal communication), the spread of a sexually transmitted disease in the community is related to the number of people who are infected, multiplied by the number of sexual partners they have a year. Some arguments say that the disease will not spread to heterosexuals; I have no faith in them whatsoever. The first argument is the low rate of transmission from infected men to women, a rate usually given as 10%. However, these figures are from haemophiliacs, and I do not believe that we can generalize from haemophiliacs. Data from artificial insemination and from other small studies involving other groups of high-risk men would suggest that the true rate of male-to-female transmission may be 30–50% — very similar to the rate of male-to-male transmission.

Second, there is the apparently puzzling issue of the allegedly low rate of seropositivity among heterosexual men in New York, despite the fact that many New York prostitutes are seropositive, intravenous drug abusers. However, the answer may be simple: the main sexual

reason why they are not spreading the virus. I do not believe that the virus is different in Africa, where there is no doubt that it is being heterosexually transmitted. In this instance, the main factor was, initially, prostitution. There is also no doubt that so many people in Africa are now infected with this virus that it no longer matters whether prostitutes are used, or how many partners one has. The epidemic has raised itself above the level at which it needs to rely on such factors.

What will happen in the United Kingdom? I believe that the virus will spread to heterosexuals, but very slowly at first. If it rises above a certain level it may begin to accelerate, but there are no signs of that at the moment. I strongly believe that we need to teach any young man or woman who is going to engage in casual sex, or is merely going to have intercourse with someone they do not know very well, to use a condom. There should be a packet of condoms in every sexually active man's pocket and in every sexually active woman's handbag. Proper use should prevent HTLV III transmission and reduce the risk of gonorrhoea, syphilis, herpes and wart virus, which may be related to the upsurge of cervical cancer in our society.

Effective health education

I believe that we now need a strong health education campaign. However, advertisements in newspapers and on television alone are not going to suffice. People need personal contact: they need to discuss the issues involved with other people as well. To have a chance of success, any health education campaign must be backed up by appropriate counselling, whether that is supplied through hospitals or whether it is supplied through voluntary organizations. Money — a great deal of money — must be put into this campaign, and not simply for full-page advertisements in the papers.

Do not underestimate this disease, just because there are so few cases at the moment. As Dr Mortimer has already quoted 'You ain't seen nothin' yet'! If we are to stop the spread of this virus we must find money and we must find it *now*. Tomorrow may be too late.

References

MULLEADY, G. AND GREEN, J. (1985). Syringe sharing among London drug users. *Lancet*, **ii**, 1425.

SAGHIR, M.T. AND ROBBINS, E. (1973). *Male and Female Homosexuality*. Williams and Wilkins, Baltimore.

17
Counselling (2)

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Introduction

We all mark our lives by anniversaries*, but for those with a life-threatening illness, anniversaries have a particular poignancy. For this reason, and with Dr Pinching's consent, I would like to dedicate this chapter to those of our patients who did not survive to this anniversary, and to those who are looking forward to anniversaries next year. Without their generous discussion of their own experiences, the development of our understanding — individual and collective — would not be possible. In counselling, we must remember, primarily, to listen to our patients, for they are telling us the diagnosis.

What is AIDS counselling?

Counselling of seropositive patients and of those with AIDS is the process of *facilitating understanding*. This facilitation applies on several levels. First is the personal and emotional level, at which the patient has to come to terms with the horrifying idea that he has reached a point of no return, in that there is no return to full immune efficiency. It also involves managing the shocking realization of personal mortality and vulnerability, which many patients have not had to do to such an extent previously. In addition, patients have to understand their own reactions to all the nebulous feelings of fear, anger, frustration, euphoria — particularly in the presence of (often) selective and sensational media reports. Counselling, on this personal emotional level, also means facilitating understanding of what an individual can do about all these factors.

The second level is the social level, which involves the generation and encouragement of understanding in patients' loved ones, friends,

associates and colleagues. A crucial point is that it involves helping patients to understand the logic of those persons' fear and prejudice, and revolves around the issue of ignorance. We must bear in mind that there is no vaccine nor any cure for HTLV III disease at present, so the only viable way to halt the spread of this epidemic and the sometimes hysterical reactions to it, is by the motivation of behavioural change. We *must* educate, and in terms of facilitating social understanding we cannot afford merely to provide support for, or limit our scope to, those with AIDS or who are seropositive: we must also provide support, education and counselling for hospital staff, for those with affected people in their workplace, and for the general public who have people with anti-HTLV III in their community, and we must do this as soon as possible.

REASONS FOR REFERRAL

We started seeing people with HTLV III disease and AIDS in 1983, since when we have become very heavily committed clinically, educationally and in research. Our referrals have come from STD clinics nationwide, from general practitioners, community agencies such as the Terrence Higgins Trust, drug-dependency units and haemophilia centres. We also get numerous self-referrals, particularly since public testing became available. *Table 17.1* shows the various reasons for referral to our clinic, showing the types of referral pattern that were seen until the time of publicly available antibody testing. The Table underlines the point, that everyone in a patient group is acutely sensitive to media reports, because any account of research into this disease is, for them, a lifeline.

Table 17.1 Reasons for referral for counselling

Reason*	Percentage
AIDS diagnosis	30
HTLV III + PGL	30
HTLV III only	17
'Worried well'	18
Lover/family	5

Symptoms and psychological implications

Uncertainty is one of the most common themes (probably the most difficult) throughout our work. A major problem faced by all health staff is our inability to remove this uncertainty. People with HTLV III infection are uncertain about the incubation period: they want to know how long they may have to wait before they can be sure that they are not going to get AIDS. Similarly, many people are very well informed about the virus and about the antibody test: if we say to the worried well 'Your test result is negative; I hope you appreciate what this means?', they may say 'But I know that there is a false positive and a false negative rate in this test, so how can I trust what you are saying?' People who do have a firm clinical diagnosis are also uncertain about what is going to happen to them next — how their lives will be affected both in the short and the long term.

Shock is an important symptom, particularly in the context of counselling, because although most people know about HTLV III disease and may be prepared, intellectually, for the worst, there is a great difference between intellectual and emotional acceptance; this may result in emotional ventilation, anger, denial or avoidance. This is important because, when people are in a state of shock, they are no longer thinking clearly. For example, one of my patients was given several hours of supportive, educative counselling by a consultant who stressed repeatedly to him that he did not have AIDS: when I asked the patient 'What did the doctor say?', he looked me straight in the eyes and said 'She told me I've got AIDS'. That is what shock can do, and that is why our counselling takes place over many sessions.

Anxiety is fundamental; it is an interesting disorder because it can generate many misleading symptoms in the patient. When people are anxious, particularly for long periods, they develop somatic symptoms such as nausea, diarrhoea, trembling, sweating, pains or skin rashes — a symptom pattern that seems to fit the very symptoms that they most fear. *Table 17.2* gives a few reasons for anxiety. First, patients are very worried about the reactions of other people to their bad news. They are also worried about the risk that they present to other people, and

Table 17.2 Reasons for anxiety

Reactions of others
Risk to and from others
Prognosis/quality of life

that others present to them. I know one particularly nice person who, whenever he was invited out to dinner, always took his own cutlery, crockery and glassware in a plastic bag. Before he received counselling he would not let anyone else touch these, for fear of passing on infection, and rather than washing up his plates at his host's home, after the meal he would replace the dirty items in the bag, take them home and virtually sterilize them. He also had another plastic bag containing household bleach, disinfectant, air freshener and rags, and whenever he used someone else's lavatory he would scrub it until it was completely spotless. Needless to say, he was always invited back! This story illustrates how disruptive such fears can be; in a setting of ignorance, people set over-cautious standards for themselves. It so easily can be made different, with a little sensible health education. People are anxious too, of course, about their prognosis and how the infection is going to alter the quality of their lives. Indeed, it *does* alter it: we should be under no illusions that this test is like any other; it most certainly is not. The impression that I consistently receive from my patients is that having HTLV III disease has been a complete personal revolution which has turned their entire lives upside down. Everything — work, finance, standard of living, sex life — is affected. However, people are amazingly resourceful, and counselling those with AIDS or HTLV III disease does not necessarily involve unrelieved doom and gloom. The courage, determination and humour shown by some of our patients is often inspirational. It is interesting that when patients have come to terms with their diagnosis, their anxieties are often no longer about the possibility of dying, but about dying alone, abandoned or in pain. We have a responsibility to our patients to reassure them that we will *not* let them suffer, they will *not* have to endure pain; the evident relief shown by patients over this news indicates its importance to them.

Control is the sense that people have about the way that they can run their lives. Those who experience a loss of control feel that they have no ability to determine what is happening to them; it is all dependent on something else — in this case, the virus. We contribute to this feeling by our 'medicalization' of the patient: when he receives a positive diagnosis he is admitted to hospital for more tests and biopsies; he is visited by five or six different consulting teams; he is poked, prodded, questioned, and left in a daze to wonder why he is treated as a medical novelty rather than as a human being. We should not have to remind people that our patients are ordinary folk, with conventional fears and feelings. It takes so little to address them effectively. In many patients, personal control is undermined because the virus has

as always waking up with a cloud over her head, which would never go away. The absence of a cure contributes to this sense of lost control.

Depression is one of the major issues in counselling, for several reasons. The first is, again, the lack of any cure, which thus leads to a sense of powerlessness or helplessness. In addition, the limits that are placed on anyone with AIDS or with HTLV III infection, can contribute greatly to a sense of depression, seen usually as a withdrawal. People also get depressed about rejection and isolation, real or imagined. Many people have scenarios in their own minds of what this disease means, just as most patients have a stereotyped picture of what a person with AIDS looks like; they are so often wrong and must therefore be reminded of the realities, which may be far less painful than they imagine. Many people temporarily become suicidal, and counselling must involve recognizing crises associated with suicidal thinking. This is one of the best reasons for urging the creation of nationwide counselling services, particularly for people who are being told their viral status. We know of six cases of suicide in people who were informed that they were seropositive; they were handled without sensitivity and were given no context in which to manage this information. It is also vitally important that every hospital and every district should have a formulated policy for admitting suicidal seropositive patients to hospital, to avoid future tragedies such as these.

Obsessional states involve some of the interesting psychological issues listed in *Table 17.3*. Most of the people that we see are obsessional during the course of their infection, in a way analogous to that engendered by the fear of breast cancer in women. In the context of HTLV III infection, one example known to me is that of a woman who feared that she might have had an affair with a bisexual man and therefore had been exposed to HTLV III infection. Whenever this thought occurred to her, as it did frequently, she would strip naked and search her body closely for signs of infection. Despite her having had two

Table 17.3 Obsessional states seen in counselling

Preoccupation with images/thoughts of illness
Continual fear of symptom appearance
Continual body checking
Social and sexual avoidance
Not necessarily with depression

negative antibody test results, it has taken months for us to be able to persuade her that she is not at risk: this is known as an obsessive–compulsive disorder and is very common. These disorders are sometimes — but not always — associated with depression, when they may be easier to treat.

Self-esteem. Most of our work is done in concert with the London community support agencies, particularly the Terrence Higgins Trust and Body Positive (*see* pages 223–231), whose representatives come to our workshops and help us to educate people about HTLV III disease. Without their assistance we could not function as we do in community patient management. At our training workshops I am struck by the number of patients who state that the issue of self-esteem has, for them, been the most prominent factor in coming to terms with their infection. Self-esteem is battered in a number of different ways. It is a cliché to think in terms of the 'social leper', but only because that is what most seropositives report feeling. People may start to blame themselves for the disease, become very self-recriminatory and — worse — may start to recriminate about their sexual orientation, which in turn can create intense distress, both personally and in relationships. Self-esteem can be undermined through rejection in the family, socially and in employment, and we have to work hard to ensure that this does not occur. Alterations in appearance (e.g. through facial Kaposi's sarcoma, and bodily wasting) are an important factor in adjustment to the new circumstances, particularly if a negative self-image results in continued social withdrawal and depressive decline. Beauty therapists may be helpful in advising patients, for example on how to disguise Kaposi's sarcoma lesions on their faces. This may not appear to be important, but it is very important indeed to the patients who then feel more acceptable and able to re-enter the community without fear of being persecuted or otherwise rejected. Such worries must be discussed with the patients, and ways of overcoming them can then be devised and encouraged.

Neurological disorders and the prospect of their increase in HTLV III infection are, to me, a most distressing aspect of this disease. Although it is too early to make concrete predictions, and it would be irresponsible to do so, clearly, where people undergo the sort of changes listed in *Table 17.4* — changes which are often irreversible — the impact on their lives and on those of their family and loved ones is profound. We must press for the establishment of community resources for dealing with this problem as soon as possible.

Table 17.4 Neurological effects of HTLV III infection

Personality changes
Memory disturbance
Poor concentration
Disorientation
Speech impairment
Visual impairment

Underlying themes

CONFUSION

With any of the psychosocial phenomena described above there are two consistent themes. The first is that of *confusion*, particularly in the short term — the period immediately after diagnosis or positive test results. Of course it is understandable that people become slightly disorientated when they have to come to terms with life-threatening situations, severe shocks or trauma. However, it is very dangerous, in that confusion and disorientation interfere with decision making at a time when very important personal decisions have to be made. Confusion demotivates patients (and can have the same effect on staff) and can undermine their confidence in themselves and in the staff, thus affecting the way in which people respond to health information. This is a most important issue, because health information is the only way in which we can stop viral spread at present.

INTER-REACTION

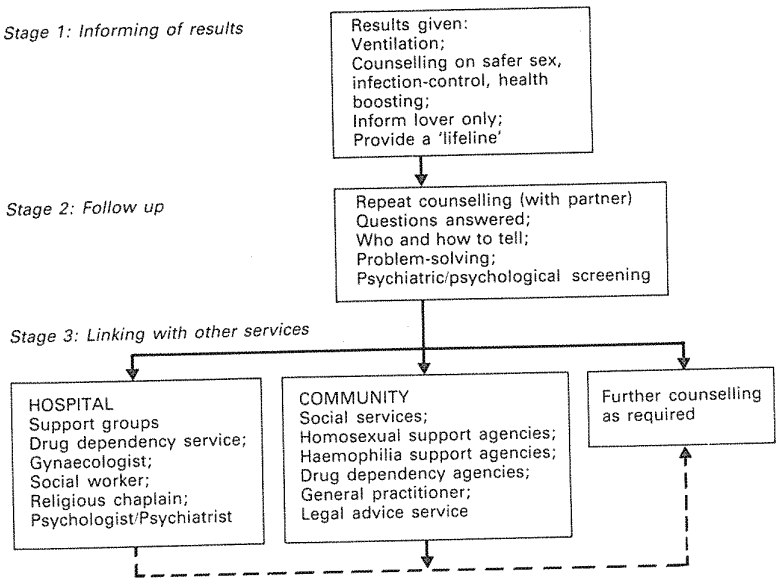
The second, equally important, theme that is consistent throughout the phenomena described, is the way in which the effects described change people's reactions to other people in their lives. We come, again, to the need to facilitate a social understanding of what one of my patients calls his 'predicament'. To examine them briefly, first, *anxiety* alters the way in which people react with each other. For the anxious person or patient it can result in clinging and over-dependence on individual staff or family members. On the other hand, it may create over-independence, so that they declare 'I'm going my own way; I don't need any extra medical or family help'. The threat posed by the virus can lead to hypochondria, which is understandable; people with HTLV III disease or AIDS also get other ailments, just like anyone else. We

person, and have coined the phrase 'pseudo-AIDS' to describe the phenomenon of people who are so worried about the possibility of infection that they generate symptoms of their anxiety which also happen to be associated with viral expression, such as nausea, weight loss, pains, rashes, lethargy and sweating, thus apparently confirming their own worst fears. This can become so overwhelming that such patients may have to be admitted to psychiatric hospital. *Fear* is a very conspicuous emotion in this setting and can stimulate a tremendous drive to find a personal cure. This may manifest itself as an often religious-like conversion to the ideas of a particular therapist, or to a particular technique. *Anger*, particularly displaced anger, is a real problem because it can alienate the people who are closest to the patient. These are often the people needed most by the patient, and include family, lovers, and members of staff. *Guilt* is quite common: some people say that they consider their diagnosis to be retribution of their past sins. Guilt can create the conceptual revolutions referred to earlier (*see* Self-esteem) and can interfere with the process of bereavement for lovers of those people with AIDS who are dying or who have recently died; this can make post-bereavement adjustment much harder. We therefore have to recognize that our intervention does not stop when a patient dies: counselling should be available for bereaved lovers and families after the patient has died. Grief gives rise to *depression*, which is seen in many ways, including loss of self-esteem, resulting in self-denigration and withdrawal from others. Where, in addition, there are neurological complications, the entire nature of the relationship changes fundamentally.

