AIDS

Psychosocial Factors in the Acquired Immune Deficiency Syndrome

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By synthesizing what is known about the broad psychosocial ramifications, the author of this book helps to demystify acquired immune deficiency syndrome (AIDS). She reviews the literature, reports the experiences of patients and professionals, and summarizes research implications. Readers will find specific information on how AIDS changes victims' lives. They will learn about the studies that thus far have been done on the spectrum of psychosocial factors, particularly but not exclusively with regard to the gay experience. They will read accounts by involved practitioners of psychiatry, nursing, administration, hospice care and political activism. They also will come to understand the social worker's unique role in integrating the multidisciplinary team and in helping patients, their friends and their families come to terms with AIDS.

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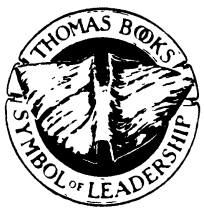

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To Reuben S. Roy, M.D.
who showed me
the valleys all have mountains
worth climbing if we dare

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ABSTRACT

AIDS: PSYCHOSOCIAL FACTORS IN THE ACQUIRED IMMUNE DEFICIENCY SYNDROME had been downplayed in the literature while scientists sought to unravel the mystery of this "new disease." While distinct categories of individuals at risk were defined, i.e. homosexuals, hemophiliacs, IV drug abusers, and (until April 1, 1985) Haitians, the affected population broadened to include heterosexuals and offspring of those in risk groups as well as transfusion recipients.

This "State of the Knowledge" paper seeks to examine the psychosocial factors affecting those individuals at risk, reviewing the literature to date. Because of the existence of a sociopolitical network as an outgrowth of the Gay Liberation Movement, and because the initial AIDS patients were gay, most of the emphasis in the literature and in this paper has been focused on the gay AIDS patients and their means of coming to terms with the disease, in an effort to determine ways in which their approach can be generalized to others in high risk categories.

The psychosocial factors affecting these patients were first specifically noted in 1983. Much has been written since that time, but in an effort to complete the picture, and because much valuable information has remained anecdotal, included in this study are interviews with two anonymous AIDS patients, as well as six health care professionals, who work closely with individuals afflicted with the syndrome.

The findings delineate many ways in which social workers, utilizing skills uniquely theirs, can work as part of a multidisciplinary team to help the AIDS patient come to terms with the illness, work through remaining problems, and find support in the face of a life threatening disease.

CHAPTER ONE

(THE STUDY)

I. INTRODUCTION

"I can't make any plans. What's the use in planning? I used to be afraid of dying. Now I just don't know" (J., 1985).

"A lot of profound things have happened since I found out about AIDS. All I can say is every day is very special, and I'm not worried about tomorrow or yesterday. I'm just worried about being in the now . . . yet I just want to fade into the woodwork" (E., 1985).

"They see themselves as lepers. They really do!" (Murphy, 1985).

Isolated comments? No, these are representative statements from people diagnosed with AIDS, or those working with them.

AIDS, Acquired Immunodeficiency Syndrome, might be termed the disease of the eighties, defined as a reliably diagnosed disease that is at least moderately predictive of underlying cellular immune deficiency in a person with no known underlying cause of cellular immune deficiency or any other cause of reduced resistance reported to be associated with that disease (Centers for Disease Control c).

Given the definition, what do we know of the origins of the disease and its epidemiology, and how does this knowledge lead us to an understanding of the psychosocial factors affecting the lives of the AIDS patients, their significant others, and the health care professionals who serve them?

To date there are 12,256 cases of AIDS in the United States. Of these cases 8861 are homosexuals, 2082 IV drug abusers, 75 hemophiliacs, 120 heterosexuals, 184 blood transfusion recipients, and 785 in none of the above categories. Until April 1, 1985 Haitians were a separate category. March 25 there were 280 cases of Haitians with AIDS, but their statistics have been combined with the "none of the above category." There are 149 pediatric patients, 104 born to parents with AIDS, 8 hemophiliacs, 23 transfusion recipients, and 14 in none of the above categories. A total

of 6171 AIDS patients are now deceased, including 103 pediatric cases (Centers for Disease Control, 1985).

