THE AIDS CHALLENGE

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by

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To the Graduate Council:

I am submitting herewith a Research Paper written by Janice Magruder entitled "The AIDS Challenge." I recommend that it be accepted in partial fulfillment of the requirement for the degree of Masters of Arts, with a major in Psychology.

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CHAPTER 1

Background and Medical Issues

In New York and California in the Spring of 1981, the medical community became perplexed over the enigma of a few formerly healthy young men who were becoming sick and dying in unprecedented ways. As clinical information accumulated, certain critical immune functions were found to be profoundly depleted in these individuals (Osborn, 1986). As the phenomenon progressed, its persistent spread in certain groups, notably homosexuals with multiple partners, intravenous drug abusers, homophiliacs and Hatians, became evident (Ginzburg & MacDonald, 1986).

Since a pervasive immune deficit was the underlying problem, the disease manifestations occurred in multiple forms. Etiology included an exotic assortment of opportunistic, weakly pathogenic microorganisms which were easily kept at bay with a normally functioning immune system but produced lethal infections in these individuals. The medical world observed infections that were previously only seen as complications to aggressive therapy for malignancies or in preparation for organ transplanation. In these cases, their immune systems were severely compromised by chemical or other means. Infections such as Pneumocystis carinii, a type of pneumonia restricted to such persons, initially prompted diagnosticians to assess the immune status of this new group of patients (Osborn, 1986).

In addition to opportunistic infections, previously rare malignancies known to have a viral origin began to be manifest among this group. In particular, a purplish skin lesion indicative of Kaposis sarcoma was observed. It had been previously noted on the skin of men over age 60; it was very responsive to chemotherapy and virtually never fatal. By contrast, it was now behaving as an invasive malignancy involving many organs and was unresponsive to therapy (Osborn, 1986). Over time this new pathogenic phenomena became known as Acquired Immune Deficiency Syndrome (AIDS). Epidemiological Considerations

Prior to AIDS the "out of the closet" gay liberation movement had already engendered alarm among infection workers because multiple sex partners spell multiple microbial trouble. The average lifetime number of sexual partners of gay men with AIDS as reported by the Center for Disease Control (CDC) is over 1000. Even before the advent of AIDS, it was recognized that the gay lifestyle was one which amplified many pathogenic micro-organisms. For example, 1% of the U.S. population had a past infection with hepatitis B virus; yet, the annual acquisition rate of hepatitis B among gay men has been 12%. The prevalence of rectal gonorrhea, many enteric pathogens, syphilis and herpes were also dramatically increased in the gay community compared to minimal incidents in the general population (Osborn, 1986).

By the end of 1981, it was clear that this strange new pathogenic phenomenon's parallels with hepatitis B were suggestive of a blood-borne, sexually transmissible agent. By the end of 1986, there were nearly 20,000 reported cases of AIDS and over one million people infected with the AIDS virus in the United States. Globally, there were approximately 100,000 incidents of AIDS and an estimated 10-25 million exposures to the AIDS virus. AIDS is present on all continents except Antartica; it is found in over 40 countries and is rampant in certain parts of Africa (Osborn, 1986). AIDS is now recognized as a world-class epidemic. Nature of the AIDS Virus

The AIDS virus is known as HIV or human immunodeficiency virus. Previously it was known as HTLV-III (human T-lymphotropic virus III). It is one of three retroviruses known to infect man. Like other retroviruses, once one is infected one is infected for life. The AIDS virus is similar to a virus found in African green monkeys (STLV-III or Simian T-lymphotropic virus III) and it may well be an ancestor of HIV. Evidence of this is suggested by the discovery of a group of intermediate viruses in West Africa that is more closely related to the monkey virus and is non-pathogenic but infects humans. In this same geographic area, recently two viruses (LAV-2 and SBL) even more closely related to HIV that cause immune deficiency have been found. The hypothesis derived from this evidence

is that the monkey virus somehow, probably through biting, entered the human population initiating a series of intermediate viruses before terminating in the fierce pathology of HIV. Having its origin in Central Africa, the virus is thought to have migrated to Haiti and from there to have spread to the Americas and Europe (Gallo, 1987). Diagnostic Signs and Symptoms of HIV Infection

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The clinical symptoms of AIDS, at first ambiguous with a gradual onset of sustained fever, weight loss and wasting, diarrhea, profound fatigue, night sweats and oftentimes enlargement of lymph nodes, is more definitively accompanied by depletion of T4 helper lymphoid cells. The T4 lymphocytes occupy such a central position in the immune response that they have been compared to the conductor of an orchestra; likewise, their removal results in predictable chaos. As they are depleted, more and more opportunistic microorganisms assert themselves. When opportunistic infections are involved at the outset of diagnosis, the average life expectancy is about one year and the absolute upper limit is two years. When Kaposis sarcoma presents, prognosis is more favorable with a life expectancy of three years (Osborn, 1986). By definition, an individual diagnosed with AIDS has at least one of certain opportunistic diseases associated with AIDS. A list of some of these diseases with the approximate incidence of them in AIDS victims is given below:

Pneumocystis carinii pneumonia (bacteria) 1. 638 Kaposis sarcoma (cancer of viral origin) 2. 128 Cryptococcus (yeast) 3. 12% Histoplasmosis (yeast) 4. 178 Candidiasis (yeast) 5. 228 Mycobacterium avium (T-B like bacteria) 6. 288 Chronic herpes ulcers (virus) 7. 18% Cytomegalovirus (virus) 8.

9. Toxoplasmosis (Sporozoan)

(Swinger, 1987).