Thus all of these factors interfere with the way in which people relate to others. There are several lessons to be learned, but I will mention only two. First, counsellors of people with HTLV III infection and AIDS must recognize that all of these reactions are, to some extent, *normal*: they are normal human responses to overwhelming and threatening life events and severe trauma. These normal reactions may last hours, days, weeks, months or years. I have found it helpful to discuss these reactions with patients; to explain why they feel them the way they do. There is no fixed timetable for grief and we should therefore beware of a second important issue — *over-diagnosing* — for example by treating patients for depression at too early a stage. We must give them time and space to ventilate their feelings before we intervene with our appropriate health education. This, of course, places an enormous burden on others, and I would make a special plea for the lovers of gay people to be acknowledged as their spouses. Established loving gay relationships have all the virtues (and all the flaws) of other more conventional and heterosexual relationships: there is very little

Structure of counselling intervention

Figure 17.1 shows the initial structure of our intervention. We believe that it is important for people to be told their diagnosis in a *constructive* way: *not*, for example, 'Well, Mr Smith, I'm afraid it's AIDS: you have only two years to live', but something more like 'You do have AIDS and we must talk about what this means, but here are some of the things that you should know about this condition'. Put advances in treatment well to the fore and make constructive discussion about changes that are going to occur. The patient will have plenty of time later to come to terms with the full import of the diagnosis. We introduce a counsellor as soon as possible in the post-diagnostic process. Allow your patients to ventilate for a while when they meet you: they are going to be very upset and it is important not to try to bulldoze your way through conspicuous grief. We provide information in the course of constructive discussion and, crucially, we give patients a 'lifeline': this is a series of telephone numbers — ours, and those of the Terrence Higgins Trust, Body Positive, Gay Switchboard, the Samaritans, the Haemophilia Society etc. (*see* Appendix A). Many patients have reported that having a lifeline is the most important factor



in these early stages; they are immensely reassured to know that they can get further information or just talk about their situation when the need arises.

The second level of intervention, also shown in *Figure 17.1*, involves the follow-up and linking with other services. It is vital that people who are told that they have AIDS, or that they are seropositive, must also be told *not* to tell anyone else who is not aware of their attendance for test results. It is, of course, helpful if they can inform their lover (if they have one), but they should not tell their employer or their parents, for instance, until we have discussed how to do it and have prepared them for it; we do this during subsequent sessions. We set up liaison with medical and community staff; we talk about infection control, risk reduction, safer sex, health boosting and eating and sleeping well. We then start problem solving, sorting out what needs to be done, what changes to be made and how to cope with those changes. We also gently screen for psychiatric problems, bearing in mind the comments made above. As we follow up, we ask the lover to attend, or anyone else who feels that they need to know more about the problem, subject to the patient's consent. Repetition of essential information and behavioural recommendations is desirable, so that everyone has the same information about the situation and how best to manage it.

Conclusions

Counsellors do not have to be psychologists: frequently, it is better that they are not. Counsellors need not have had years of training, neither do they need a 'Diploma in Counselling'. What they *must* have is a clear idea of HTLV III disease and its expression; they *must* have a clear understanding of the life-styles — and of the influences on those life-styles — of their patient groups; they *must* be able to communicate with tact, because they will be dealing with many different people at different levels; they *must* have a sense of humour, because they will need it. If people have all these qualities, they will make good counsellors.

The need for all health districts to establish effective counselling resources is paramount. As the crisis of HTLV III unfolds, it is clear that all health districts will have some experience of seropositive patients and/or people with AIDS. If we are to avoid unnecessary patient suffering and ever-higher rates of casualties, we must accept that counselling of patients, staff and the public is the number one priority in managing this tragic disease.

Part VI
Final Session

Unfortunately due to a printing error the above heading has been omitted from page 175

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Panel Discussion

(Editor's note: The majority of the questions asked in this session were anonymous written questions addressed to specific members of the panel.)

Q: Could those working in the area of blood transfusion please indicate how many of those people to whom a letter has been sent informing them that their tested blood has shown a positive result, do not subsequently get in touch?

Dr Gunson: First of all, we do *not* send a letter to a donor to say that they have a positive result; that would be very inadvisable. Donors do not necessarily open their own letters, as we have found to our cost in other instances when we have written to donors on the subject of hepatitis. Instead, we send a very bland letter saying that certain properties have been found in the donor's blood that may be important to their health, and that we strongly advise the person concerned to come to discuss the situation with one of our senior medical staff. It is early days yet but, to my knowledge, of the 13 instances in the first three months of testing, in which this letter has had to be sent, all the donors have responded very rapidly. What will happen in the future we will have to see, but I must make the point that it is, of course, a voluntary service. No compulsion can be put upon a donor to respond, if he or she does not wish to: we can only *ask* donors to come for this advice and we cannot *instruct* them to do so.

Q: In a recent edition of the family doctor publication *Pulse*, discussing vaccination and immunization for travellers abroad, it was stated that the safety of human immunoglobulin was not yet proven. Should this preparation be given routinely to travellers while this uncertainty exists?

Dr Gunson: Intramuscular immunoglobulin has been given in many millions of doses over many years and there is no reported incident of either HTLV III infection or AIDS resulting from these injections. The World Health Organization has carried out a large retrospective study and concluded that no risk could be attributed to doses of intramuscular immunoglobulin and therefore that travellers who require this for pro-

tection against the considerable danger of contracting hepatitis and other diseases while travelling in certain countries, are still being advised to take the appropriate protection.

Another group of individuals who regularly have an injection of immunoglobulin is the 10–11% of mothers who are rhesus negative and have rhesus positive babies. The use of intramuscular anti-D immunoglobulin in this instance has decimated the incidence of haemolytic disease of the newborn. It would be a tragedy if unwarranted fears about having this immunoglobulin should bring this disease back into our society, and such persons can be reassured that the risk is not there.

Dr Jones: I have been asked two questions. The first relates to the heat treatment of factor VIII. Apparently the Department of Health and Social Security have said that they have no reason to believe that the heat treatment used in this country is not effective, and that they know of no cases here. I agree with that entirely — I know of no cases here: there have been no failures with either the Scottish or the Elstree material. The reason that I included the question of possible failure in heat-treated material in my talk was because I think it is vital that we all understand that we must respect this virus and cannot be complacent in our regard to any aspect of it. I think that to consider that we have solved the problem on present evidence may be to reduce our need to continue to stress to those donors in the risk groups, that they should *not* come forward to donate blood, and we must continue, despite the very small numbers of cases of seropositivity that have been found in the United Kingdom, to test every individual donation by the most sensitive method available.

The second question that I have been asked, is what I thought of the banner headline in our local newspaper, relating to an anti-HTLV III-positive child. As a doctor and a parent I abhor this sort of headline. However, it is the responsibility of the media to inform the public of medical fact, and there is a need for everybody in society to understand that AIDS is no longer a disease confined to London, or to certain groups within society. We must convey the facts that very simple precautions need to be taken to protect people and their loved ones. Because of this dichotomy between the need to inform and the need not to sensationalize, Dr Pinching has suggested that, as a result of this conference, a group of us together with the voluntary societies should establish an award for the most responsible journalist of the year in reporting AIDS. Perhaps we should also establish a second award for the most irresponsible journalist of the year!

Q: Many professionals are aware of the enormous psychological effects that people with AIDS-related problems are suffering, or going through and as a result a lot of would-be counsellors are worried about

Dr Miller: This question raises a number of points. The first is that people with AIDS and HTLV III infection are *normal* people: they are doctors, lawyers, dentists; they are managers, manual labourers and clerks. AIDS is a disease that affects every stratum of society and every degree of life experience. So there is nothing particularly special about individuals who have acquired this infection. People often say 'How do I talk to a gay man?': the answer is that you have been talking to gay people for years, it is just that perhaps you did not know it! There is no special way of talking to anyone from any particular risk group: you just think, and then open your mouth and the words come out (on the good days!).

Everybody who came into this field had the same degree of incompetence when they started, with respect to understanding the lifestyles and backgrounds of their patients. We all had to learn from scratch: the AIDS crisis has highlighted how little we knew previously, for instance, about gay sexuality. If you want to know about the life-style of your patients there is literature that you can read, but that is often misleading or unrepresentative, so the best solution is just to ask them. Be honest in your ignorance and they will respect you for it. They will tell you what they want you to know and then it is up to you to fill in the gaps by talking to other people as well. Ask your patients: that is what we all did, and that is how we developed our knowledge.

Now, about the 'overwhelming psychological pressures' and the fear of 'taking the lid off something that you cannot put the lid back on to'. In this context there is no particular formula for dealing with people in distress. There is no 'pat' way of discussing things with them, or any special counselling technique that is optimal. I would say that anyone entering this field must simply be *themselves*. If you are relaxed, the patient is relaxed; if you are uptight and edgy, the patient will sense your unease and will not have as much confidence in you. So be yourselves and be flexible.

Finally, many people have said that, although AIDS counselling is an attractive area of work for them, they are afraid that they might pick up the infection from their patients. That will not happen unless you insist on having sex with your patients and that is not a practice we encourage! So there is no risk. Nevertheless, there *is* one risk to counsellors: AIDS-related work can take over your life, and you have to be an expert manager of your own time, learning when to stop being obsessive about the things you have to do, and carrying on with your other life activities as well.

Dr Pinching: I have been asked several questions, all of which raise extensive issues, and I will touch briefly on them. The first relates to two particular instances of women who are pregnant and who either are, or may be, seropositive. The questioner included a reference to

drugs or not is a separate issue from the question of HTLV III infection in pregnancy although, obviously, continuing drug abuse through pregnancy has its own problems. The issue is very extensively discussed in a paper in the December issue of the *British Journal of Obstetrics and Gynaecology* (Pinching and Jeffries, 1985). Ultimately, the decision about whether a person continues with a pregnancy, or indeed will wish to become pregnant, when she knows or suspects that she may be anti-HTLV III positive, rests with that patient. However, the patient can decide only if we provide her with factual information. That information is currently limited to relatively sparse experience in the United States. The more we help people in Africa to study the disease, the more we will learn about the possibility of transmission from mother to child and the consequences of pregnancy, simply because so many more women are infected in that continent. What we already know is very disturbing, because at least 50% of women infected by the virus seem to pass on that infection to their children in the uterus. Of those children who are infected, at least 50% go on to develop AIDS or AIDS-related disease in the early years of life. These are early estimates, based on small numbers, but they suggest that any seropositive mother should take very seriously the question of planning a pregnancy or, if she becomes pregnant, whether it might be more appropriate to terminate it.

The second issue relates to the health of the mother herself. She may well be asymptomatic at the time she becomes pregnant but there is evidence that pregnancy itself may act as a co-factor, if not in the first pregnancy then possibly in the second, with a very high rate of development of AIDS during that pregnancy. There are good biological reasons for this. As with other co-factors, such as intercurrent infection, the switching on of latently infected T cells produces more virus and a greater proportion of cells in the immune system become infected, until the threshold for clinical manifestation of disease is reached. Thus, there are both maternal and fetal issues that make us think that patients should consider seriously the implications of pregnancy. The decision is up to the patient and, whatever she decides, we must back her and support her needs.

The next questions are: 'Should we offer HTLV III testing to high-risk patients', and 'What should genitourinary physicians do to prevent the spread of the disease?'. To summarize, the question of testing is an issue that rests with the individual. The profession has to ensure that individuals who are at risk are able to consider how the result of testing will relate to them. They can do that only if they are informed, and our role is to ensure that they *are* informed. Society is made up of individuals and it is only through both general education and through

make these very difficult decisions. There is no absolute prescription for what should be done because it depends on the circumstances of the individual; to make a bland prescription for everyone is simply to fail to recognize the complexity of this issue. Our role is to enable people to have the facts to make their decision within their own lives. Many of the issues can be resolved without a knowledge of the test result: for instance, the question of spread of the disease. If the balance of risks and benefits is that there is greater risk than benefit to the patient, we should recognize that and, in that case, if there is another way of achieving the public health benefit, it should be used. Any patient who dies, for example through suicide, as a result of being tested inappropriately, is a casualty of an insensitive approach to a complex problem. All of us are in the business of sharing information and problems with our patients and with individuals in society.

A further question that I have been given is in relation to contact tracing. In a sense, this is an extension of the whole question of HTLV III testing, because it means seeking sexual partners of a known infected person, and telling them that they have been in contact with the AIDS virus. This is a very difficult issue and is not necessarily one that can be governed by a broad prescription for different settings. There are a number of key issues to be considered. First, once the contact has been traced, what are we going to tell this person, other than that they may or may not have been infected by the AIDS-related virus? If they are a regular sexual partner in a homosexual setting, the risk of them having been infected is about 50%. In a heterosexual setting, with male-to-female transmission, the risk is probably not very different from that; for female-to-male transmission, we do not yet have enough information. We are always talking about probabilities.

The second issue is to recognize that, apart from telling contacts that they could be tested if they wished, there is no further active intervention that we can currently undertake, nor is there likely to be in the immediate future. The other important issue is to recognize that not all the sexual contacts of an individual are going to be traceable. Should we, as health professionals, seek to do all of this work? All the ethical and moral dilemmas that arise involve the patient because, after all, a person who engages in multiple sexual exposures does so on their own responsibility; we should not assume that all the complex problems of this disease are on *our* shoulders. Individuals within society have to take the consequences of their actions. Anybody who deals with any aspect of AIDS has got to recognize that *everyone* has to make an effort and *everyone* has to take responsibilities; we have to share responsibility with our patients by providing them with the information that they need

the benefits of contact tracing are (from our experience and that of others) very small, whereas the risks in terms of the psychopathology generated are very large. In an area with a low prevalence there may be more benefit in contact tracing but we must remember John Green's points about the impossibility of isolation. We are dealing with mobile populations.

Dr Green: I have been asked about the success of counselling and the benefits involved. Dr Miller and I did study our earliest patients, looking at 112 of them, and following them up three months later. We used only their self-report, but we found that 107 of those 112 had changed their behaviour towards safe sex and had maintained it at that 3-month stage (Miller, Green and McCreaner, 1986). Counselling in this field can be very effective, especially when compared with other areas of health education. These results do need qualifying because many of our early patients were symptomatic, as this was before the introduction of routine testing; in addition, the follow-up period was short. We are now looking at a longer study to see if the patterns of behaviour are maintained in the long term.

We make extensive use of self-help groups in the community, such as Body Positive and the Terrence Higgins Trust (*see* pages 223–231). They provide a level of continuing support to patients, which helps to maintain people in safe sex behaviour. When there is not a local group that fills the same role as the Terrence Higgins Trust and Body Positive, health professionals can help by bringing patients together initially (if that is what the patients want, of course). You can bring people together just by providing them with a room and coffee, and by giving them advice and information about HTLV III disease. In that way you can help local groups to spring up and you will find that it greatly affects and improves your own effectiveness.

The next two questions I have are both about mouth-to-mouth resuscitation. I do not think that there is any risk involved, unless the person is bleeding heavily, and even then the risk is probably very small. To be absolutely safe, use a Brook airway. Firemen, ambulance men and the police should either carry these or should have immediate access to them. However, if you see a man who has just had a respiratory arrest, lying on the pavement, you have to take the decision as to whether you are going to step over him and leave him to die, or whether you are going to administer mouth-to-mouth resuscitation. Under the circumstances, I would do the latter, but this is my own personal decision, as it must be for you. Nevertheless, I would be very sorry to think that any health care worker would let someone die in such a situation — and of course the chances of the person who is in

Aid: the answer is that there is not a problem; normal hygiene is perfectly adequate.

Finally, I should mention other questions that continually crop up: you can *not* catch AIDS from head lice; bed bugs are not a problem, and you should not be worried about mosquitoes. There is no evidence at all that insect vectors are involved in transmission.

Dr Pinching: This is a very important area, affecting people who may not work in hospitals and who may be outside the channels of information that many of us have access to. Everyone should bear in mind three key phrases: *common sense*, *basic hygiene*, and *good technique*; they cannot then go far wrong. Put these three together with *information*, and I do not think there can be any reason for not helping our fellow men and women.

Dr Green: There is a great deal of information available about infection control. For instance, the Department of Health has produced the Blue Book series, which has within it the Infection Control Guidelines, and your Health Authority will have been sent these books. You should have access to them and it is disconcerting to find that so few people have actually seen them. The Guidelines are free; they were sent to every health district; the Government put a great deal of thought into them: do get a copy! Many of these issues are covered, from whether or not people should be embalmed, to mouth-to-mouth resuscitation, and all the other issues.

Dr Volberding: I have been asked about the effect of AIDS on mortality figures. I am not sure that we really know the answer to that question in the United States. However, it is clear in some areas of the United States — New York and San Francisco are the best examples — that you can demonstrate clearly that AIDS has become *the* major cause of death in certain age groups. None of our reporting of mortality includes sexual preference, and what we have done in lieu is to use surrogate markers of sexual preference. In San Francisco we have looked at single, never-married men between the ages of 25 and 44. We recognize that this population includes a lot of people who are heterosexual and unmarried, or are gay men, but that it excludes gay men who have been married, or who are married — and whether or not it is a good estimate, it is the best that we can do. Nevertheless, when we look at groups in this way, the effect of AIDS on mortality is astounding. AIDS is far and away the leading cause of death for single men in that age group in these cities. I doubt that it shows up yet in the national figures in the United States: I am sure that it does not show in the overall figures in the United Kingdom, but I am sure that it soon will.

programmes, and of all the people that we have working for us, whom would we hire first?' The point that we would make is that the putting together of an AIDS service, especially when starting from scratch with a few patients, probably does not require any additional personnel at the start. Instead, as we did, what you should do is identify the people that really want to work with this problem. As others have commented, it does not help to force people to work with this disease; they will not be sensitive to the many medical, social and political problems of AIDS. I would start by not hiring anyone, but by using existing personnel and by focusing on a physician *and* a nurse. In our experience, it is hard to separate those two functions; neither one can really exist independent of the other. Beyond that, I think our next step was to make sure that we had a social worker or counsellor, and somebody who could take care of the concrete, financial needs of the patients as well. The patients are young people who face the loss of their jobs, not necessarily because of discrimination but simply because of their illness, and they have pressing financial needs.