My first encounter with the disease was at a 1982 dermatology meeting in New Orleans where I heard an anecdotal presentation on the topic of AIDS, heightening my curiosity regarding what might be deemed a "new disease." A review of the literature showed that 26 homosexual men, 20 in New York, 6 in California, had been diagnosed as having Kaposi's sarcoma (KS), with 6 having Pneumocystis carinii (PCP) (Centers for Disease Control, 1981 a,b). Gottleib, Ragaz et al. (1981) had started interest in the investigation which lead Hymes (1981) to conclude that the homosexual population may have an increased risk of Kaposi's sarcoma. While these patients were studied for cytomegalovirus (CMV) antibodies and had positive titers, and for hepatitis B infection, the authors posed that other as yet undefined factors may be equally important.

Gottleib, Schroff et al. (1981) noted they did not think the fact that this illness was first observed in homosexual men was due to coincidence, but rather was suggestive of a sexually transmitted infectious agent or exposure to a common environment which had a critical role in the pathogenesis of the immunodeficient state. The 4 patients described in their report did not know each other; one had a partner for 7 years, 2 had several regular partners, and 1 was highly sexually active and frequented homosexual bars and bathhouses. All had been exposed to hepatitis B, but there was no history of exposure to a common prescribed or illicit drug. All had severe wasting syndrome. This included fevers of unknown origin, mucosal candidiasis, night sweats, and diarrhea.

Following Gottleib's article Thomsen (1981) noted 2 cases of Kaposi's sarcoma (KS) in homosexual men in Europe, and Brennan and Durack (1981) wrote about the "Gay Compromise Syndrome," calling it this because the disease appeared in homosexuals who seemed to be severely immune compromised. They hypothesized that CMV (Boyd, 1982) or one of the "recreational" drugs might be immunosuppressive.

Drew and Conant et al. (1982) looked at CMV and KS in young homosexual men and stated that they favored the hypothesis that a state of immunocompromise (Bardana, 1981) preceeds the development of KS in homosexual men, suspecting that these men are challenged by repeated exposure to CMV from their multiple sexual contacts.

Ziegler, Drew et al. (1982) noted an outbreak of Burkitt's like lymphoma in homosexual men in the San Francisco area, commenting that the range of malignancies in homosexual men was widening.

Then the picture began to change. The Centers for Disease Control (CDC) (1982a,b,c) reported Pneumocystis carinii pneumonia (PCP) among persons with hemophilia A and opportunistic infections and Kaposi's sarcoma (KS) among Haitians in the U.S. This brought two additional groups into the picture. Initial reports on the Haitians (Vieira, Frank et al., 1983) noted that the incidence of multiple sexually transmitted infections and frequent use of prescription or recreational drugs was generally absent in this group, but in their series 5 of the cases that had taken the drug, rifampin, for the treatment of tuberculosis, this drug has been shown to have immunosuppressive effects in vivo and in vitro. These authors hypothesized that if a viral agent were imported to the U.S. from Haiti by vacationing homosexuals, it might spread quickly within the homosexual community by means of frequent, often anonymous, sexual encounters in bathhouses.

As the figures began to mount, the picture began to change so that by 1984 Allen and other researchers came to realize that not everyone fit into the categories of homosexual or bisexual men, IV drug abusers, Haitian emigrants (cf. p. 5), and hemophiliacs. Six percent of the patients who satisfy the AIDS case definition do not belong to one of these patient categories. Half have been patients for whom sufficient information has not been available to allow classification due to early death. Ten percent of these cases have KS but normal immunologic studies, suggesting they probably do not have AIDS, even though their disease satisfies the surveillance definition. Seventeen percent of the remainder are persons who received blood transfusions and 15% are patients who had heterosexual relations with persons with AIDS or persons who are in a risk group with an increased incidence of AIDS. There has been transmission of AIDS to infants whose parents were in a high risk group, but it is not certain whether the transmission was intrauterine or intrapartum (cf. The Lancet editorial, 22 January 1983; Marx, 1983).