According to the Center for Disease Control, ARC or AIDS related complex is diagnosed when an individual tests HIV positive and has at least two of the clinical symptoms and two of the laboratory abnormalities presented in Table 1 in the absence of other identifiable causes. It is important to remember when viewing Table 1 that a diagnosis of ARC can be rendered on the basis of such findings alone; however, a diagnosis of AIDS must also be based upon the presence of at least one of the opportunistic diseases associated with AIDS.

The number of individuals who have been infected with the HIV virus yet are asymptomatic is much greater than those with ARC and AIDS. It has been estimated that for every 100 AIDS victims there are 1,000 with ARC and 6,000 who are HIV positive but asymptomatic. Indeed for at least two to three years after exposure most people are

asymptomatic. Within five years 10% to 30% of individuals infected with the AIDS virus will have developed "full blown AIDS". Most poignantly, the percentage is known to increase as time passes. A recent German study suggested 75% of the infected cases will develop AIDS within 15 years. Many experts predict that the eventual percentage could be closer to 90% (Pekkaneh, 1987).

Diagnostic Tests for HIV Infection

Blood serum tests which detect antibodies against the AIDS virus, called the ELISA and Western Blot Tests, are now used primarily to screen high risk groups and blood donors. Exposure to HIV is indicated when findings are seropositive. However, there is a window of vulnerability in that an individual who has contracted HIV will test negative for six to eight weeks after exposure and it may be as long as twelve weeks before he/she will be sero-positive on the antibody test. Further confusion may be evoked from the fairly high incidence of false-positives which may be as much as 10%. Currently, research is under way to develop more accurate screening tests which may become available in the near future. It is hoped that an HIV antigen test could identify individuals with the active virus (Hennessey & D'Eramo, 1986).

Neurological Effects of HIV Infection

From the beginning of this epidemic, it was clear that the central nervous system could be affected due to

toxoplasma or cryptococcal invasion of the brain and meninges. However, it has become increasingly evident that the AIDS virus has its own intrinsic effect on the nervous system. It can infect the CNS causing myelopathy, neuropathy and encephalopathy that progresses to dementia (Thomas, 1987). Richard Johnson, a researcher at Johns Hopkins, noted that a large percentage of AIDS patients manifest neurological problems. He admitted the precise incidence is not known, but further stated that "as many as 60% will eventually develop dementia. About 10% of AIDS patients present neurological symptoms first, including dementia, neuropathy, or opportunistic infections of the central nervous system" (Barnes, 1986, p. 1091).

While 10% of AIDS patients will have neurological symptoms before any signs of ARC, approximately 40% will show neurological symptoms after signs of ARC have appeared. The remaining 50% of AIDS patients who develop neurological problems will do so after AIDS has been diagnosed (Barnes, 1986).

In the early stages of the disease, many AIDS patients complain of forgetfulness, decreased ability to concentrate, mild confusion and being mentally slow. A few months later many are confused, unable to speak or function independently as they progress into dementia. Accompanying cognitive changes are motor problems such as leg weakness, an unsteady gait, poor coordination and trouble with handwriting. Apart

from neurological problems, many AIDS patients become apathetic, withdrawn, agitated or depressed (Barnes, 1986; Navia & Price, 1986).

There is now no doubt that the AIDS virus is harbored in the brain (Price, 1987). Typically the brains of AIDS patients are atrophied. Accompanying atrophy are lesions confined primarily to the white matter of the brain. Also typical of these victims is vacuolar myelopathy of the spinal cord which is a separation between the layers of the myelin sheath (Barnes, 1986). One of the greatest worries of researchers trying to find a treatment is that they may restore a patient systemically to an intact immune system, only to have him progress relentlessly to neurological deterioration and demise. This prospect is particularly awesome should the blood-brain barrier prove insurmountable as it already has with many of the experimental antiviral drugs recently tested as potential weapons against AIDS (Hennessey, 1985).

Medical Treatment: Vaccines, Antivirals, and Drugs

While development of a vaccine is extremely important, it is not likely to come about in the near future. Such research usually uses a double-blind approach; but, in the case of AIDS this is not ethical. There is also the need to make sure the vaccine has no untoward effects, which takes considerable time. In addition, efficacy is difficult to prove. While these factors are certainly formidable, the

most disturbing barrier to those seeking to develop a vaccine is the tremendous propensity of viruses to mutate. This mutability has already been expressed in three strains of AIDS viruses which are HIVI, HIVII, and HIVIII. The differences in the present strains and future strains may preclude the development of a universally effective AIDS vaccine. Just as it has not been possible to develop a universal flu vaccine against antigenically changing, multiple strains of the influenza virus, a universal AIDS vaccine may be an impossibility. On the other hand, evidence exists that the various strains thus far identified may have a common core structure. If this is true and future strains follow suit, a universal vaccine may be developed eventually. At the same time one must caution, this development is projected to be at least five years in the future (Hennessey, 1985).

The development of antiviral agents for AIDS is difficult because of the way AIDS enters the body and acts. Although the virus attacks other cells such as monocytes and macrophages, its effect on T4 lymphocytes is critical due to the T4 helper cells' central role in regulating the immune response. Once inside a T4 cell, HIV may remain latent until the lymphocyte is immunologically stimulated by a secondary infection. Then the virus bursts into action, reproducing itself so furiously that the new virus particles escaping from the cell riddle the T4 lymphocyte's cellular

membrane with holes and it dies. It is the depletion of the T4 helper cells that causes the immune deficit. Eventually, other components of the immune response are so overwhelmed, and later depleted, that toward conclusion of the disease there is virtually no immunity remaining (Gallo, 1987). Antivirals act by knocking out a virus; in the case of AIDS, they would help people recover their immune function and help decrease further spread of the virus. While antivirals hold promise, all of the antivirals currently being developed are effective only with actively replicating viruses (Hennessey, 1985).