The last question was already answered by the previous comments: 'What precautions should be taken after being bitten by a seropositive person?'. I think that we would all agree that the risks of seroconversion following such an incident are essentially zero. However, as always, we have to qualify our answer; nevertheless, the risks are so small that, rather than worrying about seroconversion, I would make sure that the bitten person had counselling available. The other point that I would make is that we do feel that in some situations where an individual has been at risk of seroconversion as a result of occupational exposure, HTLV III antibody testing is at least worth considering — not to identify a positive but to prove that the person is negative at that time. If a question of liability arises later, the person then has the knowledge that they were initially seronegative.

Dr Green: There are a few differences in terms of staff between America and the United Kingdom. One such difference is, of course, that we have health advisers — a very important group in dealing with the spread of this particular infection, because of their experience in dealing with the control of other infections in clinics of genitourinary medicine. You have to take into account your local circumstances and the staff available. I agree with Paul that you should start with what you have already, and build from there. However, I also think that each district should have a clear AIDS policy and should think it through, identifying clearly what they are trying to do and how they are going to achieve their ends. What worries me more than anything else is that there is very little sign that many health districts are actually doing this. There is a particular problem at present because of the

the Health Service, and it is not entirely clear whose job it is at the moment to form a clear AIDS policy locally. I would urge all health care workers to persuade their district to formulate a clear policy. You may not have any AIDS patients now; you may not have any seropositives now; but you do not want to find yourselves in the situation where the problem comes first and you have to scramble for solutions later.

Dr Volberding: Those responsible for making decisions about staffing and financing AIDS work should realize that, while you may be able to contemplate starting with your existing personnel, it soon requires financing and staffing over and above this. This is a new epidemic and it is extremely time consuming, and labour and capital intensive. I would make a plea that, as the problem expands, so services should be expanded concurrently because there is no way that people can work against the stress of this disease without additional staffing to help soften the blow.

Gayling Gee: I have been asked a question about nursing patients with a potential for violence, for instance people with AIDS who are in prison. I will answer that by referring back to the discussion about what to do if bitten by someone who was seropositive or who had AIDS. I think that the warder and those restraining the person would probably do more harm to him than he would to them. We have not had any episodes of violence in our unit. However, I do see the potential difficulty when a patient is returned to his place of incarceration. The prison guards and the nurses in the prison should be educated to make them realize that AIDS is communicable only in certain ways. In addition, they should try to avoid creating explosive situations in which the prisoner might become violent. When restraints are necessary, they should be applied in such a way that they will not harm the person (as they might if the warders were afraid of him).

The second question that I have been asked is: 'Have any links been established with hospice-based services in America?' Specifically in San Francisco, we do not have a hospice in-patient facility. Our hospice services primarily are in terms of home care: we have a group of seven or eight hospice nurses who care for terminally ill patients in their own homes. In the same way, although it is not a hospice service, Shanti (which is a counselling service for people with life-threatening illnesses; *see* page 136 and the Glossary) provides practical support for those who assist people at home.

Dr Pinching: The hospice movement in the United Kingdom, which is very well and independently organized, is looking at the issue of AIDS at present. Many hospices are responding very constructively and are learning how they can help us and our patients. In the long

community-based hospice-type or home-care based (Shanti-type) projects in this country. We have a lot to learn, both from the hospice movement in the United Kingdom and from the organizations in the United States, about how to support our patients in the community — which is where our patients belong.

Mrs M. Fearns (Newcastle): Has Dr Miller any experience or any comment on who counsels the counsellors and the health care workers?

Dr Miller: There are some definite requirements in the management of HTLV III disease, and one of them is looking after the staff. Reference has been made to staff becoming over-tired and over-burdened through lack of efficient forward planning. People have different ways of dealing with this, and a good principle is to have it as an issue in training, an issue in the familiarization process, so that all staff working in the field are aware, right from the outset, of signs of occupational stress or burn-out. They should be encouraged to discuss these matters as they affect themselves and other people, with a person or persons within the team. This is the great strength of a team approach. Although we all have our own specialties, a lot of our work overlaps as well, and part of that overlap should include the recognition of when the going is getting tough. Even if you cannot do anything practical, such as hiring more staff, at least you can share the burden and the frustration without the fear of showing that you are somehow 'weak' or 'ill-qualified' for the task. We are, after all, human beings.

We have two ways of treating this problem, in our team. The first is to have a staff support group, where we sit and talk about the frustrations, and complain to each other about why things are so bad. Afterwards, we usually feel better because we have organized changes in policy and service provision, for instance. The second way which has proved to be very successful over a three-year period, is to organize informal meetings (we use the Head Sister's office, in the Infectious Diseases ward), in which we may share some wine and have a general chat about the way things are going. We do this as necessary, usually once every three or four weeks. The important thing is that we should be able to recognize when the going gets tough, and should feel free to communicate our concerns, so that we can manage the crises as they affect us.

References

MILLER, D., GREEN, J. AND MCCREANER, A. (1986). Organizing a counselling service for AIDS-related problems. *Genitourinary Medicine* **62**, 114–119.
PINCHING A.J. AND JEFFRIES, D.J. (1985). AIDS and HTLV-III/LAV infection:

19

Closing Address — the Future

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Introduction

It is, perhaps, the mark of a good conference if the closing comments are redundant! This chapter will not attempt to review all the material that has been presented previously, but will discuss some of the points that have emerged.

It is encouraging to hear that the UK Government is aware of the problem of AIDS and is planning expenditure on an educational programme (*see* pages 5 and 64). I hope that the US Government will follow suit: it would be interesting to compare the two responses.

The African question

Many people, myself included, have fallen in too easily with the assumption that early tests have proved that AIDS started in Central Africa. Dr Tedder's and Dr Pinching's comments about the nature of the epidemic in that region should make us all realize that we must be cautious about making hasty assumptions about this disease, for every such assumption carries the risk of causing secondary problems. One of the features of AIDS is that those of us working in this field have the doubtful privilege of hearing our remarks repeated by the media and of seeing some of the political spin-offs — some beneficial, some detrimental. An example of this is that, because of our inadequate information about Central Africa, the African Governments have withdrawn from any further discussions and have adopted the position that AIDS does not even exist in some of their countries. That can only

epidemic. In everything that we say we need to be particularly cautious, realizing that our information is more than medical — it is social and political as well.

Transmission of AIDS

How is AIDS transmitted? By two means: it is transmitted sexually, and it is transmitted by direct exposure to blood. Sexually, it is transmitted by direct contact of genital or rectal mucosa to infected semen or vaginal secretions. I prefer the term 'genital secretions' to 'body fluids' because I think that this avoids many questions about tears and saliva, and gets to the real issue, which is sexual transmission of this virus. I personally think that both rectal and vaginal mucosa are able to be infected and that the virus can somehow penetrate these barriers, even if there is no trauma. I think that there is growing evidence of heterosexual transmission, although I agree with all the remarks that have been made earlier about the relative increased risk of rectal intercourse. With regard to blood, we have discussed transfusion and we have talked about haemophiliacs, but I think that we would agree that a major area of growing concern is the serious problem of transmission by sharing needles. We have discussed some ways in which we might approach that and other problems, but we need to focus on what is important about transmission, and not let ourselves get distracted by the tangential issues that have relatively little importance in the overall spread of the epidemic. Our central approach to this has to be to stop this epidemic, using whatever means we can, and in doing this we have to try to strike a balance between civil rights and public health. If we allow ourselves to adopt either position exclusively, we are not performing the service needed to stop the epidemic.

INSECTS AS VECTORS

Are insects vectors? I do not think that we can merely say 'No'; we have to look at the evidence. The AIDS-related virus is in blood; mosquitoes ingest and transmit blood cells, and AIDS is most common in areas that are infected with mosquitoes. On the other hand, the amount of blood transmitted by a mosquito is minimal; the virus has no known life cycle in the mosquito; and to my knowledge every mosquito-borne infection has a life cycle within the insect which allows

endemic are not the age groups that we would expect to be most exposed to insects, for instance, young children. Instead, in Central Africa, we see a disease that looks like a sexually transmitted disease that has been recently introduced into the population. We see a disease that is affecting young sexually active adults and infants born to mothers who have previously been infected. I think, therefore, the bulk of the evidence would be strongly against insects being any kind of a vector for this disease.

EDUCATION

Figure 19.1 shows how some agencies are trying to educate the public about AIDS. Whether we are counsellors or physicians or nurses, we have to give serious thought to how we can communicate with and reach populations that might not listen to what we would normally say in the way that we would normally say it. The Figure highlights the lack of casual transmission of AIDS.

Antibody testing

One of the issues that we are grappling with is the question of AIDS antibody testing. We should recognize that, no matter what our position is in this debate, we are all responsible people with the desire to stop the epidemic, in ways that are not socially disruptive. Some polarization is inevitable, but it is probably useful to take sides and to have proponents of one or another philosophy in antibody testing. I would hope that, as we gain more experience and as we talk to each other, we can approach the problem rationally and can come to some happy consensus.

What is the antibody test? *Table 19.1* shows the variety of techniques available. The ELISA test is the one that is routinely available commercially while the others are used either as confirmatory tests or as research tools. Whatever technique is used, we should all realize that the tests are already very accurate, detecting antibody to whole virus or to purified viral antigens which increasingly are being prepared by recombinant DNA technology. Although I was initially sceptical about the accuracy of these tests, when I saw the data I was impressed: in comparison with most of the other tests used in medicine, the anti-HTLV III test is very good. *Table 19.1* shows sensitivity and specificity data which, although varying slightly depending on the type of test

Table 19.1 The antibody test for the AIDS virus

Variety of techniques (ELISA, Western blot, immunofluorescence)
Detect antibody to whole virus or purified viral antigens
Test very accurate and getting better –sensitivity 98+% –specificity 97+% –positive predictive value varies with population

THE POSITIVE PREDICTIVE VALUE

The real problem, as far as antibody testing is concerned, relates to what is known statistically as the 'positive predictive value'. This term is applied to tests that are done especially in a screening situation; it has nothing specifically to do with AIDS antibody testing and is true of any test applied to any situation, medical or otherwise (*Table 19.2*). Any screening test for any condition is most accurate when it is used in populations where you most expect to see a positive result: positives in that situation are true positives. On the other hand, the same test with exactly the same operator, the same technique and the same reagents, is least accurate when it is used in a situation of low prevalence, where you least expect to see a positive result. With the AIDS antibody test we would expect that positive results would be most believable in the gay community, or in those using intravenous drugs, whereas the screening tests are most likely to be misleading, if positive, when they are used in low-prevalence situations such as the blood bank or for a healthy heterosexual in a small town in Great Britain who walks in off the street asking for an AIDS antibody test. In other words, in a member of a high-risk group, if the test is positive it is probably truly positive, whereas in a non-risk group member a positive

Table 19.2 The problem of positive predictive value (what does a positive test mean?)

Any screening test is most accurate when used in populations where you *expect* many positive results (positives are 'true positives')
Screening tests are *least* accurate when very low rate of positives expected (positives are 'false positives')
In AIDS, antibody tests that are: –positive in risk group member, are probably 'true' –positive in non-risk group member (blood bank, healthy heterosexual)

might very well be falsely positive. How can this be when the same test is being used and when the accuracy is 98–99%?

Table 19.3 shows the sensitivity and specificity of a test used to screen 100000 people. If we assume, before starting the test, that 30% of those we are testing will be truly positive, we thereby assume that 30000 people are infected. Given that sensitivity and specificity then, as shown in *Table 19.4*, we would find that 29100 are reactive to the test and 900 are non-reactive. Using the same parameters for the test, 700 of the 70000 people we have assumed are not infected would be found to be reactive to the test, and 69300 would be non-reactive. The positive and negative predictive values in that population would thus be very good and we would believe the results of that test in that population.

Looking at the situation that might obtain for the AIDS antibody test in a population of healthy heterosexuals (*Table 19.4*), and assuming a high level of infection, so that 100 people were truly infected, then — given the same test — we would find that 97 would be reactive and three would be non-reactive. The problem lies in the fact that, with so many people *not* infected, even with a very good test 999 would be reactive because the population of non-infected people is so high. The positive predictive value here is only 9%. Of the 91% of these 100000 healthy heterosexuals that we are screening, the test is truly positive in less than 10%.

Table 19.3 HTLV III antibody testing

Sensitivity is 97·0%
Specificity is 99·0%
100 000 persons screened

Table 19.4 Positive predictive value and actual prevalence of HTLV III antibody

Actual prevalence of HTLV III antibody (%)	Reactive or non-reactive	Infected	Not infected	Predictive value (%)
30	Reactive	29 100	700	97·7
	Non-reactive	900	69 300	98·7
0·1	Reactive	97	999	

This is the heart of the problem in trying to apply a screening test in populations of low incidence. We cannot merely consider the test and its accuracy, we must also consider the population that is being tested. The American Medical Association seriously considered (and fortunately declined) the option of premarital testing of all people by the AIDS antibody test. It has been emphasized repeatedly in previous chapters that this test, if positive, carries an almost unimaginable stigma. From the Tables you will appreciate that we could be labelling people as infected when they are not, and could needlessly be giving them lifelong problems about how to conduct their sexual lives, and whether or not to have children.

IMPLICATIONS OF POSITIVE RESULTS

What are the implications of a positive AIDS antibody test? Some people contend that it means nothing except that an individual has been exposed to the virus. I think that we must counter that with a very strong statement: a positive test means a great deal. It means that an individual has been infected, not merely exposed. The virus can be cultured from the blood of 60–80% of seropositive people even if those people are asymptomatic. Bearing in mind the difficulty of culturing this virus, this to me means that everyone who is antibody positive is truly infected and that in almost all those cases the virus is replicating. From our knowledge of all other retroviruses and of HTLV III so far, the infection is chronic, at the very least, and probably is lifelong. The infected person represents a contagious risk to unprotected sexual partners or to anyone exposed to his blood. Finally, although the HTLV III antibody test is not a test for AIDS, we know that the risk of health problems in a seropositive person is high. To my mind, we cannot say that the risk of developing AIDS is *only* 5–10%: it is *at least* 5–10% in the time span within which we have seen infected people so far. That is a substantial risk to bear and that is why we are so concerned about how we approach the antibody test and how we recommend it should or should not be used, as the case may be.

We have heard of the social implications of AIDS antibody testing and *Table 19.5* shows some of these. What are the responsibilities of the carrier of the virus to sexual partners or to people around him? We think that the seropositive person does have an obligation to inform his contacts. On the other hand, we know that there is little that we can do to help people even though we know that they are infected.

Table 19.5 Some implications of HTLV III testing

1. Does an 'AIDS carrier' have a moral or legal responsibility to inform potential sexual partners?
2. What effect will a positive test have on insurability and employment?
3. Given the difficulty of reaching i.v. drug abusers, should sterile syringes be made available for addicts?

sterile needles and syringes available to the person who is anti-HTLV III positive? (*See also* pages 233–238; 249–253).

USE OF THE ANTIBODY TEST

I believe that we should be more receptive to the possibility of testing populations than we have been, or at least to the possibility of testing individuals who are members of populations. What uses of the antibody test can we recommend (*Table 19.6*)? The use of the AIDS antibody test in blood bank screening, organ screening and in sperm banking is not debatable. We recognize that it will be necessary, occasionally, in establishing a diagnosis of AIDS: there are situations, for example in lymphoma or some of the uncommon infectious diseases, where the AIDS antibody test is required for diagnosis. More commonly it will be used by physicians to establish a diagnosis of AIDS-related complex (ARC). As I see it, the problem is that of separating medical testing from the social implications of that testing and its use in other non-medical situations.

Table 19.6 Uses of AIDS antibody testing

Valid	Not valid	Problematic
Blood bank and organ donor screening	Employee screening	Case contact finding
	Military screening	Use in life insurance (eligibility, premiums)
Establishing AIDS diagnosis (uncommon)		In high-risk persons for education, risk reduction
Establishing ARC diagnosis (more		

There are some situations in which the AIDS antibody test clearly is not valid and in which we should resist its implementation. I can see no indication for AIDS antibody testing for employment: the virus is not transmitted by any occupation (apart from prostitution) and, with this possible single exception I can not think of a reason for employment screening. What about military screening? The US military authorities want to screen people so that in the case of battlefield transfusions they will not transmit AIDS. My own reaction is that, if I were on the battlefield I would worry about matters other than the possibility of getting AIDS. I do not mean to minimize the problematic areas but would suggest that more thought is needed about how to address them.

CASE CONTACT FINDING

In recognizing Dr Pinching's views that there are problems with case contact finding, I have been considering a particular problem recently. In San Francisco we now have approximately 12000 active intravenous drug abusers — a great many for such a small city. We estimate that 10% of them are seropositive and we are wondering what will happen to that population and what threat it poses to the rest of the population. We know that there is a possibility that i.v. drug abusers represent a 'bridge' between established risk groups and the general population. The thought that has occurred to me is that if we could turn the clock back to 1979 in San Francisco where, in the gay community, we probably had a similar number of infected individuals to those now in the drug-abusing population, if we then knew what we know now about the virus and had the antibody test available, would we have made any different decisions and would those decisions have resulted in any alteration of the epidemic? If we say that we *would* have done aggressive case contact finding in the gay community at that point, and if we think that it *would* have slowed the epidemic down, then we should consider whether a similar approach now in a different population might also slow down the epidemic.