Fauci and Lane (1984) note that some present a chronic lymphadenopathy, which has been termed pre-AIDS. They also comment that the clinical manifestations of the disease vary, with PCP without KS most frequently seen; then KS is found without PCP. Haverkos, Pinsky et al. (1984) found in their series of 87 that 45 patients had KS but not PCP, 20 had PCP but not KS, and 20 had both. They found patients with PCP were less sexually active, used fewer illicit drugs and inhaled sexual stimulants, had lower rates of non-B hepatitis by history, and lower incomes. Klein (1984) concluded that in patients at high risk for AIDS,

the presence of unexplained oral candidiasis predicts the development of serious opportunistic infections more than 50% of the time. Joy (1984) in response to Klein's article replied that oral candidiasis might be the proverbial tip of the iceberg of the underlying disease.

Weber, Carmichael et al. (1984) said that in the United Kingdom they did not find PCP in any of their cases, nor was there CMV in the blood, stool or urine of any of the patients. However candida albicans was found in all of the patients, seen both as oral and esophageal candidiasis. The authors state that homosexual men with symptoms of severe malaise, loss of weight, night sweats, fevers or prolonged diarrhea should be seen immediately.

About the same time came a look at the African connection with the disease (De Cock, 1984) proposing that the infectious agent causing the disease is endemic and unrecognized in parts of sub-Saharan Africa, from where it recently disseminated into external populations. De Cock states that Burkitt's lymphoma is most common in areas constituting a band across Africa, the "lymphoma belt." This belt encompasses the areas where Kaposi's sarcoma (KS) is endemic. To broaden the problem, the author notes that there are now an increasing number of well documented cases of AIDS in black Africans, mainly Zaireans, in whom obvious risk factors were lacking, with the first case dating back to 1977. In continental Europe heterosexual black Africans and their sexual partners now constitute an important risk group for AIDS (cf. Edwards, 1984; Downing, 1984).

As early as 1982 Groopman and Gottleib had noted that KS, while a well-recognized but nevertheless rare endothelial neoplasm, generally occurring among elderly men of Mediterranean and Jewish ancestry, also occurs in an endemic form in certain areas of equatorial Africa. They believed the common link epidemiologically between KS, opportunistic infection, and the initial American cases was male homosexuality, and they postulated that there might be a genetic predisposition to the syndrome, or that CMV infection among homosexually active men may "wear down" the immune system and lead to cellular immunodeficiency.

The sexual contact component was examined by Auerback, Darrow et al. (1984), who studied a series of 29 patients who were linked and interviewed (72.5% of 40 patients) and 49 non-linked patients who were interviewed (23.6% of 208 patients). The linked were significantly more likely than the non-linked patients to have met sexual partners in bathhouses, to have been frequent users of amyl or butyl nitrite, and to

have participated in the sexual practice of "fisting," i.e. manual-rectal intercourse. Patients in both groups tended to have large numbers of sexual partners. Drug usage was about the same for both groups. They state that their cluster may represent a group of homosexual men linked by an interest in sexual relations with many different partners, or specific sexual practices. Nonsexual activities such as drug use may have also contributed to AIDS.

AIDS EXPOSURE FEARED WIDER was the headline in the Washington Post (Russell, 1984) stating that while the greatest risk is still among sexually active homosexual men, intraveneous drug users, hemophiliacs, Haitians and their sexual partners, James Curran of the Centers for Disease Control (CDC) believes that there is evidence supporting the hypothesis that 30 to 50 times as many as the number of reported cases have been exposed to the virus. He estimates 10% of those will come down with the virus in the next 5 years.

It is of interest that the total number of AIDS cases has gone from 6402 15 October 1984 to 12,256 on 6 August 1985 in the United States.

Henderson (1984) stresses that male and female sexual partners of patients with AIDS are at risk, as are recipients of multiple transfusions and infants and children of high-risk populations. The overwhelming majority of the patients are male, and the majority are white. Over 90% are between the ages of 20 and 49. Although Asian Americans are 1.5% of the U.S. population, fewer than 0.2% of the AIDS patients are of this ethnic origin.

Henderson found a high incidence of sexual promiscuity, frequenting public bathhouses for sex, and a previous history of syphilis as significant factors. Additionally he emphasizes that while sexual partners are at risk, by no means 100% of them get the disease.

Coutinho, Wertheim-van Dillen et al. (1984) also found the prevalence of antibody to CMV correlated with duration of homosexual activity, number of different sexual partners in the preceeding 6 months, history of syphilis and anal sexual contact.