Trial testing has been conducted with the immunotherapeutic agents interferon and interleukin; unfortunately, neither of these agents has proved successful when used alone. On the other hand, when used in combination with other treatment modalities, it is hoped that they will prove efficacious (Hennessey, 1985).

AZT (3'-azido-3'deoxythymidine) was approved for use with HIV victims by the FDA at an unprecedented rate without the extensive testing normally required, demonstrating the alarming urgency to find a substance to treat this lethal disease. There is evidence that AZT has toxic effects on bone marrow. We still do not know what adverse effects may be incurred from its continued use. We now know we can stabilize an ARC patient with AZT. Although dubious, it may be possible that they may not progress on to the AIDS stage of disease. AZT has prolonged the lives of AIDS victims. It is a suppressive drug, not a cure; as such, a patient must take it for the rest of his or her life. Recent evidence suggests that AZT appears to slow or even reverse some of the neurological symptoms in a subset of AIDS patients (Barnes, 1987; Hennessey, 1985).

Professionals dealing with this AIDS epidemic must have adequate and accurate information on not only the pathophysiology of and medical treatment for the disease, but also knowledge of routes of transmission; current demographics and trends; social, ethical and civil ramifications; and understanding of the psychological response of the AIDS victims and society at large. In addition they must be able to communicate this cognition in a constructive manner, using it prudently and judiciously in aiding clients and their communities in making decisions.

CHAPTER 2

Transmission of Aids

Transmissibility of the HIV Virus

AIDS is the social issue of the late 1980's. Unlike previous epidemics we are fortunate that AIDS is unique in that it is avoidable. An individual can make personal decisions to completely avoid risk. As a society, we already have the medical information to halt the transmission of HIV in our society but we are impotent to deploy it because of gaps in our usable knowledge of social and behavorial sciences (Osborn, 1986).

Requirements for Transmission

Although HIV has been isolated in tears, saliva and other body fluids, without equivocation, transmission of the virus has occurred primarily through blood and semen. Two basic characteristics are essential for transmission of HIV: (a) an effective <u>route</u> of transmission and (b) an adequate <u>quantity</u> of the virus in the transmission to produce infection. Blood and semen are the only body fluids which harbor HIV to any great degree. Therefore, most of the transmission is through these two mediums. Since more virus is contained in semen than vaginal fluids, transfer from male to female in vaginal intercourse is more efficient than vice versa. There are two times in a woman's cycle that she is at particular risk of contacting the virus from an

infected sex partner. One of these is during her fertile period when the cervical mucous plug has softened so that semen can enter the womb for conception; the other is during her menstrual period. Of course, some break in the mucous membrane of her vagina may put her at risk at any time; however, vaginal intercourse does not entertain the risks that anal intercourse presents (Swinger, 1987).

Anal Transmission

There is a 10% chance of HIV transmission with each incidence of anal intercourse with an infected partner. The rectal cavity has not been designed to withstand the trauma of intercourse and childbirth as the vagina with its thick muscular wall, extreme elasticity and tough mucous membrane. The rectum is extremely vulnerable to polyps, hemorrhoids, fissures, fistulas and small breaks in its comparatively thin, fragile mucous membrane from strain and trauma. Thus, it is a highly efficient route for HIV transmission (Swinger, 1987).

Transmission in Bodily Fluids

Since the quantity of HIV in saliva is very small, there is little risk of transmission from oral sex, unless an infected ejaculate comes into contact with a break in the oral mucous membrane. If semen is swallowed the virus is killed by the acidic pH of the stomach's gastric juices. Likewise, because of an acidic pH, HIV is not viable in

urine and certainly cannot be contracted from a toilet seat (Swinger, 1987).

Transmission by Food

For all of the controversy about possible risk to the public by infected gay food handlers, the risk is nonexistent. The AIDS virus is an extremely fragile creature that is not viable in air, away from its host; and certainly food or drink is not a viable medium for its existence (Swinger, 1987).

Blood Transmission

Blood and blood products are highly efficient carriers for transmission. In the United States approximately three million people a year receive blood transfusions. Hence, our society is duly concerned about efforts to monitor the donor blood supply. Now that there are screening tests to detect HIV contaminated blood, the supply is much safer. Due to the 6-12 week window of vulnerability in the serum antibody tests, the Red Cross requests that high risk groups refrain from blood or plasma donation. In facing this crisis, the U.S. Public Health Service became aware that some high risk individuals might be so intent to learn their antibody status that they would enter the blood donation system to learn the results of testing. To circumvent such an action, "alternative test sites" were established and funded by the federal government. Indeed, a questionnaire distributed at one such test site indicated that fully onethird of those tested would have ignored the self-exclusion appeal and donated blood in order to be tested. This underscores the importance of continuing funding for these relatively inexpensive safety values to our nation's blood supply (Osborn, 1986).

Intravenous drug abusers are represented in the potential high risk group for AIDS due to the practice of sharing needles and syringes. The risk can be lessened by first encouraging them not to share IV supplies; if they do share, treating equipment with bleach, or at least diluting the virus by cleansing with warm soapy water, which will decrease the risk of transmission (Swinger, 1987).

Health professionals have been concerned about the possibility of contracting HIV from an accidental needle stick. However, it takes sufficient quantity of the virus and fresh injected blood (or blood component) to produce transmission. Although there have been such accidental sticks, to date none of the health care workers have tested sero-positive. This is thought to be due to the lack of <u>quantity</u> of virus residing on the end of the used needle (Swinger, 1987).