Once again, my basic position is that we should do what is necessary to stop the epidemic: that it is unacceptable to have transmission of this virus. We know that we can do nothing once the prevalence is 50% of the population. If we feel that aggressive case contact finding in gay men in San Francisco in 1979 would have been of no avail, then we should feel the same about the i.v. drug-using community now — that case contact finding is unlikely to stop the epidemic. I do not know what the right answer may be but I am open to debate about case contact finding. The problem in America is that of limiting such an

arise in the course of attempting to control the epidemic in any one population might outweigh the benefits and add to the overall complexity of the debate.

LIFE INSURANCE

The use of AIDS antibody testing in qualifying for life insurance is problematic and I respect the position of the Terrence Higgins Trust, that this should be fought. Nevertheless, from the business point of view, should people taking out life insurance have to bear the additional cost involved in covering those in the insured group that are at much higher risk of developing a fatal disease? Other problems are screened for in this context: we screen for diabetes; we screen for heart disease; why should AIDS be so different? Perhaps one approach might be to ensure that the person who is infected with the virus is not unfairly excluded from life insurance cover, but that the rates should be adjusted accordingly. This view may be unpopular but these are far from being easy issues. Easy solutions often need to be reconsidered because they will be challenged.

RISK REDUCTION

Another controversial area is the value of AIDS antibody testing in high-risk people for education and risk reduction. Admittedly, such testing has its problems. Nevertheless, I have worked with AIDS when it was an utterly mysterious disease and when nothing was known of the mode of transmission: as, no doubt, every other person working with this disease has done, I became convinced at one stage that I was infected with the virus. I was very anxious about the result of my AIDS antibody test and was extremely reassured to find that I was antibody negative. The point is that sometimes we focus too much on the effect of the positive test result, and tend to overlook the reassurance that can come from knowing that one is seronegative.

Whereas our risk reduction recommendations should be the same for everyone, I find it hard to believe that the drastic changes in sexual behaviour that are called for — changes that affect a central part of people's personalities, are not going to be very difficult to sustain. It might require the added incentive of an antibody test, to know whether one is positive, to help reinforce any recommended changes in behaviour. Obviously, the situation would be eased immeasurably if a drug were available for the treatment of seropositives. However, even in the

should not be recommended on a case-by-case basis for people in high-risk groups. I agree completely that screening of members of high-risk groups is a much more serious issue; we should resist any compulsory or forced screening of anyone because the social implications are so great.

AIDS in health care workers

AIDS is not a risk to health care workers, even in the case of direct exposure to contaminated blood in the form of needle-stick injury (*Table 19.7*). There has been only one confirmed case of seroconversion in a health care worker and that was a person who was also injected with a small amount of infected blood. Needle-stick injuries by themselves have not transmitted the virus: in our own hospital we have done a long and careful study of hundreds of health care workers and found no seroconversions in any, irrespective of occupational group.

Table 19.7 Is AIDS a threat to medical staff?

Type of contact	Evidence for risk
Breathing same air	None
Droplets of saliva (mucous membrane contact)	None
Contamination through skin	None
Bloody 'splash' on mucous membrane	Minimal, no confirmed case. Less risk than hepatitis B
Contaminated needle-stick	As above, no confirmed seroconversion in simple needle injury

Risk to heterosexuals

In the previous chapters there has been frequent reference to the epidemic in Africa. Is the virus different? Is the disease different? What is known about the transmission? It is obvious that we do not know enough and I hope that we can reassure the African governments that we are sincere in our wish to help them with their epidemic. In the United States it appears that heterosexual transmission is rare (*Table*

Table 19.8 AIDS: risk to heterosexuals

In Africa:	Serious epidemic in Central Africa Heterosexuals predominate Men and women equally affected Number of sexual partners implicated Specific sexual practices and other potential modes of spread not defined
In USA:	Cases from heterosexual contact increasing but still uncommon Increasing seropositivity in i.v. drug users, prostitutes, STD clinic patients

Table 19.9 The future of AIDS — key problems

The virus	Which cell types (macrophage, fibroblast etc) are infected? Must cells express T4 to become infected? What controls viral replication in cells? Will reactivation of latent infection occur (when, why)? What are the *long-term* consequences of infection?
The immune system	What is the nature of the pathogenic effect? Does effective immunity occur (and why does it usually *not*)?

studies, and increasing evidence of heterosexual spread in the CDC figures, we cannot afford to be complacent.

Conclusions: key problems

No doubt everyone has their own list of key problems. With regard to the *virus* itself (*Table 19.9*), what are the cell types that are infected in the body? Do the cells have to express the T4 antigen to become infected, or will we find that cells have other receptors? This will be important in antiviral drug development. What controls viral replication and what effect will reactivation have later? What about the person who is asymptomatic and seropositive now and who lives for the next 15 years in a healthy state? What happens as that person encounters the normal immuno-attrition of ageing; will reactivation occur? What are the long-term consequences of infection?

What is the nature of the pathogenic effect on the *immune system*, and why do we not see evidence of effective [illegible]

Table 19.10 The AIDS vaccine — how likely, how soon?

Production will take time:
New virus (vaccine for similar viruses very difficult)
Important safety considerations — no risk of AIDS or immune dysfunction from vaccine
Clinical trials will take time:
Long incubation period might imply *years* of clinical trial to establish safety, efficacy
Legal and financial concerns:
Who bears liability? If *companies*, they probably will not produce the vaccine

Table 19.11 Future problems to be resolved

Clinical	Can AIDS be prevented by inhibiting viral replication? Can AIDS be reversed with anti-retroviral drugs alone?
Educational	How can we reach intravenous drug users and reduce transmission? Can we educate the general population without causing hysteria?
Political	Balancing civil rights and public health considerations

infection? This is a key question for the success or failure of vaccine development. Development of the AIDS virus vaccine will take time, and perhaps will never be achieved (*Table 19.10*).

What are the problems to be resolved *clinically* (*Table 19.11*)? Can we prevent AIDS by inhibiting the virus? Can we reverse AIDS with anti-retroviral drugs or will we need to do more to boost and restore the immune system?

The *educational* problems that we face have been discussed at length. Perhaps the most central problem is that of reaching the population of i.v. drug abusers to reduce the transmission in that community. How can we educate the general population in an effective way without causing hysteria, and how can we balance civil rights and public health?

What can we say about *stopping the epidemic*? We know that decreasing the number of sexual partners is likely to help stop the spread of the epidemic. However, we have to recognize that it is not *how many* partners, but *what is done* with those partners that is import- [illegible] essentials are (1) the use of condoms; (2) knowing partners

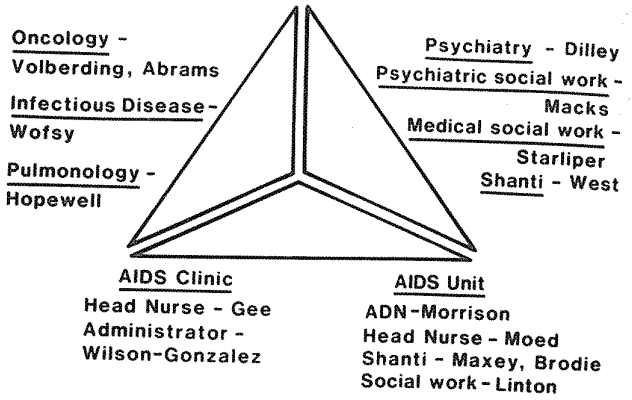

Figure 19.2 AIDS activities at San Francisco General Hospital

referring here primarily to intravenous drug abusers). Most controversial of all is the decision about whether people should know their own antibody status and that of their partner, with all the attendant problems. Although it is reassuring for someone to know that he and his partner are seronegative, he then has to consider *when* were they negative; were they falsely negative; were they recently infected and have they seroconverted since they were tested?

With regard to spread of the infection by *blood transfusion*, we have already come a long way. There appears to be *in vitro* evidence that pasteurized concentrate is safe. The problem of AIDS and intravenous drug abuse must be tackled, either by trying to reduce the incidence of drug abuse itself (which I do not think is likely to be successful and we should encourage our governments to recognize that) or by encouraging intravenous drug users to behave in ways that will stop the spread of the virus.

Finally, I would like to acknowledge the contribution made by all the staff of our organization in San Francisco (*Figure 19.2*). They provide a uniformly high level of commitment to the problems of AIDS and a real, sincere interest in delivering the best possible services. I know that this is not unique, because every programme that we have heard about in this conference involves similarly dedicated staff members.

Part VII

Special Interest Group Reports

R1

Report of the Special Interest Group for Nurses

Practical problems associated with the treatment of haemophiliacs who are HTLV III-positive or have AIDS
(Presented by Patricia Lilley)

GROUP DISCUSSION

A variety of issues was raised to enable a wide choice for group discussion: staff education, transmission of HTLV III infection, available tests and their significance, counselling, training, confidentiality, and who cares for the carers?

Safety measures

The greater part of discussion was spent exchanging information on safety procedures. It appears that in some areas staff do not have clear guidelines or an updated Health and Safety at Work policy and, therefore, in some situations felt unsure and confused.

Counselling

Before counselling others, we need to come to terms with our own prejudices, inhibitions and cultural backgrounds. We also need to be in possession of the facts. In some instances, nurses had difficulty in discussing issues (e.g. safer sexual practices) with patients, especially with young men of their own age.

A minority of nurses had attended counselling courses and had found them very useful. It was generally thought that more should be offered the opportunity to attend.

Confidentiality

confidentiality. Samples and laboratory forms could have patients' names coded. Information should be given only to those directly concerned.

Staff education

Although it is up to individuals to keep abreast of advances in their particular field, the most useful way was thought to be through regular staff meetings. They serve as a useful forum for exchange of ideas, especially where a team approach is required and therefore good communication is essential. Issues can be raised and staff consulted: members of staff then feel part of the team and are generally more committed and therefore more productive. It is important that they understand the reasoning behind changes in procedures or current research: they can then educate other disciplines and enable smoother implementation of any changes.

Staff meetings can also be useful for staff support, especially with increasing workloads and pressure. Those who are the least well informed are the most anxious.

Caring for other at-risk groups who are HTLV III-positive or have AIDS

(Presented by Catherine Levy)

GROUP DISCUSSION

The possibility of the HTLV III virus being passed on via insects, such as fleas, was discussed. This was of particular interest following the reports which have suggested that the mosquito may be one source of infection. For those health carers in the community it is of particular relevance when dealing with drug abusers who do not always practise good personal hygiene, and are often admitted to the clinic infested with fleas. It was decided that there would be no personal risk to health care workers as long as they adhered to the DHSS guidelines for nursing those who are HTLV III-positive or have AIDS (*see also* p. 183).

The DHSS guidelines were discussed in greater detail and the general consensus of opinion was that the practical issues were dealt with adequately although other aspects of caring for patients in these at-risk groups may need more in-depth information.

Members of the group discussed the problems of positivity associated with drug abusers. Previous publications and media coverage have

the group were worried that not enough discussion and information was available relating to drug abusers, as they could be a high source of infection spread. It was felt that health education should concentrate more effort in publicizing the risks of HTLV III positivity in drug abusers.

STD clinics are governed by laws of confidentiality. Those nurses who had not worked in this type of setting were interested in confidentiality relating to HTLV III positivity in relation to STD clinics. This was particularly pertinent when referring a patient from one area to another. They discussed whether it was permissible to pass this information to another health adviser if a patient transferred to a different area. One nurse working in an STD clinic explained that in some circumstances it was possible to pass information about sexually transmitted diseases to another health care adviser if this was relevant to controlling spread of infection.

One member of the group raised the question of the care of pregnant female drug abusers. It was felt that, in general, drug abusers, when pregnant, did not readily seek antenatal care, and a special point should be made of education for this group of people.

Implications of HTLV III testing for staff and patients

(Presented by Maureen Fearns)

Topics raised:

1. Should testing be available for staff? If so, how should this be managed?
2. Should testing be available to patients and their relatives? If so, what was the need and the consequences?

GROUP DISCUSSION

Testing for staff

This was equated to previous experience with hepatitis B testing. Some people thought this should not be done as confidentiality might not be guaranteed. What one does not know about, one does not need to declare.

The other thought was that testing should be carried out for staff working in at-risk areas. This should be done with coded specimens and the results should be personal and confidential.

The 'pros' for testing were that it gives grounds for future arguments

evidence in an industrial claim. Some professionals felt an obligation to know that they were negative to ensure that they were not putting their sexual partners at risk; in the case of female nurses contemplating future pregnancy it was mandatory for them to know that they were seronegative before planning a pregnancy.

Testing for patients

This was briefly discussed. There was felt to be a need for wives and other sexual partners to be tested, especially where pregnancies were contemplated. However, it was noted that patients might encounter problems with insurance medicals, etc. if they had been told they had a positive result.

The conclusion was that HTLV III testing has a place and may be a necessity in some circumstances. This testing, however, must be carried out carefully, confidentially and not used indiscriminately. Testing must be available but requires a back-up service for advice and counselling in order that both health care workers and patients can make their decisions about their own needs for this test.

Psychological effect of positivity or diagnosis of AIDS on patients and staff

(Presented by Pauline Sharp)

Mrs Sharp stated that some people, even in the caring professions, revel in something bad. They do not bother to educate themselves with facts. They stand by their uneducated opinions and thus give rise to rumour which affects the situation in a negative way. The whole topic of HTLV III positivity and AIDS has a greatly changing nature with regard to the disease itself, to research and to advice and nursing care. It can be very confusing to the patient and to the carer to accept, explain about and re-educate oneself about HTLV III positivity and AIDS: today's advice differs from yesterday's, and probably will be different again tomorrow; nevertheless, some basic aspects of the effect on health care workers and patients remain unchanged.

Fear is a natural response in both patients and staff who are immediate carers as well as those people widely removed from the subject. Fear arises from the uncertainty of what positivity means or what it will lead to, and from the knowledge that at present the diagnosis of AIDS is like being on Death Row, sometimes getting reprieves but not knowing when those reprieves will end.

Anger. The patient experiences great anger. He may ask himself 'Why me? What did I do wrong?' Health care workers experience anger about whether they could have done anything different in their caring which would have avoided this situation, anger that this happened to their patient and to that specific patient.

Loss of self esteem. For the patient, the destruction of self image is influenced by his inability to participate normally in life's activities. There may be loss of human contact with partners and friends, to the extent that they will no longer be able to relate even to their children.

Lack of control is experienced by both the patient and the health care worker, both of whom feel that they can no longer control the situation because of the destructive element of HTLV III positivity or AIDS.

Denial. As for other diseases, the patient may deny the diagnosis, therefore endangering others by ignoring the precautions that should be taken by those who are positive and those who are in intimate contact with positive patients.

Stigma. Being positive or having AIDS carries a great stigma in society, making the positive person feel like a leper. This may lead him to lose trust in the carer in relation to confidentiality.

GROUP DISCUSSION

Discussion related to all of these psychological aspects and showed that there is a general feeling of anger and fear in health care workers and patients, because of the lack of consistent information. Information that has been given in the past has often been proved to be incorrect. It was felt that there was a lack of nurse education programmes that could help nurses deal with their personal feelings and their patients' feelings.

There was some expression of fear of an unknown subject, particularly as it had been grossly sensationalized by the media. It was also suggested that there could be more support from unions and more education for nurses nationally. Some nurses expressed frustration that they were unable to understand the subjects which were discussed in relation to psychological influences. However, all members of the group had a great desire to learn more in order to help them to nurse the patients and to deal with the practical and psychological elements

R2

Report from the Social Care Workshop for Social Workers and Those in Social Care Planning

Introduction

The session was chaired by Mrs Jean Lovie, Social Worker, Newcastle upon Tyne Haemophilia Reference Centre. The speakers were:

1. Dr Colin Griffiths, Health Education Unit, Swansea
2. Mrs Riva Miller, Senior Social Worker, Haemophilia Reference Centre, Royal Free Hospital, London
3. Mr John McCreadie, Assistant Director of Social Services, Gloucestershire County Council

I. Education of Social Work staff

CHAIRPERSON'S INTRODUCTION

Social workers are as exposed as others to the inaccurate reporting about AIDS in some parts of the Press. The medical/social aspects of the disease are complex. It is imperative to educate staff to allay fears and to inform, before they can proceed with the work. Social workers are in a position to help those in the at-risk groups, but also must contribute to the task of educating the public.

In the first instance, training programmes are needed for staff within social work agencies. The task of education is being undertaken by different personnel in various parts of the country.

DR COLIN GRIFFITHS

AIDS has been unique in the amount of publicity it has attracted, but

public and many professional groups. It is essential to disseminate the known facts in order to allay fears. In West Glamorgan an educational programme has been set up for hospital staff of all grades — not only nursing but also auxilliary staff, such as domestic staff and porters.

This programme has been organized on a direct contact basis, and is in addition to the specialist medical and research lectures about AIDS that are given in the hospitals. Video material and pamphlets were not enough: staff have wanted to ask questions and to approach the speaker on an informal basis afterwards. As many hospital staff as possible have been covered, with talks arranged at half-hourly intervals between 9.0 a.m. and 5.0 p.m. This approach has been so successful that the programme has been extended to cover other hospitals in the area, and now includes sessions for dentists, social workers, community health workers, the prison population in Swansea, members of the gay community attending a local club, police, fire services, ambulance services and students at local colleges. An educational programme has also started within the local schools. In all, 620 talks have been given to 11 800 people. Each talk is standardized to include details about HTLV III, how it is transmitted, and details of the various groups that are at risk. Other information has been included to suit specific groups, for example, nursing procedures for hospital staff, and ways of modifying sexual behaviour with gay groups. In this way, basic information about AIDS has been disseminated to a wide range of people in the West Glamorgan area.