Darrow, Jaffe et al. (1983) say in their series that passive anal intercourse did not seem to be statistically significant or put some homosexual men at increased risk, but they concluded that if AIDS is caused by a transmissible agent, the agent may be spread from infected host to susceptible partner during certain sexual activities. As with syphilis, hepatitis B and other sexually transmitted diseases (STD), having a large number of different partners seems to increase the chance of acquiring

the disease (cf. Darrow, Barrett et al., 1981). They advise that intimate sexual contact with partners who might have AIDS should be avoided, and homosexual men should be aware that the risk of acquiring AIDS increases with an increasing number of sexual partners.

Castro and Hardy (1984) list the following guidelines:

1. Sexual contact should be avoided with persons known or suspected to have AIDS.
2. For the time being members of groups at risk for AIDS should voluntarily refrain from donating blood and/or plasma.
3. Physicians should adhere strictly to medical indications for transfusions and autologous blood transfusions are encouraged.
4. Work should continue toward developing safer blood products for use by hemophiliac patients (cf. Desforges, 1983).

They also outline the precautions which should be taken by clinical and laboratory staffs regarding the handling and disposal of blood, secretions, and excretions.

In an attempt to discover the viral agent responsible for AIDS, researchers considered the Epstein-Barr virus (EBV) and cytomegalovirus (CMV) as well as the human T-cell leukemia viruses, since all had been isolated from the cells of AIDS patients (Taube and Goldberg, 1983).

Both Dr. Robert Gallo (1984) of the National Cancer Institute and Dr. Luc Montagnier (1984) of the Pasteur Institute in France were pursuing the viral approach. In the spring of 1984 Gallo isolated HTLV-III, the human T-cell leukemia virus subgroup closely linked to the disease. Montagnier identified the lymphadenopathy associated viruses (LAV) which, like the HTLVs, have RNA as its genetic material. Both HTLV-III and LAV appear to infect the same subpopulation of T cells (cf. Bartlette, 1985).

The work of these two scientists marked another step forward toward determining the etiology of and a vaccine for the disease.

The Gallo group continues its research on these viruses in patients with AIDS and pre-AIDS (1984). Frequent newspaper articles headlined DISCOVERY MAY HELP FIGHT AIDS (Times Picayune, 1984), talking of a receptor protein for the virus, or ANTIBODY DISCOVERY IS STEP TO VACCINE, (Times Picayune, 1985a) noting a neutralizing antibody identified by Dr. Roberg-Guroff of Gallo's laboratory at the

National Cancer Institute (NCI) and Dr. Martin Hirsch at Massachusetts General in Boston.

While we can see that an increasing number of populations were at risk for the disease, IV drug abusers have never been a popular group of people (cf. Vieira, Frank et al., 1983; Pincus, 1984). This group, however, frequently sells blood, and their contamination via the use of shared needles with multiple blood contacts came to be viewed as a threat to the blood supply in the United States, and later in other parts of the world.

AUSSIES BEAT GAYS OVER BLOOD, (Times Picayune, 1984d) was the lead to a story noting that some of the gay community in Sydney, Australia had been beaten up and threatened with dismissal from their jobs. Thirteen of 18 people who received transfusions of blood contaminated with the AIDS virus had died, including 2 babies. Politician Angus Innes said, "Any homosexual who ignores the blood bank warning not to give blood and consequently causes another to die from AIDS could be charged with manslaughter under Queensland law." And in a follow-up story FEMALES' BLOOD SOUGHT TO AIDS (Times Picayune, 1984e) the Australian government launched a campaign to have women donate blood to lessen chances of transmitting the disease.

Adams (1984) also notes the Australian blood problems commenting on one homosexual donor who said that he had seen signs in the blood bank requesting that promiscuous homosexual men refrain from donating blood, but thought this description did not apply to him. Thus, in this case the utilization of signs as a screening mechanism failed.

Bayer (1983) reported the Public Health Service's recommendation that as a temporary measure, members of groups at increased risk for AIDS should refrain from donating blood and blood components. They limited the recommendations to sexually active homosexual or bisexual men and those with multiple partners. Denial will also be a potent force under these circumstances, and economic motivations will impact the willingness of some to change their behavior. Since blood products are a commodity on the market, the decision to forego the sale of one's blood will require an act of self-denial.