The possibility exists that blood borne transmission may result from shared use of razors, toothbrushes or any skin-piercing instrument contaminated with HIV containing blood. As a result, getting a tattoo or having one's ears

pierced can carry some risk if noncontaminating procedures are not used (World Health Organization, 1987). Intrauterine Transmission

An infected woman of child-bearing age should be counseled that there is a 50% chance that the virus will cross the placental barrier, thus infecting her unborn child. There is also a possibility that HIV could be transmitted via vaginal fluids during birth or later through breastfeeding (Swinger, 1987).

Casual Transmission of the AIDS Virus

It cannot be overemphasized that professionals counseling individuals about AIDS need to be aware of the truths and fallacies regarding HIV transmission and convey them with clarity. HIV is definitely not spread by casual contact whether at home, school, in the work place or at public facilities. Due to the prejudice inflicted on many AIDS victims, it needs to be emphasized that the virus cannot be contracted from toilet seats, casual kissing, handshakes, hugs, eating after victims or by infected food handlers. Neither is it spread by mosquitoes or other insects or vermin (World Health Organization, 1987).

Guarding Against Transmission

Condoms are now being purported as one of the "safe sex" techniques to guard against AIDS transmission. Unless there are breaks or defects in the latex sheath, the AIDS virus cannot penetrate this barrier method. To adequately protect, a condom should be worn from the beginning of sexual activity until after ejaculation due to possible seepage of seminal fluid. Studies have shown that couples who utilize condoms as their method of birth control risk a 5% to 10% chance of pregnancy within a year's span despite unerring use. There is no reason to believe that the risk of HIV transmission is any less with the use of a condom despite scrupulous use. Hence, the term "safe sex" is a misnomer and would more accurately be expressed as "safer sex." The use of a spermicide would also reduce risk since contact with such an agent has proven effective in killing the AIDS virus (Hennessey, 1985). At this point, only abstinence or monogomy with a non-infected partner is a 100% assured means of preventing transmission.

Demographic Trends

The current demographics on AIDS victims in the United States shows 93% of cases to be in men and 7% in women. Sixty percent of the victims are Caucasian, 25% are Black, 14% Hispanic and 1% Asian. In inner city areas 80% of the victims are Black or Hispanic adults; 15% are children of Black or Hispanic descent. In these areas 5% of victims are women who have largely contracted the virus due to their boyfriends' drug abuse or their own drug abuse. Once women are infected, children become infected. From 60% to 70% of the prostitutes in inner cities are sero-positive for HIV (Ginzburg & MacDonald, 1986; Swinger, 1987).

Trends Among Homosexuals and Heterosexuals

It is projected that by the year 1991 there will be 270,500 cases of "full blown" AIDS. The rate of overall increase is expected to decline due to safer sex practices. In particular the rate among homosexuals and bisexuals is expected to decrease due to safer sex, while rates among heterosexuals are expected to increase due to less caution being employed in their sexual practices (Ginzburg & MacDonald, 1986; Swinger, 1987).

Trends Among Blood Recipients

The rate among hemophiliacs is expected to decline due to safer blood supplies and recent techniques developed to kill HIV in blood-clotting products; while the trend among those who have contracted the virus from transfusion is expected to lag behind for a few years. There is usually a lag of two, three or more years from the time an individual becomes infected with HIV until the time one develops ARC or AIDS. When hemophiliacs began to develop AIDS, there was more judicious use of blood supplies with them. Other segments of the population largely received blood in situations of necessity before antibody screening for blood donors was available. For these reasons the incidence of AIDS among those contracting HIV from transfusions is expected to increase by 2.5%, so that there will be approximately 300-400 cases per year for about three years

after which the rate is expected to decline (Ginzburg & MacDonald, 1986; Swinger, 1987).

Epidemiological Trends

The AIDS epidemic began primarily in large cities on the East and West coast, such as New York and San Francisco; however, the epidemic is expected to move more toward medium size cities. In addition to an increased incidence among heterosexuals, the projected trends show an increase among IV drug abusers, women and children. Drug abusers are now viewed as the greatest problem due to their recalcitrance in the face of real threat and continued warnings. The epidemic is expected to spread faster in this group than any other single group. Some European governments are attempting to stem this tide in their countries by supplying addicts with free sterile needles and syringes (Ginzburg & MacDonald, 1986).

CHAPTER 3

Social Issues

Negative Attitudes

The negative attitude that AIDS is self-inflicted permeates a substantial segment of society. In accordance with such thinking, the unsavory behavior of gays and drug abusers is to blame for their plight. As a logical consequence of such a view, individuals with this "selfinflicted disease" are not accorded the privileges associated with being physically ill. This attitude denies the empathy, sympathy, support and assistance usually displayed to the afflicted. Victims of sexually transmitted diseases are punitively regarded as victims of their own low moral character and licentiousness. Intravenous drug abusers are also regarded as "social pariahs." Once such a judgement has been passed on an individual, ones' suffering is met with much less compassion, mercy or concern (Siegal, 1986).

Much progress has been made medically in understanding this worldwide epidemic; however, our social understanding, attitudes and decisions are lagging behind. Even many highly educated professionals consider AIDS as a punishment for deviant behavior. Some individuals or organizations purport ostracism and discrimination in the form of quarantines, terminating employees, evicting tenants,

expelling school children, dissolving friendships and abandoning family members. Ostracism is often a "knee jerk" reaction to those we feel threatened by, especially in cases of ignorance and misunderstanding. Confusion, panic, irrationality and prejudice can be more contagious than a disease. Hence, it is wise to emphasize that ethical and social decisions must be based on <u>facts</u> not <u>misinformation</u>.

Siegal (1986) viewed mental health professionals as the appropriate societal agents to combat the prejudice and misinformation surrounding the AIDS crisis. According to Siegal such individuals should assume a public leadership role to alleviate emotional anguish entailed in AIDSassociated social problems. "They should seek not only to alleviate distress, but also to combat the prejudice and social discrimination that produce such suffering" (Siegel, 1986, p. 172).