There is no doubt that we underestimated the level of anxiety and demand for knowledge about AIDS when we started the programme, and we now realize the importance of distinguishing between the problems of positive antibody status and the AIDS syndrome itself. A counselling and educational programme is now available for seropositives and their families, and we plan to publish information sheets for the various professional groups that are likely to come into contact with people with HTLV III infection or AIDS-related problems.

CHAIRPERSON'S REMARKS

Dr Griffiths' initial programme has had the main objective of giving information to as many different professional groups as possible. Those working in depth with people who are seropositive or have AIDS require more specialist information and training. A list of addresses of specialist groups from which material and information can be obtained is given in Appendix A (pages 241–244).

II. Dealing with 'at-risk' groups

Some aspects for consideration by social workers when dealing with at-risk groups and the AIDS issues, with special reference to those with haemophilia

CHAIRPERSON'S INTRODUCTION

Social work with groups at risk from AIDS is exacting and time consuming. It makes use of many social work axioms relating to the right of the client to confidentiality and self-determination, and to be treated with compassion and dignity. A requirement of testing for HTLV III positivity is that those who come for testing should be aware of the possible implications of the testing, before it is carried out.

Counselling is not just the giving of medical information. What is also required is the opportunity for people to discuss with counsellors the implications of the test results, in terms of their own particular life-style. This sometimes involves interviewing a number of family members, at the request of the person being tested. The results can bring uncertainty for many, and ways of coping with the stress so caused must be found. Social isolation has been increased by the fear of families that they will be identified in the Press.

MRS RIVA MILLER

Introduction

AIDS and all its ripple effects came at a time when the generic approach to social work was the generally accepted policy in most local authority social work departments. In hospitals, apart from a few exceptions where there is specialization, referrals are generally dealt with through 'intake systems'. Where social workers were either attached to Haemophilia Centres or were dealing regularly with these referrals, their involvement with all aspects of AIDS dates from as early as 1984. They were placed in a good position to gain this experience. Several important aspects need to be understood when working with those with AIDS or HTLV III disease, concerns which call for specialization or regular access to those with day-to-day contact both with professionals and patients and their families.

Some aspects for consideration

1. 'At risk' groups. It is important to understand something of the life-style, any dilemmas resulting from it, and the particular medical aspects of all the at-risk groups, which include the following:

Haemophilia is a life-long inherited bleeding condition, requiring replacement infusions of blood products to treat bleeds. Before heat-treated blood products became available, haemophiliacs were at risk from HTLV III infection because some blood donors were infected with the virus.

Homosexuals and *bisexuals* and their partners are at risk from sexual transmission because of their sexual practices.

Intravenous drug abusers are also at risk, primarily because of the common practice of needle sharing, whereby HTLV III can be transmitted from person to person.

Heterosexual spread within the general population can no longer be ruled out.

With all at-risk groups there is the possibility of infecting a sexual partner, and thereby a fetus if a mother is seropositive.

2. Up-to-date medical and epidemiological knowledge and awareness of the legal and ethical conditions are all vital. This information helps social workers to approach the issues with confidence. Unfortunately, no real assurance can be given to infected people about the prognosis, and the meaning of the HTLV III antibody test and status. A knowledge of current research is essential to ensure that accurate information is given. When counselling in isolation, social workers should make sure that both they and their clients should have regular contacts with those with appropriate medical expertise and experience.

3. Prejudices inevitably arise, for example:
'They ought not to have children and continue this inherited condition' (for haemophiliacs); 'God's revenge' (for homosexuals); 'They have brought it on themselves' (for drug abusers).

AIDS and related issues raise many questions which lead to examining one's own prejudices which, under stress, get in the way of dealing effectively with clients/patients. These may be about sex, life-style, disability, disfigure[illegible]

4. At present there is no known cure once AIDS is diagnosed. Infected people are largely in the younger age group. Medical and nursing staff in particular have to find ways of reducing stress, as they can do little for their patients' health. This calls for time and increased counselling skills. Most social workers are well placed to contribute in this area, with medical knowledge and back-up.

5. Staff stress has been recognized in Centres dealing with AIDS and HTLV III issues. This has largely resulted from attempts to get correct and clear information from various sources, when the day is crowded with patient care and practical concerns. Staff find themselves discussing personal/sexual aspects, which neither client and worker are accustomed to. Any efforts to relieve staff stress — such as meetings, seminars and additional training — are important.

6. HTLV III antibody test. The full significance of this test should be understood by the worker before a client or patient can be adequately informed or counselled. Precounselling is very important if possibly devastating social, emotional and practical consequences are to be avoided. Points to consider are: (1) a seropositive result means that the HTLV III virus has at some time been encountered by the client. It does *not* mean that the individual will necessarily develop AIDS, or that the person concerned is in any way protected against the virus; (2) groups that are at risk must be advised to take suitable precautions to avoid becoming infected; (3) practical consequences regarding life insurance and life at work or school must be considered; (4) the value of anti-HTLV III testing must be assessed, both clinically and from the viewpoint of public health; (5) should the client be told about the results of the test, and what might be the consequences of disclosure?

Some dilemmas

1. The mood of optimism has been reversed. Over the past 20 years or so, effective treatments for haemophilia have been developed and, until the advent of AIDS, prospects for leading a 'normal' life had never been so good for haemophiliacs. In the words of a 40-year-old haemophiliac, 'With the successful treatment for bleeding, and the advances in surgery, I thought the battle was over. Now it has started all over again'. Until recently, homosexuals were beginning to be more open about their life-style, and to lead 'normal' lives; AIDS then

2. Treatment dilemmas. People with haemophilia depend on suitable treatments to prevent damage to their joints and to reduce the risk of death from untreated serious bleeding. The dangers of contracting AIDS from contaminated blood products has increased the problems regarding treatment for haemophilia. The visible crippling, pain and immobilization resulting from not treating bleeds, are considered to be worse by most haemophiliacs than the prospect of possibly contracting AIDS or hepatitis B as a result of the treatment. Homosexuals do not face this kind of dilemma, but haemophiliacs and their families are angry that they have been given blood products that have been contaminated.

3. 'Contagious' and 'infectious' aspects. For those with haemophilia, the complications of AIDS are no longer restricted to the patient. There are risks to the sexual partner and, if female, through her to unborn children. The risk of passing on AIDS, whether real or imaginary, can affect family and personal relationships, and also attitudes at work or school. The lives of homosexuals are also very much affected by this aspect, which can accentuate the social and emotional isolation of many gay men. Drug abusers can also be a source of HTLV III infection, not only to others who share their needles, and their sexual partners, but also to unborn babies and infants, through breast feeding.

4. Labelling. The diagnosis of haemophilia is now linked in many people's minds with AIDS, carrying with it the label of 'contaminated' or 'infectious'. Haemophiliacs have also found it difficult to describe their illness to others in attempts to avoid being labelled 'handicapped' or 'disabled'. They fear rejection and social isolation in their relationships because they suffer from haemophilia and are at risk from AIDS. These fears have been realized in some school and work situations. Homosexuals have always been labelled, but now they have the additional stress of being a possible source of AIDS. Drug abusers now also carry a label because of AIDS.

5. Risks for children. Parents of haemophiliacs, who may already have feelings of guilt about passing on the condition to their offspring, now have to face additional dilemmas over treatment for haemophilia because of the possible dangers of contracting AIDS from contaminated blood products. There has been a re-emergence of patterns of 'over-protection', which were so common in pre-treatment days.

Although homosexuals do not have to consider the implications of AIDS for their own children, they do have to cope with the reactions and often uninformed fears of family and friends who, for example,

persons. There are also fears that seropositive i.v. drug abusers may infect children by careless hygiene, although normal household contact has not proved to be risky in this respect.

6. Having children. In recent years, since effective treatment became available, haemophiliacs have often decided to have children, in spite of the knowledge that their ailment could be passed on to future generations. AIDS has changed this, and such couples are now advised to postpone decisions about pregnancy, because a man with haemophilia who had become infected with HTLV III could pass on the virus to his wife, and through her to their unborn child. AIDS information must therefore be included in genetic counselling. This can place severe strains on existing relationships, and can also affect youngsters infected with HTLV III, as they prepare to form their own future relationships.

Seropositive bisexuals and i.v. drug abusers can also transmit HTLV III to their children. In the latter group particularly there is strong evidence of prenatal transmission and through breast feeding, so the advice to them is not to have children at present.

7. Sexual partners and close personal relationships. The fact that most severe haemophiliacs are HTLV III positive has affected patients, because of the fear of transmitting the virus to their partner. Staff are now having to find ways of discussing safe sex and giving hope to people who feel that their lives are devastated. It is the adolescent and young group who face the hardest, apparently insoluble dilemmas. However, humour and imaginative discussion can help them to see things in a different light.

Homosexuals also suffer from these problems. The fear of rejection and isolation is paramount, and the loss of a previous life-style is devastating until they, too, can be helped to see things differently. Because many possible contacts are infected with HTLV III, one effect of the AIDS scare could be to keep homosexual partners together. Intravenous drug abusers not only have to cope with the above problems but, in addition, have those of addiction, including withdrawal symptoms, and these problems can affect their ability to act rationally or responsibly. Their general health is often poor, and they frequently have many sexual partners.

8. Facing death. Those with haemophilia and their families may have already faced the prospect of death through life-threatening bleeds. The threat of AIDS has forced them to think about guardianship [illegible] and making wills. Homosexuals, mostly of a very

knowing the fatal and short-term prognosis. Drug abusers are already at risk through their general health and hepatitis B infection. However, AIDS is an even more clearly life-threatening condition.

9. Medical care. Haemophiliacs and their families, because of the structure of haemophilia care in Great Britain, may remain under one Centre for many years, or even for their lifetime. They establish close relationships with the staff and it is not uncommon for the boundaries between professional and personal relationships to become blurred. This can get in the way of giving and receiving effective information, particularly because of all the uncertainty related to AIDS/HTLV III issues. Homosexuals may have no special medical contacts, apart from the STD clinics. They may be reluctant to go to their own doctors, who may know nothing about their homosexuality. Taking the first step to obtain medical advice could be difficult, and maintaining constant care may also be a problem. Drug abusers may attend a special clinic, but often they have no clear medical support, and there is difficulty in obtaining comprehensive help.

10. The media. For haemophiliacs the media have raised public and government consciousness to their concerns, particularly the supply of blood and blood products. On the other hand, it has linked AIDS and haemophilia closely, affecting social, school and work life. Homosexuals have had their profile raised through the media. One beneficial aspect may be the spread of information about precautions that they can take to avoid HTLV III infection; the same might apply to drug abusers.

11. Family links. The haemophiliac usually has strong links with his family, influenced by the inheritance and constant care patterns that have been developed over many years. Some families often attempted to keep the implications of haemophilia from the outside world, even before AIDS; AIDS has now made this a major dilemma. Homosexuality is often kept from the family for social and personal reasons, and the first that families may know about it is when illness, including AIDS, forces the subject into the open. Drug abusers may also be estranged from their families, whose first knowledge of the use of drugs may, as with homosexuals, follow the development of illness connected with AIDS.

12. Schools and employment. In the past, many haemophiliacs avoided telling their employers about their ailment, because they feared discrimination. As their chances of employment improved with the availability of more effective treatments, this

Haemophilic children are sometimes teased, and are even sometimes called 'AIDS'. Parents struggling to bring up such children as 'normal' have been faced with this new nightmare. Homosexuals may well experience prejudice in the workplace and encounter acts of discrimination. Youngsters with homosexual tendencies now have additional burdens and fears, and need to be educated about 'safer sex'. Drug abusers should be identified and educated about 'safer sex' practices. However, fear may make it hard for them to seek help and advice, particularly if they have already encountered social isolation and discrimination.

Some ways of responding

1. Sessions with individuals, partners and families. The purposes of such sessions include the following: (1) to identify the risk of infection, and to identify the source; (2) to assess how much of a concern AIDS and related issues are to them. You cannot take for granted that they are a major concern with everybody; (3) to find out the extent of their knowledge and understanding about AIDS; (4) to assess the fears, anxieties and needs of the people concerned; (5) to give information; (6) to allocate sufficient time, and to correct misapprehensions in an attempt to allay fears and anxieties.

The methods available for use in these sessions include the following: (1) take time before a session to consider what is known about the individual, couple or family concerned, in order to plan the interview; (2) take time before the end of the session to reflect on the interview before giving your conclusions; (3) take nothing for granted, either knowledge or the lack of it; (4) repeat the last sentence spoken by the interviewee at the start of your next question to ensure that you move at their pace — this also allows the interviewer time to think; (5) always give a follow-up appointment, even if it is in a year's time. This helps people to feel contained; (6) the time between sessions will depend on your assessment of anxiety and signs of depression, and the amount of information you think has been absorbed and understood. I prefer to give plenty of time between sessions to give people the opportunity to find their own solutions during that time.

2. Sessions with groups. Group sessions can be used to give members the opportunity to exchange ideas, concerns and information. Members can learn quickly from each other, and staff also learn more quickly about their concerns. Group meetings benefit from skilled

problems, clarify situations, and seek solutions to their concerns and difficulties.

3. Written material. The provision of appropriate leaflets, pamphlets and booklets containing important information is another way of meeting the needs and concerns of staff and patients; constant 'updates' are necessary.

4. The involvement of medical and other staff. It is very important to discuss issues with medical and other staff and to keep a dialogue open.

Conclusions

AIDS and HTLV III infection are major challenges to patients and their families, and to those who care for them, whether professional carers, friends or volunteers; the uncertainty and life-threatening aspects of AIDS can be overwhelming. The disease concerns everybody, even those in society who think that they are not involved. The major challenge facing us is to become able to view things from a different angle, whether this in the realm of ideas, sexual relationships or the practical issues of life.

CHAIRPERSON'S REMARKS

Mrs Miller's paper highlighted the importance of attached workers to the at-risk clinics, workers who can develop specialist skills and maintain an active link with the changing medical scene as new information comes to light. These workers should be willing to share their information, when asked, with colleagues more isolated from direct medical advice.

Social workers were already finding that the HTLV III virus was implicated in other areas of Social Services Department work beyond the clinics for the at-risk groups, for example:

1. In fostering and adoption where a mother is seropositive, pregnant and may pass the virus on to the child she is carrying;
2. In Day Care Nurseries, Day Centres and in Hostels where a seropositive child or young person may need help with bathing, toileting or counselling;
3. In court reports in respect of the appropriateness of a custodial sentence:

4. In Home Help and Meals on Wheels Services, where there was a need to allay staff anxiety about casual spread;
5. In termination counselling where a person may be seropositive and pregnant;
6. In Artificial Insemination by Donor where some couples were seeking reassurance from social workers that semen donors have been tested for the HTLV III virus;
7. In young people known to be sexually active, especially in a casual way;
8. In referrals to area team offices for financial, practical and counselling help, or assistance seeking accommodation where the distance to an at-risk clinic or non-availability of a social worker there makes it necessary to seek help locally.

III. Some aspects of AIDS and HTLV III positivity for Social Services Departments

(JOHN MCCREADIE)

It will be only a matter of time before the AIDS problem arrives on your doorstep, if it has not already done so. I hope that, as a result of this exercise and similar ones being organized in the UK, that you will be in a better position than I was when the 'knock came on my door' in the autumn of 1985. Preoccupied by the daily round and its pressures, I was faced by an immediate and unavoidable dilemma. An Area Director telephoned to seek guidance as to how he should respond to the news that a haemophilic volunteer, who was helping out in the Area Office as part of his own therapy, was a confirmed carrier of the AIDS virus, having at some time received contaminated blood products. I had to consider my obligations, on the one hand, to the individual concerned and, on the other, to the Department, the Gloucestershire County Council and its staff. I needed more than a little guidance in this matter, because I did not know enough about either the medical or the personnel issues that were essential to proper decision making in this matter. Following a meeting with the Chief Executive and the Council Personnel Officer, I advised the Area Director to counsel the volunteer as to the advisability of withdrawing his voluntary services temporarily until the matter could be sorted out. I now realize that this advice was not in accord with current medical guidance, which rates the chances of transmission in the work situation as negligible or non-existent, provided that everyday rules of hygiene were observed. In any event, the volunteer did withdraw his services following counselling.

A period of comparative calm followed this self-suspension by the volunteer, but this was not to last for long. We soon received letters from the parents of the volunteer and from their Member of Parliament, and I was also asked by the Area Director for permission to reinstate him. My decision was made easier by the fact that the volunteer had personally told everyone in the Area Office that he was HTLV III positive, and that none of the staff objected at all to his return. I was therefore able to agree to his return to 'work'. Unfortunately this was not possible immediately as he was admitted to hospital following a bleed and was reported to be very poorly. The news that he could return when he was well, which was personally conveyed to him in hospital, undoubtedly hastened his recovery. After his discharge from hospital, he has been attending the Area Office regularly, in spite of not usually being very well because of his haemophilia, and has behaved most responsibly in matters of hygiene.

Following this experience, the Occupational Health Unit of the Council decided to deal with the question of precautions against AIDS within the wider context of handling body products generally, to avoid raising undue anxiety about AIDS. They prepared a document entitled *Procedures for Dealing with Body Products*, which is reproduced in Appendix D (pages 255–256), and which the Department Management Team has sent to Heads of Residential and Day Care Establishments and to Home Help Organizers, together with a covering letter suggesting ways in which this information should be passed on to their staff. In addition, a draft booklet entitled *Children at School and Problems Relating to AIDS*, prepared by the Department of Education and Science, has been circulated by the Chief Medical Officer to all general practitioners, paediatricians and haematologists, as well as to the District Health Authority responsible for the School Health Service, in the County. Copies of this draft booklet are available from the Department of Education and Science, and Local Authority Education Departments. A letter accompanying this draft booklet states that a 'guidance document is being prepared, which will cover the wide range of situations where Social Services Department Staff may be involved in AIDS-related problems'. This document is awaited with interest.