As early as 1983 Marx felt the blood would have to be screened. Curran (1984) described 18 adults without other risk factors in whom AIDS developed after transfusion, with 7 of the completed donor investigations providing circumstantial evidence that exposure to as little as 1 unit of blood may result in transmission.

Bove (1984) urges that patients be reassured that the blood banks are

taking all possible steps to provide safe blood transfusions, while cautioning physicians to use blood products only when unquestionably indicated.

Deresinski, Cooney et al. (1984) report 1 homosexual donor with more than 500 partners in 5 years who had also had contact with a deceased AIDS patient. They concluded that there may be a carrier state that could represent a significant public health problem, but note that the risk is only about one in every million transfusions.

Desforges (1983) commented that preventing the complications of the present treatment for hemophiliacs using Factor VIII since the AIDS problem may take precedence over preventing the complications of hemophilia itself. And Ragni, Lewis et al. (1983) reported an AIDS-like syndrome in two haemophiliacs. An editorial in The Lancet, 22 January 1983 cited problems with Factor VIII, and Palmer, Ramsey et al. (1984) reported 2 patients dying of PCP as a result of blood transfusions and large amounts of Factor VIII (greater than 50,000 U/yr).

Because of the problems related to the blood supply, including the recent deaths of a nun and an 82 year old grandmother (Times Picayune, 1985c) in the San Francisco areas from transfusion related AIDS, the Department of Health and Human Services has initiated a nationwide system of serum screening (Broder and Gallo, 1984).

A test approved by the Food and Drug Administration (FDA) to screen for the HTLV-III antibody was sent to blood banks throughout the country in March, 1985. News of this test was reported in the 18 February 1985 issue of U.S. NEWS AND WORLD REPORT, pointing out that the presence of antibodies in a person's blood merely indicates the individual may have been exposed to the AIDS virus, but does not mean that the person has or will get the disease. This test and its results can have far reaching repercussions, which will be discussed later. It also launches a huge new industry with an annual market of from $60 million to $80 million annually (Henderson, 1985).

All of the knowledge we have of this disease has been generated over the past four years, with articles on all aspects of AIDS filling medical and mental health journals as well as the lay press since its definition. Bender and Quinn (1984) note that editors of THE NEW ENGLAND JOURNAL OF MEDICINE, ANNALS OF INTERNAL MEDICINE, JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, and SCIENCE have announced that they will expedite publication on AIDS related articles. One disadvantage is that occasionally promising data

may be published early and final results which may be negative or different may never be published, with the ultimate findings of such a study lost to the scientific community. Peer review practice must remain intact to ensure high quality.

Armed with an overview of the identification of the disease and a concept of the ever widening boundaries of those individuals meeting the case definition, we can see that while there are differences in the risk groups, there are specific points at which their lives intersect and the disease impacts accordingly.

Since it was initially defined as the "Gay Plague" (Krauthammer, 1983) or "Gay Compromise Syndrome" (Brennan and Durack, 1981) the initial focus of attention was on the homosexual community. Because of the politically active component in the gay community, especially in New York and San Francisco, where the disease was first noted, the rudiments of a support structure and lobbying component were already in place. Thus, while no longer viewed as a gay disease, the greatest amount of emphasis in the literature has been directed to the care of the gay AIDS patient.

Hemophiliacs and those acquiring the disease from blood transfusions were the groups receiving the next degree of attention. Carmen (1984) says that the National Hemophilia Society in the United States has served as a central point of contact during a state of near panic.

Haitians, who remained one of the risk groups until April 1, 1985, have been politically scapegoated as the possible connection with Kaposi's sarcoma as it exists in Africa, with others seeing the link established because some American homosexuals engaged in sexual activity with Haitian male prostitutes while on vacation in Haiti. Thus in some people's eyes all Haitians became suspect. They have worked to counteract their bad publicity, believing it has adversely affected their country's economy (Times Picayune, 1983b). They claim social discrimination, a drop in tourism, and racism, as a result of the AIDS publicity, although now some physicians say that there was more homosexuality or bisexuality in Haiti than had been previously admitted (Altman, 1983). In the United States, many Haitians have either lost their employment, or are unable to obtain it (Bazell, 1983). Some researchers take exception with the inclusion of Haitians in the high-risk category group (Olle-Goig, 1984) and their objections have been heeded by the CDC.