Screening for HIV Infection

While the serum antibody testing for HIV made vast inroads toward securing a safer blood supply, it came with its own intrinsic problems. It was hoped that diagnosis of HIV infection would now be made more on clinical criteria than "biased epidemiological" grouping. It was hoped the testing would provide more objectivity in the diagnosis of HIV infection. Unfortunately, this hope was rapidly replaced by fear that the test would be misused, leading to more discrimination, prejudice and misunderstanding. In any screening test the specificity of finding positive only those who actually have the infection verses the sensitivity of picking up all the infected has to be weighed. To obtain the highest possible sensitivity the criteria for positivity has been set very low. As a result there is a high rate of false positives who are not actually infected with HIV. On the other hand, there are some false negatives due to error or the "window of vunerability" period who are actually infected. This factor is of particular importance when counseling individuals regarding the results of testing and providing recommendations for further testing (McCombie, 1986).

To deal with this, a series of seminars was conducted by the Centers for Disease Control (CDC) in 1985 to educate health workers about HIV testing, and recommend counseling strategies. Before testing individuals were classified as high risk if they fell into any one of five categories. If a high risk individual tested positive on the ELISA, the test was not repeated as it was of the low risk people. If the low risk person was positive on the second trial, the Western Blot which is less sensitive, more specific and more expansive was performed. Four sets of counseling recommendations were given: high risk positive, high risk negative, low risk positive and low risk negative. Suffice it to say the high risk groups were chastised, admonished and warned while the low risk groups were consoled and

reassured. Thus, in their counseling strategies, the CDC adopted a policy of confusing assumed characteristics of populations with those of individuals (McCombie, 1986). Screening with Isolation Objectives

Unfortunately, some people have entertained the idea that testing can be used to control HIV contamination in situations other than blood product administration. They assume that widespread testing, contact-tracing and counseling will halt the sexual transmission of HIV. Cuba has already started mandatory testing and isolation of all sero-positive individuals; it is quite possible that other totalitarian countries will follow suit (Rosenthal, 1987). Adoption of such a policy in the U.S. may destroy the rights and liberties citizens cherish. It must be borne in mind that quarantines should be instituted for only one reason; that is, that they are effective in halting the spread of infection. This is not the case with HIV infections. Mandatory Screening

Mandatory screening, lack of confidentiality, and threatened misuse of test results will make it much more difficult to track and control the epidemic in a free society. Many will not risk loss of employment with accompanying loss of insurance, eviction from their homes, rejection and other adverse consequences resulting from the revelation of their infection. An authoritarian approach is apt to result paradoxically in an underground epidemic; thus, many of the gains that have been achieved in controlling this plight by using a noncoercive approach could be lost very quickly. Indeed, some gay organizations that originally opposed testing are now cooperating as a result of the sensitive treatment their members have received (Osborn, 1986).

Psychological Impact of Screening

Counselors and other professionals need to be cognizant of the dramatic psychological impact test results have. A positive test can result in severe anxiety and depression. Some people interpret it as a death sentence and in a few cases suicide has resulted. For some insensible individuals, a negative test is viewed as a license to resume imprudent sexual behavior. Many professionals have viewed testing as the panacea for the "worried well." These individuals realize their life styles have put them at risk and are concerned about developing AIDS. Although they are asymptomatic for AIDS, they have significant psychological distress manifested by anxiety-related symptoms as generalized anxiety, panic attacks, excessive somatic preoccupation and fears of the disease (Faulstick, 1987). While testing may function as an anxiety-reducing agent, it may backfire, especially if the professional is not prepared for a positive result.

Screening and Insurance

Insurance companies for both health and life insurance are now performing HIV screening on prospects for their individual plans. This testing cannot be performed without the prospects knowledge; they must sign an individual consent. Since approximately 85% of insurance is group insurance, such screening is not required of most people. In a few incidences there has been gross insensitivity resulting in leaking of test results. Such information can result in loss of employment, other insurance, domicile, family and/or friends. While the CDC favors manditory testing of high risk groups, they stress maintenance of strict confidentiality due to such ramifications (Christ, Wiener, & Moynihan, 1986; McCombie, 1986).

Some companies who fear expensive medical payments have proposed pre-employment screening. People participating or desiring to participate in both public and private programs, such as Jobs Corps and drug treatments, have been excluded after required testing showed sero-positive results (McCombie, 1986).

Screening Among Armed Forces Recruits

In October 1986, the Armed Forces began HIV screening of recruits. Two rationales were officially given for this action: (a) that the health of HIV carriers is further jeopardized by the multiple live-vaccinations received by personnel sent to endemic disease areas; (b) to protect the "buddy" blood donor system required in the battlefield or under contingency conditions (Herbold, 1986). Critics of the Department of Defense (D.O.D.) consider these rationales a smoke screen. They point to the fact that those found to be sero-positive are not deferred from vaccination or blood donation, but instead are excluded from military service (McCombie, 1985). However, LTC Herbold, Senior Policy Analyst within the D.O.D., freely stated "because the condition existed prior to service, the Department avoids potential medical costs associated with progressive infection and the possibility that the infected individual will not complete his or her service commitment" (Herbold, 1986, p. 624).

The D.O.D.'s policy regarding communicable disease reporting is to comply with civil authority requirements of the local, state or federal health jurisdiction unless such reporting compromises the national security. In most states AIDS is a reportable condition but HIV antibody positivity is not. A D.O.D memorandum, issued October 11, 1986, emphasized that it is contrary to policy to report HIV antibody positivity to civilian health authorities except in response to a valid request (Herbold, 1986).