Our Departmental response has been to provide immediate training for Hospital Social Work Staff. Further in-service training of a more general nature and the provision of written material are planned. There is a need for a member of the senior management team to become acquainted with the issues, and to co-ordinate a planned Departmental response. This is likely to involve interdepartmental discussion. Management strategies have to be developed. These requirements are time-consuming and depend also on co-operation and good will.

Gloucestershire County Council has recently also announced that the general public and County Council staff are now able to obtain advice on a wide range of health topics, including AIDS and other sexually transmitted diseases, from local libraries that use viewdata terminals. This service will be available in Cheltenham, Cinderford, Cirencester, Dursley, Moreton-in-Marsh, Stroud, Tetbury and Tewkesbury during normal working hours. For those requiring further information, the viewdata screens will also show relevant local contact addresses and telephone numbers. This system, which contains more than 100 pages of information, resulted from co-operation between the County Council and the Gloucestershire Royal Hospital.

Finally, in order that attempts to combat the spread of AIDS may be effective, Districts should concentrate on high-risk groups, complementing the publicity campaigns, and including provision for testing and counselling services; the provision of facilities on a multi-district basis may be appropriate in some places. Plans for 1986–87 should be submitted by 30 June 1986, and for subsequent years should be included in regional short-term programmes. Finance is being made available for regional short-term programmes from central government funds. For example, £2·5 million is being made available in 1986–87 to the NE, NW and SE Thames Regional Health Authorities for treatment and counselling services. This large sum is in recognition of the disproportionately high incidence of AIDS in these regions. This central funding is expected to continue, but will be reviewed for different regions as further information about the spread of AIDS becomes available. However, Health Authorities will have to meet all the costs associated with testing blood donations (except confirmatory testing by the Public Health Laboratory Service), and the extra cost of heat treating Factor VIII.

CHAIRPERSON'S FINAL REMARKS

Mr McCreadie's paper raised a number of important issues relating to confidentiality and the position of staff who might default on a procedure and possibly place themselves at risk.

It is important that information from the grass roots finds its way speedily to senior management, and that management decisions are made in an informed decisive way to help reduce the pressures upon staff working with the strain of the AIDS issue on a day-to-day basis.

It has been pointed out that there are still regional variations as to the number of AIDS sufferers and those believed to be seropositive, and differences in the representation of the various at-risk groups. It

is most important that, at a local level, services should develop in a unified way between the Local Authority, Health Education Council, voluntary sector and Health Authorities at a district and regional level.

From a Social Services Department point of view this might mean the appointment of a social worker as an AIDS adviser to co-ordinate the development of a social care response locally. Some authorities are already drawing up guidelines for the various staff groups within their Social Services Department. In other areas this task might be assigned to a member of the senior management team as part of his or her work-load.

The use of the voluntary sector to pioneer new initiatives has been a long-established principle. The closest co-operation between Social Services Departments and local groups setting up telephone information and counselling services, some of which would be closely associated with the Terrence Higgins Trust, is highly desirable.

Guidelines on social care issues relating to the HTLV III virus and AIDS are awaited in England from the Department of Health and Social Security. The news that the British Association of Social Workers (BASW) is currently writing guidelines of its own is also to be welcomed. It is an expression of all that was said at this workshop that these guidelines should not address themselves purely to practical issues such as the handling of body fluids (important as these are), but that recommendations about counselling should be made. Social Services Departments are used to seeking ways of meeting changing social needs within the community, and it is important that the services offered are imaginative and flexible.

R3

Report from the Terrence Higgins Trust

Introductory Report (Alex Mills and Nick Partridge)

The Terrence Higgins Trust exists to help anybody who has AIDS, or an AIDS-related disease, or who is just concerned about AIDS. The Trust has developed a number of different services. Among them are a medical briefing and other leaflets, such as *AIDS — The Facts*, and *AIDS — More Facts for Gay Men*, which is an *explicit leaflet* about sex; this is reproduced on pages 246–247 of this book. Another important service that we run is our telephone counselling line, which is a telephone link open every evening, seven days a week, and which receives 150–200 calls per week. We also provide a range of support services for people who are known to be anti-HTLV III positive. Many people are not too worried about this knowledge but, for others, adjusting to this information can cause many problems; they have to work out the implications for their own lives. We support several groups and discussion groups, mainly at present based in London, one of which is called 'Body Positive'; this is a social group, with a fortnightly disco, and with the open offer of support and counselling for those who are anti-HTLV III positive. We also have a most important role of providing what is called a 'buddy service'. This involves providing those who have been found to have a terminal illness, who are living alone or with a lover who is worried about catching AIDS, with someone who can act as a well-informed 'best friend' — that is the best way to describe him. The 'buddy' knows about the range of medical and social services that are available, and how to help with practical things. Buddies keep in touch — they visit regularly and provide support for people with AIDS. Currently, we are buddying about 50 people, two of whom are intravenous drug users and the rest are gay men. This is probably the largest buddy supporting system for people with AIDS in Britain so far.

There are a wide variety of skills within the Trust, organized in [illegible] include medical, counselling, social services, legal and

in the organization and development of the Trust. We liaise with other organizations in Britain, where the number of local groups is steadily increasing: for instance, there is a new one in Newcastle called 'AIDS North'. There are also many others, particularly in Scotland, for example 'Scottish AIDS Monitor' based in Edinburgh, which is very active and well established. We also liaise with similar organizations in America and Europe. Another important function is that we try to be a 'voice' for the gay community in their relationships with official bodies, for example hospitals and government. Obviously we cannot represent the full gay community, but we are involved in many important high-level discussions at various times.

To give a better indication of what we do, the contents of five recent telephone calls illustrate the sort of thing that people contact us about.

The first call was from a gay man in his thirties, who telephoned to ask 'What is this test all about? What does it mean?' He wanted simply to know what a positive test for antibodies against HTLV III would mean. It is often difficult for people to appreciate why a positive test means that they are still infectious, especially when they have been taught that antibodies are things that *protect* one against disease. I spent quite a long time trying to explain this, and why it happens. He then asked whether, in view of the fact that his test was positive, he was now infectious. What should he do about safer sex — indeed, what *was* safe? This was an explicit phone call, but fairly routine.

The second call was from someone in a provincial British town who was very worried about his mother. She had had her ears pierced in London a year ago and had complained of marked diarrhoea for the last six months; she was convinced that she had AIDS, and what should she do about it? It is sometimes hard to take requests like this seriously, until you realize the fear and terror that this woman must have experienced for weeks, a fear built up by all sorts of misrepresentations in the media. Here was a woman suffering from some ailment that almost certainly was nothing whatsoever to do with AIDS. Her ailment might well be highly treatable, and would certainly be worthy of help and management, but she was too terrified to see anyone about it because she thought she had AIDS. That sort of call makes up a large proportion of the total. These are people who have no real cause for concern as far as AIDS is concerned, but they are genuinely worried about some symptom of another, probably minor, illness.

The third call was from a woman, whose fiancé had left her to have a relationship with a man. That homosexual relationship had floundered and they were planning to get back together again. She wanted to know what her chances were of picking up AIDS from her fiancé

do about it. This took us into areas of quite difficult discussion about sex and her emotional relationships, and illustrates how many aspects of HTLV III disease can arise from what at first seemed to be a very simple, straightforward call.

The fourth call started with a fairly standard opening gambit, namely 'What are the symptoms of AIDS?'. Our usual reply to this is 'Is there something you are particularly worried about?' This caller went through a list of little spots and pimples and sore throats and, after we had skirted around the subject for a little longer, he suddenly burst into tears and said 'I am going to jump off the bridge'. It then came out that his lover had hanged himself recently, because he thought that he had contracted AIDS. The caller had not told anyone about this tragedy, even his parents, partly because he was introverted and partly because he feared that he might lose his job. He imagined that he would also develop AIDS, in which case the whole world would know, as was the case with Rock Hudson. Some people like this caller feel the need to unburden their minds of things about themselves that they had never dared to reveal before.

On another occasion someone with AIDS telephoned to say that he was desperate because he was about to go back into hospital, but would have nowhere to go when he was discharged home. He was living in a squat, which was to be evicted while he was in hospital, and he would therefore have no home to go to. Because his major problem was diarrhoea, it was difficult for him to manage without proper facilities anyway. He was now totally alone, because he had no close friends and had always been an itinerant sort of person. Here was obviously someone who would benefit greatly from the buddy scheme.

The gay life-style is something that is very well known to those of us who are themselves gay, but is a closed book to those who are not; the latter cannot therefore give proper advice. Health education materials, counselling services and advice telephone lines are pointless, unless they are based on what actually happens, and are run by people with the correct knowledge. No-one knows how many gay or bisexual people there are in Britain, although an estimate can be made from counts of 40-year-old men who are not married. It is particularly difficult to calculate the numbers of bisexuals, who are mainly married men who have occasional gay sex. It is important to remember that the gay community is not something separate from the rest of society in Britain: they are in every walk of life.

I have found that many straight people are unable to grasp the fact that gay sex is much more than anal intercourse. There is a whole range of sexual activity, encompassing many different things that

before he or she can start giving information, let alone advice. In giving advice, it is insufficient to say 'You should be careful when you are having sex' or 'Avoid sexual intercourse'; it is necessary to deal with the varieties of sexual expression, all the things that people try out, such as anal sex, sado-masochism and fisting (which is the act of putting the arm or fist into someone's rectum) — this is part of sex, it happens and must therefore be talked about when giving advice. The spectrum of gay sex ranges from anonymous sex in bath houses or saunas through to deep loving monogamous relationships. Gay people are not just sexual animals, and gay relationships are as loving as any other. Care and emotion come into the management of a gay patient, his sexuality and his partners, as much as they do in dealing with heterosexuals. I have heard someone with AIDS being told, in the presence of his lover at the bedside, 'Well, you must never have sex again'. No-one would ever say that to a straight person.

The many pressures on gay people in Britain mean that many of them do not 'come out', i.e. tell others about their sexuality. When one of these people is diagnosed as having AIDS, many of the normal roots of support that are generally available to those with a terminal illness — when they would turn naturally to their close friends and to their family — are absent. If they say 'I've got AIDS', others will know that they are gay, a fact that they have previously tried to hide, probably for many years.

It is important to remember that the British experience with AIDS differs from that of the United States: the patterns of gay life-styles and gay sex are not the same in the two countries. For example, in San Francisco, one could walk into a bath house and have anonymous sex with 10 or even 20 men on the same night; anonymous sex does not occur to the same extent in Britain. Another difference is that in the United States there is quite an overlap between the gay community and the use of i.v. drugs, whereas this overlap in Britain is small. In Britain, other non-i.v. recreational drugs, such as inhaled nitrites (known as 'poppers') are freely available over the counter in nightclubs and sex shops, and are used quite widely in the gay community. Poppers are used in two ways: in discos and dancing, and in sex. In both activities, poppers can heighten the excitement and pleasure, particularly around the time of orgasm. Although there is no convincing evidence that poppers are involved with AIDS, there remains the possibility that they are one of the co-factors that help in the conversion from anti-HTLV III positivity to AIDS.

The Terrence Higgins Trust is educational, and we believe that education can help the AIDS problem. Although it is difficult to

The first concerns blood transfusion testing. Although blood donations have been screened in the UK only since 1985, the Trust has advised for a long time that anyone in a high-risk group should avoid giving blood. Hepatitis B monitoring suggests that this advice may well have been heeded, as do the figures given by Dr Gunson (Chapter 10). One of the difficulties with both hepatitis B and HTLV III disease is that both have incubation periods during which people are seronegative, and long pre-clinical stages. In both cases, people may be infectious even though they feel perfectly well. However, early indications from the Blood Transfusion Service are encouraging, and it seems that gay men are heeding the advice about not donating blood.

Secondly, at the first Terrence Higgins Trust Conference, when we were told that it was dangerous to donate organs, semen or blood, people in the audience immediately destroyed their kidney donor cards. Again, advice was heeded and education works. The third, more recent, point concerns those STD clinics in London, which are used by many gay men. Figures from these clinics show that patterns of STD are changing: for example, there has been a drop in the incidence of rectal gonorrhoea. Rectal gonorrhoea is spread by anal sex, whereas genitourinary gonorrhoea is spread mainly by 'straight' sex; although the rectal figures have fallen, there is an upward trend for the other forms of gonorrhoea. These trends suggest that gay men are, indeed, changing their sexual practices. However, not all gay men are going to change their sexual practices overnight. It is difficult to stop doing something you know you enjoy, just because of a danger in the remote future.

I want to touch briefly on the subject of antibody testing. Although it has been suggested that anti-HTLV screening is a good way to try to control the AIDS epidemic, it seems from the discussions between the speakers at this conference that there is much scepticism about the true value of routine testing. Indeed, the harmful effects in individual cases may very well outweigh the possible beneficial effects to society as a whole.

Finally, I want to refer to financial matters. The Terrence Higgins Trust operates on a shoestring, with just two paid workers and around 300 volunteers. We work from tiny, cramped offices with minimal facilities. We get a small grant from the DHSS, and we would appreciate more funding from official sources. To date, our main source of funding has been from fund-raising efforts in discos and pubs, and from sponsored events, most of the money presumably coming from the gay community. Such fund-raising is hard work and is an uncertain source of income. It also takes up a great deal of time, which could probably be better spent in counselling and looking after people with AIDS-

Terrence Higgins Trust — Discussion

Question: People who are antibody positive cannot get endowment mortgages or insurance and cannot go to places like Saudi Arabia. How do you advise people who telephone you to ask if they should have the anti-HTLV III test?
Answer: Because of the problems with endowment mortgages, life insurances and difficulties in terms of jobs, we advise caution. We have had many instances of people losing their jobs when it has come out that they are anti-HTLV III positive. We have also had cases of gay men being sacked solely because they *are* gay men, even if they have been able to prove that they are anti-HTLV III negative. So one of our main pieces of advice is that, if you do decide to take the test, you should keep very quiet about the results. The result should be personal knowledge for you only.
Question: So, if you are in a high-risk group, whether you have a test or not should not really affect the way you conduct your life?
Answer: It should not. If you are a gay man, our advice if you are seronegative is to have safer sex, just as the advice if you are seropositive is to have safer sex.
Question: Is it not important for some people to know their status, because it does help them to avoid practices that might infect others? It might also help them to avoid some of the co-factors that may increase their chances of developing AIDS.
Answer: I think that is true for some people, just as some people say 'I will give up smoking when I have had a heart attack'. Others do not need the extra push of some health event to make them change their behaviour; they have read the literature about the injurious effects of cigarette smoking on their health, and have made a rational decision to give it up.
Question: In areas of the country like Newcastle upon Tyne, where we know that the seropositivity rate is much lower than in London, do you not think that screening has a part to play in reducing the risks of transmission, as long as confidentiality is closely guarded?
Answer: I would say no to this, simply because Newcastle, for example, is *not* a closed community — it is only 3 hours away from London by high-speed train. The second point is that you cannot identify all the gay and bisexual men in Newcastle, so you could never be sure that you have identified every seropositive in the city. This approach also leads to the idea that it is safe to have sex with anyone who is not known to be seropositive, and that idea is, for various reasons, very dangerous. Some seronegatives may be incubating the disease and would be infectious.

Question: Is it right to try to trace contacts, because that is at present one of the only ways we can modify the spread of infection?
Answer: No, I do not think that it would be right, for several reasons. First, you do not know when someone became infected, or for how long he has been seropositive, so you do not know how far back you should go in your tracing. Second, you do not know whether the people concerned are willing to be tested. And third, you could offer them only simple, straightforward advice, which you should be offering them anyway. So if you knocked on someone's door and said 'Hi, we have come to test to see if you are seropositive or not. If you are negative, you must have safer sex anyway. If you are positive, you have got a one-in-ten chance of dying in the next 2 years', I think that that kind of intervention into someone's life would be quite unwarranted.
Question: But, on the other hand, will not the success of your health education programme be judged in the end by falling, or at least static, seropositivity rates?
Answer: Absolutely.
Question: And in a region like Newcastle, surely it will be important for the high-risk groups to continue to come forward for testing, so that we have some way of measuring the success, or otherwise, of the programmes, which you are so rightly promulgating?
Answer: Screening programmes differ entirely from the testing of individuals. It is clearly very important to conduct population studies so that we actually know what is happening with this virus in Britain. But there are ways in which this can be done without relating the results to individuals. We should be able to get some idea of the incidence and prevalence of infection without giving each individual person the burden of coping with the knowledge of their HTLV III status.
Question: Taking the test is a voluntary decision for the individual. I think that the sort of epidemiological studies now being conducted are open to question, because they are so reliant on individual decisions. That makes it difficult to ascertain how many people really *are* seropositive. This concerns not only the gay community and bisexual men, but also i.v. drug users and their sexual partners, and many others. Many gay men go regularly for checkups at STD clinics, although these are often regarded as stigmatized areas. So is it not true that whatever figures you get from surveys will be biased?
Answer: Before AIDS was even heard about or thought of, a standard procedure in gay counselling was to advise people to go to a clinic for regular check-ups if they had lots of sexual partners. So I do not think that people are going to ignore their health now, or that they will no longer wish to have their health monitored. However, it is important

even if that test is being carried out for screening or epidemiological reasons.