Of the four major original groups, IV drug abusers have received the least attention in the literature. They have never been a popular sub-

culture sociologically, and their contamination via the use of shared needles with multiple blood contacts of the blood supply was perceived as a problem in identification and management. These are often transients, difficult to follow.

Children with the disease have either fallen into the hemophiliac category, or have been the offspring of IV drug abusers or Haitian women. Scott, Buck et al. (1984) say that the appearance of the syndrome in infants coincides with the national appearance of AIDS and appears to suggest transplacental, perinatal or postnatal transmission. One of the mothers in their series had clinical AIDS (cf. Schearer, 1984; Scott, 1984).

Dr. Jeffrey Laurence (Times Picayune, 1984c) of the New York Hospital says that drug abusing mothers with no evidence of AIDS may still pass it on to their children. And in Miami a child with the disease was abandoned in the hospital by the father after the mother's death (Times Picayune, 1983d). Children with AIDS, unable to be cared for in the family, are virtually impossible to place in foster care, relegating the child to spend his/her remaining life in the hospital.

Now attention is shifting to include the heterosexual population. Altman (1985) quotes Dr. Harold Jaffe of the CDC, saying that the heterosexual risk may be the greatest to promiscuous heterosexuals, particularly those who have sex with female prostitutes. Last year in San Francisco physicians diagnosed 4 cases of AIDS in heterosexuals in no known risk group. Dr. Dean F. Eichenberg of the San Francisco Department of Health said to Altman: "If you have had multiple sexual partners, or your partner has had multiple sexual partners since 1978, you should not be sharing body fluids." Thus far only San Francisco health officials have seen a need for warning heterosexuals, although no one can rule out the possibility that there will some day be a real threat to this population.

Columnist Bob Greene (1985) comments that it's time to quit ignoring the AIDS epidemic, and notes that now that the non-homosexual population is threatened, more interest is being shown.

The 2 February 1985 Times Picayune predicts that 300,000 may be infected by the virus that causes AIDS!

From many perspectives the hemophiliacs, recipients of blood transfusions and infants acquiring the disease are truly the innocent victims. Even prior to AIDS, IV drug abusers have been at risk to a variety of diseases such as hepatitis transmitted by needle contact.

Since, as stated above, most of the literature focuses on the gay AIDS victim, and since there is a sexually transmitted component to the disease in the exchange of body fluids, Bolan (1981) writing on sexually transmitted diseases (STD) prior to the AIDS outbreak would be worth heeding. He commented that those individuals using gay facilities such as bathhouse patrons or those with a higher number of sexual partners checked more frequently but he continued that the message coming out was that rectal sex is a high-risk activity, condoms may protect against "most of the invaders," and analingus is not safe outside a strictly monagamous relationship. Bolan added that to be maximally effective, guidelines for modification of sexual behavior must be stated in non-judgemental, positive language, and must stress consciousness about health. Cultural diversity within the homosexual population will be reflected in different senses of personal and social responsibility and decision making.

The question of social responsibility while encompassing sexual responsibility also includes familiarizing members of the helping professions with an individual's lifestyle and sexual orientation. Baker and Peppercorn (1982) comment that physicians often fail to identify patients at risk because many patients will not tell physicians of their sexual orientation, and many physicians feel uncomfortable with homosexual patients or fail to take an adequate social history. Dardick and Grady (1980) say that knowing the sexual orientation of patients would be helpful to the medical community for a number of reasons, including having the ability to include a person's significant other as an invaluable support member. Only half of the people they surveyed had explicitly identified themselves as homosexual to their health care provider (cf. Schram, 1984). Additionally, people seldom identify themselves openly as substance abusers.

While researchers strive to learn more about the disease, hoping to fulfill Koch's postulates, first observing the microorganism in all cases, then second growing it in pure culture, third, innoculating the pure culture in susceptible animals to reproduce the conditions, and fourth recovering the microorganism from experimentally infected animals (Krause, 1984; Altman, 1984), let us focus instead on the equally difficult task of determining the psychosocial factors implicit in this disease called AIDS.