Screening Among Active Duty Forces

The entire active duty force is being screened to identify and track all sero-positive individuals. The D.O.D. thought it was necessary to establish a policy that would permit the collection of clinical information and elucidate the natural progression of HIV infection. Rather than starting with AIDS patients and trying to retrospectively trace the history of infection, the military has the unique opportunity to follow recent sero-positive individuals through the course of infection (Herbold, 1986).

Each sero-positive individual is medically evaluated to determine the status of their infection. An epidemiological assessment of potential transmission to close personal contacts is performed to ensure preventative medical counseling is provided to the individual and his or her personal contacts. In addition to providing preventive medical counseling to individual patients, the military provides public health education materials to its personnel; conducts longitudinal epidemiologic evaluations of HIV infected individuals; and prepares reports to facilitate periodic review of current policy guidelines (Herbold, 1986).

According to D.O.D. policy, HIV infection cannot be used as a basis for punitive action against an individual. If they are asymptomatic, they are retained on active duty. On the other hand, the Service Secretaries have the authority to limit assignment of these individuals with respect to the nature and location of the duties performed if service or operationally unique circumstances warrant (Herbold, 1986). Some may advocate the military's guidelines as the ideal prototype for society at large. This is an issue which will probably be debated for some time. Suffice it to say the military's more authoritarian approach will probably be more difficult to implement in our free-wheeling society because it may infringe upon the liberties civilians expect to maintain.

Moral and Social Rights

Although somewhat debatable, most experts in the field are upholding the following moral and social rights with regard to the AIDS issue. (a) The individual needs to give his or her consent to HIV testing. If positive, he/she should have the right to appropriate counseling and education about the disease. (b) A health care worker has the right to know the diagnosis of the patient with whom he/she comes into contact. He or she also has the right to quality updated information and teaching on the disease. The health care worker has the moral obligation to care for the AIDS patient and the patient has the right to expect adequate, humane health care. (c) The uninfected individual has the right to know if his or her sex partner is infected, assuming ones' partner is aware of his or her status in this regard. Uninfected people have the right to preventative quality education about AIDS. (d) Children have the right to education about AIDS from home and/or school (Copello, 1987).

In our society, health education and counseling is not only the most appropriate strategy to fight this epidemic, it is the most effective strategy. This may seem simplistic in view of the compelling forces of sexual drives and drug addition. On the other hand, the fear of death or progressive, degenerative neurological disease is also a compelling force (Osborn, 1986).

Legal Issues

Within our legal system there has been long standing liability for wrongful acts leading to spread of sexually transmitted diseases. Tort liability has to do with any private or civil wrong by act or omission for which a civil suit can be brought; however, it does not include breach of contract. Negligence may be claimed if reasonable information and reasonable care were not exercised. For instance, if one has been counseled that one is seropositive and should take special precautions but does not comply in his or her conduct and thereby endangers another person, he or she is negligent. Some people have engaged in negligent misrepresentation by keeping silent about their sero-positive status to those having intimate contact with them. They have found in court that the precedent set by genital herpes cases has been readily applied to their cases. Fraud can be charged to those who falsely claim they do not have the HIV virus; in this case, punitive damages may be set. A good faith belief that one is not an HIV

carrier may not absolve one from responsibility if one is in a high risk group. If one knowingly consents to sex with an HIV carrier without using safe sex techniques, he or she assumes the risks of the act. A physician is liable for failing to tell others who might come into sexual or intimate contact with a newly diagnosed HIV sero-positive client. The AIDS issue has even extended from civil to criminal problems; for instance, two guards were deliberately bitten by an inmate with AIDS. Civil suits or criminal charges may result from such actions (Smith, 1987).

AIDS issues have come to the attention of the federal judiciary. In June 1986, it was ruled that the Federal Handicap Statute doesn't apply to persons testing seropositive to HIV; they must have AIDS. In 1987, the Supreme Court rejected this decision. As it now stands one must in fact be handicapped by the disease to be declared disabled. It is yet to be determined if sero-positive individuals who don't meet the criteria for AIDS, yet are disabled by the virus (i.e., neurologically impaired), can be determined to be handicapped under the statute (Smith, 1987).

Financial Strains

Unique characteristics of AIDS patients make them particularly vulnerable to social and psychological dysfunctions. A pilot study performed at Memorial Sloan-Kettering Cancer Center between April 1981 and December 1982 found over one-third of the AIDS patients had no insurance or had lost their insurance upon being terminated from their jobs after their diagnosis was made known. Applying for Medicaid and Social Security is a new experience for most of these individuals. To be eligible for some of these benefits, they must divest themselves of most of their resources which may mean leaving familiar surroundings and drastically changing their lifestyles (Christ, Wiener, & Moynihan, 1986).

Living Arrangements and Support Structures

Approximately three quarters of the patients in the Sloan-Kettering pilot study said they lived alone. Only half of these AIDS patients said they had neighbors, friends or acquaintances who could assist them with daily chores. Although visiting nurses care for AIDS patients, they cannot always give 24-hour care. Unfortunately, the patient who lives alone is less likely to have immediate care and help when he or she needs it (Christ, Wiener, & Moynihan, 1986).

Over 62% of the patients in this study had minimal or no contact with their families. Since the family is less available for many of these patients, they are more dependent on lovers and/or a wider network of friends. Those lacking such a network are more dependent on gay or drug rehabilitation organizations and hospital support structures. These become vital to their ability to cope with the stresses of AIDS (Christ, Wiener, & Moynihan, 1986).