Question: I would like to follow up the question on contact tracing. Do you not advise it?

Answer: I would advise contact tracing for other sexually transmitted diseases, because you are then able to offer immediate treatment and help. In terms of the HTLV III disease, our feeling is that you do not always know when someone is infected. A seropositive result today may relate to several partners, perhaps 10 over a 2-year period. Any one of those partners could have caused the infection, or it could have been the result of sex more than 2 years previously. And as that person may have had sex with many others, the whole population of gay people in that particular area could be involved. In such a situation, attempts to trace contacts would probably be fruitless. However, if contacts were found, we could offer them very little help at present. Things would be different if we could go to such contacts and say 'You may have got HTLV III infection. Take this pill, which will cure you if you are infected'.

Most of the distressed people who contact us have been found to be seropositive in tests which they did not initiate themselves. For example, some have found that one of their sexual partners is seropositive, or they have gone into hospital for an operation, and were routinely tested. Such people have usually had no precounselling and find it very hard to adjust to the fact that they are infected with HTLV III. So if you are tracing contacts, you must realize that those people who turn out to be seropositive are not always ready to receive that information; they will not appreciate all the implications and will not know where they can obtain the right support. Tracers must therefore be prepared to take the consequences of their actions.

Question: You have suggested that one of the reasons for *not* tracing contacts is that there is now such freedom of movement between communities. If this is so, why are less than 4% of our gays in Newcastle infected, compared with a much higher percentage in London?

Answer: Part of the answer may be that many gay people from Newcastle have their tests carried out in London.

Question: The work of the Terrence Higgins Trust has made a great contribution to health education in London. Should not some of the Trust's literature and help be directed to local communities outside London?

Answer: I agree with you absolutely. Much of the finance, counselling effort and dissemination of information should go to areas where seropositivity is not yet a big problem. Many people in the South East of England are unaware that their region is being hit.

traumatic and very unpleasant experience, and finance for education and the setting up of proper facilities is vital.

There seem to be two main groups of people: first, those who travel widely; second, those that remain in one place. The latter group do not yet think that they are at risk from AIDS. It is our clear role as health care workers to protect individuals at risk, pending the development of specific therapy or vaccination. The only way that we can do this is to identify them, counsel them and educate them. It will be tragic if, in 10 years' time, we have to look back and realize that people have become infected when, by comparatively simple means, we could have prevented this happening.

R4

Report from the Workshop on Drug Abuse: AIDS and the Injecting Drug User

BILL NELLES

Terrence Higgins Trust, London, UK

Introduction

HTLV III infection is now a major threat to injecting drug users who share needles, as shown by recently published prevalence figures from Scotland. The Newcastle conference offered a timely opportunity to explore the problems of health education and infection control among drug users.

Bill Nelles, of the Terrence Higgins Trust — who was, at the time of the conference, seconded to undertake research for the Standing Conference on Drug Abuse — outlined some of the problems that still confound a systematic health campaign to reduce the incidence of drug-related HTLV III infection.

Provision of syringes — the debate

One of the most difficult issues to resolve is whether or not it is helpful to provide clean hypodermic syringes to drug users as a means of infection control. There are potential, but not insurmountable problems in this approach.

Besides the fear of appearing to condone or facilitate an undoubtedly unhealthy activity, many professionals worry that the increased availability, or even free provision, of syringes might lead individuals who are not at present injecting drugs to start to do so.

It was observed that Edinburgh, with its extremely high prevalence of infection, was an area where syringes had become unobtainable, and [illegible] drugs was the most common form of drug taking.

of drug taking that did not involve injection seemed far more common in this city. A clear question seems to be, did making syringes far more difficult to obtain not add, in fact, to the glamour, and hence desirability, of injecting, while increasing the risk of infection through the non-availability of clean syringes?

The continuing risk of sexual transmission

In a study of attitudes to HTLV III infection and AIDS among drug abusers, by Dr Peter Selwyn and colleagues of the Department of Epidemiology and Social Medicine at the Montefiore Medical Centre, New York City, some interesting data were obtained from the drug users themselves on how they felt they might best reduce their risk of infection. Eighty-four per cent of a sample group of 261 i.v. drug users said they would stop sharing needles if they had ready access to a supply of sterile needles. Dr Selwyn also found that the majority of needle sharers did so out of expediency and desperation rather than ignorance. The researchers also found that almost all of the 261 users questioned were aware of the existence of AIDS and how it could be spread. Nevertheless, although the dangers of sharing needles seemed to be understood, sexual methods of transmission were not, as 48% of the sample reported that their sexual activity had not changed.

'In a high-risk population that reports a significant number of sexual encounters with other i.v. drug users — but perhaps an even larger number of sexual contacts with non-drug-users — the implications for heterosexual transmission of AIDS are alarming', Dr Selwyn recently told an annual conference of the American Public Health Association. 'Effective education among high-risk drug abusers might prove to be as important in the area of sexual risk reduction as that of drug and needle use.'

Bill Nelles noted that the limited campaigns that are now under way among drug users tend to focus only on the risk of infection through needle sharing, ignoring anything other than the most cursory details of sexual risk reduction.

SYRINGE SUPPLY

The potential benefits of syringe supply were contrasted with the potential dangers, and a route through the difficulties was suggested, using

Whether we like it or not, we have perhaps 30000 individuals at risk of infection because of their use of injectable drugs, and many more at risk of infection through sexual contact with drug users. Many of the drug users are not yet ready or willing to change this behaviour. Was it fair to the individuals at risk, and those they may infect, not to consider syringe supply because we, as a society, disapprove of the behaviour? Uninfected drug abusers may live to mature out of their addictive behaviour — but the rehabilitation of infected users will be far more problematical.

EDUCATION

Many professionals working with drug abusers have questioned whether or not education initiatives can be effective at all with this group of individuals. Bill Nelles commented on some of the studies in the United States to gauge the response to risk reduction messages — especially those of Dr Don DesJarlais of the Department of Substance Abuse in New York State, and those undertaken by the Haight-Ashbury Free Medical Clinic in San Francisco. Results showed that educational materials framed in language that drug users can understand, and free of moralism about drug use, can substantially reduce needle-sharing behaviour. However, another recent American study undertaken in Texas makes the important point that merely increasing the availability of syringes is not, in itself, enough and could be problematical if these moves are not accompanied by effective health education on the hazards of needle sharing.

Treatment options

There was also discussion in the workshop on whether or not treatment options currently available or denied to drug users might curb the spread of HTLV III infection. The appalling lack of treatment facilities in many areas offering *any* type of treatment drew some comment. Edinburgh still has no statutory drug dependency unit for its residents.

There is currently much debate, at times acrimonious, among those who treat addiction as to the type of treatment that best helps drug users to gain control over their problem — and whether or not treatment should involve the prescribing of oral substitutes such as methadone — or even the provision of sterile injectable drugs.

Those who oppose prescriptions feel that they merely postpone the [illegible] confront the problems underpinning their addiction.

drug users time to sort out personal and social problems by getting them out of the clutches of the black market and on to more controllable methods of drug taking in non-injectable form. This form of treatment has recently become unpopular with most statutory units treating drug dependency. Yet it is the form of treatment that is most popular with drug users themselves. Its availability might attract drug users into coming forward for treatment at a time when it is all the more important to reach them with messages that may help to save their lives, and also the lives of others.

Dr Selwyn commented on this form of treatment in his study, and concluded that, although researchers found that they could educate i.v. abusers about risks and AIDS, education was not enough. He found greatly reduced i.v. drug use and needle sharing among methadone-maintained patients, bolstering claims for drug treatment as a deterrent to continuing unrestrained needle use.

Don DesJarlais has found in his studies that as many, if not more, individuals go on to achieve abstinence after a period on methadone therapy than those individuals offered only immediate abstinence treatment. It was acknowledged that abstinence therapies are the best rehabilitative approach for those who are well motivated, and have a clear commitment to coming off drugs. However this commitment takes time to nurture — and may be very shaky at first in the absence of 24-hour support without the 'half way' step of oral substitution. In New York the decision has been made to triple the availability of methadone treatment slots, because it is the treatment that is the most acceptable to the drug users themselves, and gets them away from the needle.

There is accumulating immunological evidence that the taking of unsterile drugs with unsterile instruments may have a significant role in the development of AIDS in an infected individual. Bill Nelles commented that any treatment that both limited injecting behaviour and induced individuals at risk away from continuing to use syringes might have some merit.

Antibody testing

The last topic covered in the workshop was the issue of antibody testing. Testing drug users could be fraught with problems for individuals because of their emotional vulnerability to anxiety and stress. A positive test result given insensitively could have a profound effect on individuals and their perception of the value of rehabilitation and eventual abstinence.

Some clinicians appear to feel that drug users are incapable of giving informed consent to the antibody testing [illegible]

the blood tests commonly done on drug-dependent patients entering treatment. This was felt to be most unsatisfactory, as a badly handled test done without the consent or understanding of the individual would be invasive and discriminatory, and could lead to drug users staying away from those hospitals that were known not to consult them on the decision nor to take their feelings into account. It was, however, acknowledged that in dealing with a physically debilitated drug user it was important for a clinician to be able to rule out HTLV III infection as a possible problem.

Bill Nelles felt that his personal view, of encouraging but not compelling drug users to take the test, might be justified, in view of the risk of infant infection from seropositive pregnancy and the fact that, apart from the sharing of needles and future sexual contact, most heterosexual drug users were not currently in a sexual high-risk group.

Knowing where they stand might be important to drug users following rehabilitation: knowledge of negative status might reinforce a position to stay negative and avoid risk, while a positive result might help individuals to obtain the support and counselling they may need, in order to understand how they may (and may not) be a risk to others.

Drug users might tend to ignore the 'unknown but possible' threat but take more notice of the actual fact of being infected and thus take better care of themselves. It may not be feasible to expect drug users to behave in the way gay men are asked to behave if they decide not to be tested, i.e. to assume themselves to be positive, to refrain from high-risk sexual activity and to explore 'safer sex'. Few drug users understand 'safer sex' — and there is no social ethos in their group that supports and nurtures a 'no test' alternative.

However, Bill Nelles stressed that the decision in the end should be for the individual to make. He would not advise drug users to seek testing until there were far more trained counsellors and support facilities available than at present in drug treatment centres. He pointed out that there had been virtually no funding for testing facilities or extra counsellors given to drug units to date.

Conclusions

The workshop closed with a clear consensus that much more effort and resources are needed to contain HTLV III infection in this risk group — and that, for the present generation of injecting drug users, the time available for effective preventative work is running out.

Part VIII

Appendices

Appendix A

Useful Addresses and Telephone Numbers

AIDS organizations in the United Kingdom and Eire

The following organizations have volunteers trained to help people with AIDS or related problems, and are in contact with the Terrence Higgins Trust. Where no contact address or telephone number is given, the group can be contacted through the Trust, 01–833 2971 or by writing to: BM AIDS, LONDON, WC1N 3XX.

Haemophilia organizations may be reached through the Haemophilia Society, 01–405 1010; agencies for injecting drug users through the Standing Conference on Drug Abuse (SCODA), 01–430 2341; or by writing to SCODA, 1/4 Hatton Place, Hatton Garden, London EC1N 8ND; and gay counselling groups through London Lesbian and Gay Switchboard, 01–837 7324.

AIDS Concern Midlands, Birmingham
021–622 1511 (Tuesday 7.30–9.30pm)

AIDS North, PO Box 1BD, Newcastle upon Tyne NE99 1BD.

Body Positive, London
Self-help group for people who are HTLV III antibody-positive. Provides an evening telephone service, accessible through the Terrence Higgins Trust's helpline.

Bournemouth AIDS Support Group
0202–38850 (Monday, Tuesday 8–10pm)

Bradford Gay Switchboard Collective
0274–42895 (Sunday, Tuesday, Thursday 7–9pm)

Cambridge AIDS Help Group

Cara-Friend, Belfast
Belfast 222023 (Monday–Wednesday 7.30–10.30pm)

Colchester AIDS Support Group (PASAC)
WRITE: PASAC, PO Box 130, COLCHESTER, Essex, CO1 1GD

Coventry Area Gay Community Organisation
WRITE: c/o CVSC, PO Box 8, COVENTRY, W. Midlands

Coventry CHE AIDS Helpline

Gay Health Action, Cork
(Eire) 021–967660
WRITE: c/o 24 Sullivans Quay, CORK, Ireland

Gay Health Action, Dublin
(Eire) 01–710939 (11am–4pm Mon–Fri)
WRITE: c/o 10 Fownes St Upper, DUBLIN 2

Gay Men's Health Network–Avon and Aled Richards Trust, Bristol/Bath

Glasgow AIDS Information and Counselling Service

Leeds AIDS Information and Counselling Service (AICS) (setting up)

Leeds AIDS Line
Leeds 441661 (Tuesday 7–9pm)
WRITE: Leeds Gay Collective for Women and Men, c/o Rockshots 2, Call Lane, LEEDS LS2

Manchester Aidsline
061–228 1617 (Monday, Wednesday, Friday 7–10pm)
WRITE: PO Box 200, MANCHESTER, M60 1PU

Medway and Maidstone Gay Switchboard, Chatham
Medway 826925 (Thursday, Friday 7.30–9.30pm)
WRITE: Gay Switchboard, PO Box 10c, CHATHAM, Kent, ME4 6TX

Merseyside AIDS Support Group, Liverpool

Milton Keynes Gay Switchboard
0908–312196 (Monday 7–9pm)

Oxaids, Oxford and Oxford Body Positive
0865–246036 (Wednesday 6–8pm)
WRITE: c/o Harrison Dept, Radcliffe Infirmary, OXFORD, OX2 6HE

PASAC, Norwich

Reading Area AIDS Support Group
0734–503377 (Thursday 8–10pm)
WRITE: PO Box 75, READING, Berks.

Scottish AIDS Monitor, Edinburgh
031–558 1167 (24 hr answering machine)
WRITE: c/o 23 Dublin St, EDINBURGH, Scotland

Solent Aidsline, Southampton
0703–37363 (Solent Gay Switchboard, Tuesday, Thursday, Saturday (7.30–10pm)
WRITE: c/o PO Box 139, SOUTHAMPTON, Hants.

Sussex AIDS Helpline, Brighton
0273–734316 (Monday–Friday 8–10pm)
WRITE: PO Box 17, BRIGHTON, BN2 5NQ

West Yorkshire AIDS Support Group

Some other organizations involved in the production of educational and other literature. Please note that payment may be required, and that, even when material is free, most are charitable organizations and would welcome cover for postage and packing

Gay Men's Health Crisis
254 West 18th Street
New York NY
USA
Tel: (212) 807 6664

San Francisco AIDS Foundation
Materials Department
333 Valencia Street
4th Floor

Shanti Project
890 Hayes Street
San Francisco
California 941117
USA
Tel: 558 9644

UK Haemophilia Society
PO Box 9
16 Trinity Street
London SE1 1DE
England
Tel: (01) 407 1010

UK Healthline Telephone Service
(01) 981 2717
(01) 980 7222
(0345) 581151

Healthline address (College of Health):
HEALTHLINE
PO Box 499
London E2 9PU

UK Government AIDS Information Booklet
Dept. A, PO Box 100
Milton Keynes MK1 1TX

USA National Hemophilia Foundation
19 West 34th Street
Suite 1204
New York NY 10001, USA
Tel: (212) 563 0211

World Hemophilia AIDS Center (WHAC)
2400 South Flower Street
Los Angeles
California 90007
USA
Tel: (213) 742 1354 Telex: 6502283270 MCI

Appendix B

Reproduction of *AIDS—More Facts for Gay Men*, an explicit leaflet from the Terrence Higgins Trust

What if you are HTLV III Antibody Positive?
Firstly and most importantly remember that you are most likely to stay entirely well.

You must accept though that you are very likely to be infectious to others if you have 'unsafe' sex with them. This means that they could eventually die because of it. Be responsible.

You will probably need a lot of support and information, both of which can be hard to come by at this critical time. The Terrence Higgins Trust exists to provide these and can also put you in touch with Body Positive, a support group of antibody positive men who have all been through the same problems.

Go back to the clinic which did your test. They should be prepared to help you with your problems. If not, ask us which ones will.

Why do only some Antibody Positive people get AIDS?
We don't know for sure but there are some ideas.

1. As with all infections, some people are just born better able to fight this virus.
2. Some other infections such as syphilis, hepatitis and CMV may make the virus more active in the body.
3. Recreational drugs (including alcohol and tobacco) can lower your resistance to disease.
4. A balanced diet, rest and relaxation may assist your body to fight infection.
5. Having other men's semen inside your body may in itself reduce your ability to fight infection.

AIDS is a terrifying disease but with a little care and knowledge you can still enjoy sex and life and be sure of staying healthy. It's up to you.

THE TERRENCE HIGGINS TRUST
A registered charity to inform, advise and help on A.I.D.S. (Acquired Immune Deficiency Syndrome)
The Terrence Higgins Trust Limited, BM AIDS, London WC1N 3XX. Telephone: 01-833 2971
Charity Reg. No. 288527 Company Reg. No. 1774149 Registered in England

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AIDS

Remember

The more men you have sex with, the greater your chance of getting AIDS.

Anal sex carries the highest risk.

DO NOT donate blood or semen.

DO NOT carry an organ donor card.

THE TERRENCE HIGGINS TRUST
HELPLINE
01-833 2971
7-10PM MONDAY-FRIDAY
3PM-10PM WEEKENDS

Our leaflet 'AIDS — The Facts' which you should also have been given or can get from the Trust, will tell you the basic facts about AIDS. As a gay or bisexual man you need to know more.

Safer Sex

You risk catching HTLV III (the virus which may lead to AIDS) through having sex. We want to tell you how you can reduce this risk.

The virus is passed on when semen or blood from an infected person enters the body of an uninfected person. This happens most easily through the anus or cuts in the skin. There is possibly a small risk that saliva (spit) and urine could also be infectious, but this is much less likely.

The more people you have sex with, the more likely it is that at least one of them will be infected. Cutting down your number of sexual partners will reduce the number of risks you take.

We know that people who have had anal sex with more different partners have a higher chance of being infected. Using a condom (rubber, durex) will help *if* it stays together but they very often burst during gay sex. You can't rely on them, but if you are going to screw, you should use a condom and a water based lubricant (such as K-Y). It is safer to avoid anal intercourse unless you are sure that both you and your partner are uninfected, or you are involved in a long-term monogamous relationship.

While we know that anal sex is the highest risk activity, we have estimated the risk of other sex acts working from basic principles. The lower the risk category, the safer the sex!

RISK FREE SEX (no problems)
Solo masturbation (wanking) and fantasy
Sexy talking
Massage without masturbation
Sex toys (like dildos) used by you and only by you

LOW RISK SEX (fairly safe)
Mutual masturbation (wanking together)
'Dry' kissing (**almost** anywhere on the body)
Sex toys used on another person — but **never** shared
Bondage, spanking etc — but never break the skin
Body rubbing — try warm oil!

MEDIUM RISK SEX (definitely less safe)
'Wet' (deep or French) kissing
Putting fingers into the anus
Cock sucking — it is probably even less safe if he (or you) comes. Spitting the semen out afterwards won't help.
Water sports (pissing on someone). This will be more dangerous if it gets into the eyes, mouth or breaks in the skin.

HIGHER RISK SEX (positively dangerous)
Using someone else's dildo, butt plug etc. It's almost impossible to sterilise them reliably.
Rimming (licking or tonguing someone's anus). There are several unpleasant infections you can catch this way.
Fisting (putting the fist or hand into someone else's rectum). You are almost certain to cause at least a little bit of dangerous bleeding.

HIGHEST RISK SEX (**known** to be very dangerous)
Anal sex (fucking, screwing). Read about condoms above.
Anything which draws blood.

Is there a test for AIDS?
Briefly — no.

There is a test available in clinics which will now tell you fairly reliably whether you have been infected with the HTLV III virus. We know however that only about one in ten people who are infected will develop AIDS. Some others will develop less severe illnesses but most will stay completely healthy. This test (the HTLV III antibody test) will **not** tell you whether you will become ill.

BUT people who get a positive test result will be very likely to be infectious and should **always** take precautions to avoid passing the infection on to others. For gay men this means safer sex.

If you don't have the test done, you must accept that there is a chance that you **could** be infectious to others. Again safer sex is the only safe way.

There are strong arguments both for and against having this test done. Many people find a positive result very hard to cope with, however strong they are. Read the Trust leaflet 'HTLV III Antibody; to test or not to test?', and discuss it with our helpline or your local AIDS phoneline if you have doubts. Do this **before** you have the test done.

What if you have had sex with someone who develops AIDS?
Your risk of illness is small. Talk to a doctor at a sexually transmitted disease (VD) clinic. If you are offered the HTLV III antibody test, don't decide straight away. Read the Trust leaflet or talk to the helpline (see the section on "Is there a test for AIDS?").

Appendix C

HTLV III Infection and AIDS in Injecting Drug Users: Report from the Standing Conference on Drug Abuse

Introduction

Agencies which are tackling the problems of HTLV III infection and AIDS in drug users are only now beginning to receive the help and support that they need. Access to the expertise and resources which are required for the scale of the problem is still limited.

The Standing Conference on Drug Abuse (SCODA) and the Terrence Higgins Trust have attempted over the last six months to provide urgently required information, both to professionals and to those at risk from infection. The goal has been to alert both groups to the action which needs to be taken to combat one of the most serious public health problems of our time. Posters and leaflets are now being distributed, advising on risk reduction.

Professionals have many ideas for schemes aimed at offering some protection against HTLV III infection and AIDS to those at greatest risk. There is, however, a major dilemma: measures which might be effective in limiting the spread of the HTLV III virus in injecting drug users are in conflict with those measures which are currently good practice in the treatment of drug misuse. For instance, a shortage of needles and syringes is a factor in the sharing of injection equipment between drug users, but good treatment practice is seen as not prescribing injectable drugs and the means of injecting them. The goal of treatment for drug users is seen as abstinence and therefore drugs should not be prescribed as part of that treatment, but control of the spread of infection requires risk reduction, including not sharing injection equipment, and the prescribing of oral substitute drugs may be essential for those not yet ready for abstinence or a rehabilitation programme. The conflict is profound and challenging.

Which approach should have priority — attempts to limit the spread of the virus, to which injecting drug users appear one of the most

theirs but that injecting drugs and sharing injection equipment can lead to and spread infection and result in AIDS, in addition to other serious consequences?

It is difficult, if not impossible, to summarize the dilemma in a short introduction. Answers are even more difficult to find. This brief paper is an attempt to present some of the problems, to provide an update on a number of current prevention initiatives and to offer substantial food for further thought.

Increasing incidence of infection

The incidence of HTLV III infection in drug users appears to be slowly increasing, although some areas are showing much higher levels of infection than others. It is clear, however, from the pattern of reports of antibody-positive drug users, that the virus is now present in all areas of the country. Drug-free residential rehabilitation communities are now admitting individuals from all parts of the country who are subsequently found to be infected. The last published estimate of HTLV III prevalence in drug users from the Public Health Laboratory Service, based on limited sampling and excluding areas of Scotland, shows a 5–6% level of antibody-positive returns.

In 1985 much of the attention has been focused on parts of Scotland where screening of drug users for antibodies had been undertaken. Whether this screening was being done with adequate pre- and post-test support is open to much debate, but the results were of considerable importance. Many cases of infection were detected in Edinburgh and Dundee, with some cases in Glasgow. Even assuming *no* rise in the number of drug misusers infected, it must be conservatively estimated that some 40–50 young drug users in Scotland alone will develop frank AIDS within the next 2–3 years. Given the unlikeliness of the assumption, as infection is almost certain to spread for some time, then the numbers may well be higher.

Moreover, it may well be that the situation is far more serious than has previously been believed in other areas outside Scotland. It is often difficult to reach injecting drug users at risk and to obtain the necessary support facilities for antibody screening. In consequence, the information base in these areas is likely to be substantially lower than that in areas where testing has been undertaken for some time.

The role of treatment centres

Drug dependency units in the United Kingdom now recognize the need

However, the services which they offer to injecting drug users are often not perceived by the drug users as worth pursuing. Few, if any, will prescribe drugs in an injectable form and many will not prescribe substitute drugs as an alternative to street drugs.

Many professionals share the belief that, with this new and potentially lethal threat of HTLV III infection, it is all the more important to induce those at risk to make contact with agencies and treatment centres. They are, however, divided on how this should be achieved. Some would argue that a policy of offering an oral substitute drug is a strong inducement to individuals to stop what is their primary AIDS-risk behaviour (unless they are also homosexual): namely, the using and sharing of injection equipment. Others would argue that they are in the business of helping people to get off drugs, not of providing drugs which would perpetuate the situation they seek to remedy — drug dependence. Yet others would argue that, in this situation, where infection is spreading rapidly but is not yet endemic among drug users, the provision of injectable drugs with injection equipment, or at least greater access to injection equipment, is a method of prevention which is well worth trying.

At a recent meeting held at the Public Health Laboratory Service in London, the need to fund large-scale programmes that can counsel drug users and offer the antibody test was widely recognized. No plans have yet been made to accomplish this. It is unrealistic to expect the sexually transmitted disease clinics to continue provision of counselling and testing for injecting drug users, especially in Metropolitan areas: services designed for drug users will have to become involved.

Prevention of spread — the goals and the problems

Thus, the difficulties are considerable. Although injecting drug users who share injection equipment are most at risk of becoming infected or of infecting others, those who are not at present injecting but have done so in the past may already be infected. They risk infecting others through intercourse. They are a potent group for spreading infection more widely into the population generally believed not to be at risk. Prevention has two goals: first, to limit the spread of infection among the most at-risk groups, namely those injecting drugs and sharing equipment; second, to limit the spread of infection from drug users to the general population through counselling and advice about safe sexual practices.

The task of motivating those who are drug dependent to understand that there are alternatives to continued drug use is a long and involved

achieved quickly and harm reduction as part of the process towards abstinence is an essential element in any treatment intervention. With HTLV III infection now such a real threat, can we allow ourselves the luxury of refusing to deal with drug users except from a position of saying 'Abstinence is the only goal and everything we do will be designed to achieve this as speedily as possible, whether you are ready to accept such an arrangement or not'?

There is clearly a need for more resources. Many drug users who seek help with their drug problem cannot be accepted into treatment or rehabilitation because these services are already full. But there is also a need to develop existing treatment services which can counsel drug users, advise them on risk reduction both in their drug use and sexual behaviour, offer them alternatives to continued dangerous injecting practices and, if necessary, offer them injectable drugs and the means of injecting them.

Using drugs, particularly by injecting them, is one of the most stigmatized and labelled forms of behaviour in today's society. It will not suddenly cease, however, just because we disapprove of it. Although it is an unsafe activity, especially when someone who knows little about drugs and the dangers associated with injecting chooses to experiment indiscriminately, we cannot afford to ignore the facts. If sharing drinking glasses were a high-risk AIDS activity, would not all those who chose to drink have been given sterile glasses for their own use by now? Although this is not an exact analogy, because of the other risks involved in injecting whether or not the equipment is shared, it is essential that we do not reject out of hand particular risk-reduction measures because of our antipathy towards the behaviour.

Essentially the question is whether our own feelings about drug use (as with the feelings about homosexuality) at times cloud our judgement when it comes to devising strategies to beat this virus. The tests of any intervention should be: has the drug user ceased sharing injection equipment; is s/he aware of the risks involved in sharing injection equipment, and are his/her drug-using friends aware of these risks; has s/he ceased taking drugs by injection; has the drug user become more controlled in his/her drug use; has abstinence from drug use become a goal for the drug user?

These tests are not incompatible with the goals of drug treatment, but they do challenge the limited alternatives offered by many drug-dependence centres. It is understandable that the idea of supplying clean injection equipment or of prescribing substitute drugs either in oral or injectable form to drug users may be unpalatable. In the light of the spread of HTLV III infection, however, is it not better to have uninfected drug users who may survive their addiction than to h...

infected drug users who may not? For this to be achieved, it is essential that a greater range of alternatives should be made available to drug users, rather than a continued limitation which they find unacceptable and in many cases not worth seeking.

Appendix D

Procedures for Dealing with Body Products (*see* page 220)

ALL body products, from whatever source, (vomit, urine, faeces, blood, etc.,) should be treated as potentially *INFECTIOUS*. Appropriate precautions should, therefore, be taken in dealing with them.

The following guidelines are intended to safeguard the health of employees who may be called upon to dispose of body products, whatever the nature of possible infection. (They, therefore, cover and should allay anxiety with regard to gastroenteritis, hepatitis, AIDS, etc.).

1. The single most important measure is the use of adequate amounts of *cold water*, both in clearing up spilled products and in washing after the completion of the disposal. (Hot water may result in protein-containing substances becoming more adherent).
2. *Rubber gloves* should be worn, if available. Those habitually needed to perform these duties (Home Care Assistants, etc.) should have gloves supplied and should always wear them when engaged in such duties.
3. If gloves are not available, infection is still unlikely, provided there are no open wounds on the skin and hands are vigorously washed with soap and cold water, after contact. Attention should be paid to cleaning under the nails and a *nailbrush* should be used.
4. *If open wounds are present* they must be adequately covered with a waterproof dressing before dealing with potentially infectious material. If the skin surface is broken during the course of the cleansing operation, thorough cleansing with running cold water and soap and the encouragement of bleeding, will make infection unlikely. Such wounds should be reported to the Occupational Health Nurse on completion of the disposal operation.
5. The most readily available and most suitable disinfectant is *HOUSEHOLD BLEACH* freshly made up at a strength of 1 part in 10 with water. This should be used liberally to clean down contaminated surfaces and left to dry. When not available, most domestic and industrial disinfectants will deal effectively with the majority of

6. Disposal of possibly infectious waste should be carried out as soon as reasonably possible. It should be mopped up and the contaminated disinfectant solution emptied down a toilet bowl, taking care not to spill it further. The mops or cloths used should be subsequently well cleaned in fresh disinfectant solution.

A.G. Samuel-Gibbon
Medical Officer for Occupational Health,
Occupational Health Unit,
Gloucestershire County Council

Glossary

AIDS The acquired immune deficiency (or immunodeficiency) syndrome. The name was given to the disease after investigation of the first cases by CDC in 1981. 'Acquired' means that it is caught as an infection rather than inherited; 'immune deficiency' means that the body cannot defend itself properly; 'syndrome' means the illnesses that result.

Anti-HTLV III The non-protective antibody of the AIDS-related virus. A person may be anti-HTLV III positive (which means he or she has been infected and is infectious to others under certain circumstances) or anti-HTLV III negative.

CDC Centers for Disease Control (USA).

CDSC Communicable Diseases Surveillance Centre (UK).

CMV Cytomegalovirus.

Co-factors Events which may help to precipitate the development of AIDS in somebody who is anti-HTLV III positive. Co-factors currently recognized include other infections (especially STDs), age and pregnancy.

EBV Epstein–Barr virus.

Factor VIII Blood-clotting ingredient deficient or absent in haemophilia A.

Factor IX Blood-clotting ingredient deficient or absent in haemophilia B or Christmas disease.

Hepatitis B Serum hepatitis, now preventable by safe vaccination. Hepatitis B spreads in similar ways to HTLV III, and the general precautions to prevent spread are identical.

HTLV III Human T-cell lymphotropic virus, type III (3). The AIDS-related virus, third in a series of retroviruses to be discovered. Discovered by Dr Robert Gallo and his colleagues working in Bethesda, USA. The same virus is also called LAV.

HTLV III disease A collective term for all the disorders associated with AIDS.

Incubation period The time between infection and the appearance of symptoms or signs of disease. Not to be confused with the time between infection and the appearance of laboratory markers for

ITP Idiopathic thrombocytopenic purpura. A deficiency in the numbers of blood platelets leading to a bleeding disorder.

Kaposi's sarcoma: KS A vascular tumour first described by Dr Moriz (Cohen) Kaposi in 1872. Rare before AIDS. KS presents as purplish pigmented painless raised lesions of the skin, sometimes surrounded by bruising. Other body structures, especially the hand, foot, palate, gastrointestinal tract and lymph nodes are frequently involved (*see Frontispiece*).

KS Kaposi's sarcoma.

LAV Lymphadenopathy associated virus. The AIDS-related virus discovered by Dr Luc Montagnier and his colleagues working at the Pasteur Institute, Paris. The same virus is also called HTLV III.

Lymphadenopathy Enlargement of the lymph nodes.

Lymphocyte A type of white cell programmed to repel infection. T lymphocytes are thymus-dependent; the type targeted preferentially by the AIDS-related virus is the T4 or T-helper cell.

Lymphoma A cancer arising in the lymphatic system. Hodgkin's disease is one type of lymphoma.

OI Opportunistic infection.

Opportunistic (opportunist) infection: OI Infection with an organism usually kept at bay by the immune (defence) system in health. Opportunistic organisms may be viruses (for instance herpes simplex — the 'cold sore' or herpes zoster — 'shingles'), fungi (*Candida* or 'thrush'), parasites (*Pneumocystis carinii*), or bacteria (*Mycobacterium tuberculosis*). It is important to remember that most of these infections occur in the population for reasons other than AIDS.

PCP *Pneumocystis carinii* pneumonia.

PGL Persistent generalized lymphadenopathy.

PHLS Public Health Laboratory Service (UK).

***Pneumocystis carinii* pneumonia; PCP** The commonest opportunistic infection recognized in people with AIDS. *Pneumocystis carinii* is a commonly occurring parasitic organism which is of no consequence to people with intact immune systems. Common presenting features of PCP are cough and shortness of breath. Chest radiology may be normal. The organism is difficult to culture; bronchial lavage or biopsy, or sputum induction are required for diagnosis in most patients.

Persistent generalized lymphadenopathy Lymphadenopathy involving at least two extrainguinal sites for at least 3 months' duration in the absence of any current illness or drug known to cause lymphadenopathy.

SCODA Standing Conference on Drug Abuse.

Seropositive In the case of AIDS, anti-HTLV III positive, or HTLV III-antibody-positive.

Shanti Project Shanti is a Sanskrit word meaning 'inner peace'. It was adopted by Dr Charles Garfield of San Francisco in 1974 as the name of an organization dedicated to the care of the terminally ill, their loved ones and those grieving their death. Services are provided wherever they are needed by carefully screened and educated volunteers in complete confidence. Shanti Project of 890 Hayes Street, San Francisco, California 94117, USA publishes a training manual for emotional support volunteers. The manual contains a wealth of information on the Project and its policies, counselling skills, death and grief, general medical and ethical information and papers on AIDS. Current cost is $35.00 plus postage.

STD Sexually transmitted disease. STD clinics are also called Genito-Urinary Medicine clinics or Special clinics.

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