CHAPTER 4

Psychological Issues

Psychological Effects of AIDS

The emotional reactions of AIDS patients resembles that of dying patients. However, the reactions of AIDS patients tend to be more intense and labile. Initially, there may be shock and expressions of guilt. Gay men, in particular, may express a resurgence of antigay feelings or internalized homophobic reactions. Homosexuals who have not previously discussed their sexual preference with family and friends fear the added burden of exposure and negative consequences of "coming out of the closet." Bargaining (i.e., I'll be good, just take this disease away) begins early and often returns throughout the course of the disease. Sadness may intensify to depression and fear may intensify to panic; consequently suicidal ideation is not uncommon. There may be considerable venting of anger on the path to acceptance and resignation (Nichols, 1983).

Psychological Themes

Three basic psychological themes are noted with AIDS patients. In the theme of "uncertainty," anger and anxiety are expressed due to uncertainty regarding the disease and the medical care. Anger is often displaced to the patient's caregivers in form of verbal outburst or passive-aggressive behavior. The theme of "isolation" occurs as a result of

hospital infection control procedures, abandonment of social support systems and/or separation from family members. The third theme, "illness as retribution," emerges as an expression of guilt over promiscuous sexual relations, a homosexual lifestyle and/or drug addiction. Individuals with this psychological theme usually experience intense guilt, depression and dysphoria requiring more support and psychological intervention than the other themes (Salisbury, 1986).

Reactive Phases of AIDS Patients

The reaction of AIDS patients has been divided into four phases. During the first phase, "initial crisis," the patient vacillates between anxiety and denial. His or her unsettled emotional state may interfere with his or her ability to comprehend and follow medical instructions. Alternating waves of anxiety, anger, guilt and self-piety are characteristic of the "transitional state." During this second phase the patient may portray homophobic reactions, obsessive thoughts and suicidal ideation, although actual suicide attempts are rare. During the "deficiency state," the patient accepts the diagnosis of AIDS, while attempting to live a constructive life that allows for the limitations resulting from the disease. As new difficulties arise there is considerable regression from this third phase to the "transitional state" until further adjustment is achieved. The patient has reached the fourth phase, "preparation for

death" when he/she begins to involve himself/herself in completing unfinished business and displays the ability to realistically plan for and discuss his/her death (Salisbury, 1986).

Stresses of AIDS

Christ, Wiener and Moynihan (1986) likewise view the psychosocial impact of AIDS into four parts. However, they differentiate according to the stresses patients encounter with different events rather than temporal phases of adjusting to the progression of the disease. First, the stresses associated with the diagnosis of AIDS are especially critical due to the threat on their long-term survival, and the implications for immediate change in their lifestyle. The emotional cushion of denial is less likely to be effective after AIDS diagnosis, compared to other fatal diseases, because of the constant publicity of AIDS and first-hand encounters of the death of other AIDS victims they have known. Another tramatic stress is the fact that most AIDS patients are between 25 and 49 years of age and at the peak of their productive years. Facing the prospect of death at the prime of life represents the particular trauma of an unanticipated event. With the diagnosis of AIDS, they are confronted with the issue of being contagious. Hence, they must concern themselves with transmitting the disease to others, protecting themselves from opportunistic infections, and dealing with the fears of significant others and the public about AIDS. At diagnosis many are confronted with the prospect of revealing their homosexuality or drug use to others.

A second major stress comes from the clinical syndromes of AIDS, which are debilitating and at times disfiguring. AIDS patients do not have structured treatment regimens to follow as do individuals suffering from many other disease entities (i.e., cancer), which help offset fear of and lack of control over the progressive effects of their disease. The opportunistic infections must be treated as they occur. Although an infection may be treated, they must face the fact that there are presently no effective treatments for the underlying immunodeficiency. Multiple reinfections become relentless and the patient experiences chronic fatigue and malaise. The AIDS victim faces the reactions of others to an obviously emaciated, sallow appearance. The patient with Kaposi's sarcoma also has a constant visual reminder of his disease in his purplish skin lesions (Christ, Wiener, & Moynihan, 1986).

AIDS patients who have progressive dementia become severely incapacitated; thus, they often need extensive help with activities of daily living. The patients' cognitive changes have a profound impact on their close relationships. Their progressive decline becomes a tremendous strain on their caretakers, especially if they are unaware of the organic cause or are confused and frightened about the ensuing changes (Christ, Wiener, & Moynihan, 1986).

Special stresses are incurred by patients with ARC due to the lack of clarity about the relationship between ARC and AIDS. Because of this ambiguity, having support groups for ARC patients separate from AIDS patients better facilitates the need to cope with their fears of developing AIDS (Christ, Wiener, & Moynihan, 1986).

Treatment represents a third area of stress for AIDS clients. Some of the treatments incurred have side effects such as weakness and depression. Additionally, treatments often require multiple clinic visits and painful tests and procedures. Prolonged hospitalization with isolation precautions is especially stressful at a time when an AIDS patient needs the closeness and emotional comfort of others (Christ, Wiener, & Moynihan, 1986).

The fourth major stressor is the termination of the treatment. Ceasing an activity that the patient believes controls the disease along with no longer being under intense medical surveillance greatly increases his or her fear that the disease may exacerbate (Christ, Wiener, & Moynihan, 1986).

Effects on Self-Esteem

Generally, throughout the course of the disease there is a lowering of self-esteem that occurs concurrently with each decrease in quality of life. With each decline in

physical well being the patient becomes increasingly dependent. Persistent fatigue and medical complications eventually render the AIDS patient unable to work or participate in many social activities. The loss of employment subsequently creates financial problems, often loss of medical insurance and perhaps loss of housing. Necessary restriction of sexual activity, awareness that one is contagious, along with change in body image due to weight loss, weakness, malaise and/or cancer lesions further demoralizes him or her. Hence, self-image is demeaned in the areas of work achievement, social relations, sexuality, and physical attractiveness (Salisbury, 1986).

Psychosocial Goals

The psychosocial goals for patients are twofold: (a) acceptance of the diagnosis of AIDS; (b) maintenance of control over one's life as long as possible and preplanning before the loss of one's faculties. Such activities as exploring possible reactions and feelings one may experience, participating in support groups and learning stress management techniques can enhance the accomplishment of these goals (Salisbury, 1986). Although other referrals to community or professional support services may be elicted over the course of the illness, psychosocial intervention by mental health professionals schooled in the unique needs and circumstances of the AIDS patients should begin immediately. Such early intervention is important in resolving such basic

practical issues as financial support for those without jobs, payments of medical treatment and suggested ways of talking about his or her disease with family and friends (Christ, Wiener, & Moynihan, 1986).

Professional Assistance

AIDS is so pervasive in its effects on its victims that they require a multitude of professionals to assist them. Since the total care of AIDS patients requires a variety of professional services, it is helpful if the patient can rely on one central advocate who coordinates these activities in a wholistic, therapeutic approach. This may be a significant other, a social worker or a counselor. Referrals may be made to a hospice, home health agency and psychiatric or psychological services facility. Most AIDS patients want to discuss their code status with their physician. The issue of wills, living wills and durable powers of attorney need to be settled as early as possible. Additionally, he/she may need pastoral services, legal assistance and a social worker for information about finances, resources and AIDS organizations (Salisbury, 1986).

The overall goal of psychological intervention is to help patients accept their illness, regain the ability to manage their lives, maintain control of their affairs as long as possible, and plan for the possible necessity of delegating decision-making to a person of his or her choice. This involves a process of restructuring, which entails finding new meaning in life and adapting to the limitations of the illness. From the onset a counselor must support the patient in facing his or her fear of death and his or her fear of becoming helpless which is usually the more distressing of the two fears. In particular, homosexuals and addicts are leary of becoming dependent on a medical and social system they perceive as insensitive to their life styles. To deal compassionately with AIDS patients, counselors must address their own bias toward homosexuals, addicts, and disadvantaged people and seek to neutralize negative attitudes (Nichols, 1983).

Communication and Support

Counselors need to be knowledgeable about the latest research; however, it is important to answer questions simply in language their clients can understand rather than lecturing with esoteric terms and statistics not easily grasped. More importantly, they need to explore the anxieties that prompted the questions (Nichols, 1983).

Following the initial reaction to the diagnosis of AIDS, the immediate needs of the patient are educational and supportive. The issue of confidentiality is paramount due to social ramifications of an AIDS diagnosis. Counselors and their clients need to throughly communicate about what information is to be disclosed and who is to receive it. Truthful, open communication is crucial to assessment,

therapeutic intervention and constructive, responsible decision-making. Since potential development of neurologic deficit may deprive the client of the ability to participate in decisions, the counselor should initiate discussion of life supports and power of attorney as early as possible. This is critical in the case of a gay couple who desire that the healthy partner assume the power of attorney. Since the law does not recognize their relationship, conflicts have later arisen between relatives of the patient and the patient or his or her lover regarding treatment decisions (Dilley, Shelp, & Batki, 1986).

As the patient becomes more and more debilitated, he/she anticipates and mourns the loss of important people and objects; hence, the counselor must support him or her through more detailed grief counseling. Often there is a loss of hope and emotional exhaustion. Assessment of suicidal ideation is an ongoing task of the counselor, as is his or her support of the client's existential search and completion of unfinished business (Dilley, Shelp, & Batki, 1986).

Counseling Issues and Treatment

Price, Omizo and Hammett (1986) noted four relevant therapeutic issues that are encountered in counseling AIDS clients. These are: (a) isolation and alienation; (b) decreased self-esteem and self-condemnation; (c) denial; and (d) transference.

Transference is an extremely difficult issue for AIDS counselors. In this emotionally draining work one must avoid the pitfalls of personalization and the tendency to overidentify with the patient.

Price et al. (1986) proposed a psychoeducational model of treatment to meet the needs of AIDS clients. Central to their model is the dissemination of updated, accurate information in an organized, planned manner. At the same time, this is adapted to each client individually as the counselor assesses how the information can be utilized and in what way it can induce the client to assume an active role in treatment. Hopefully, this will lead to a greater sense of personal control and direct energies productively that may otherwise be misdirected.

In this cognitive approach, clients are encouraged to learn and implement good nutrition, stress management, relaxation techniques, coping by using visual imagery and various other positive self-awareness approaches to treatment. The counselor assists the client to rechannel his or her energies toward a healthier more satisfying life style. Price et al. suggest the counselor obtain written permission from the client to consult with physicians and hospitals concerning suggestions for diet, rest, leisure, work, exercise, sexual practices, and other activities. Decision-making strategies, establishment of priorities, assertiveness training and values clarification techniques are employed in the selection of healthier social and sexual outlets.

Since AIDS patients do not necessarily follow similar psychosocial sequences, Price et al. (1986) emphasize attending to the client's uniqueness. They value individual psychotherapy when necessary; however, they feel group therapy is the best modality with most clients for the bulk of their treatment. Groups reduce the isolation and alienation felt by many AIDS victims. A sense of family and connectedness can be obtained from participation in a group. This is particularly comforting to clients experiencing a life-threatening illness. Groups can provide confidential and supportive outlets for discussion of personal concerns, ventilation of feelings and exchange of information. They provide the opportunity to witness effective coping strategies and to explore self-destructive behavior patterns. Hence, it provides increased opportunity for positive role modeling so that necessary life style alterations can more readily be undertaken.

A Model of Comprehensive Treatment

Memorial Sloan-Kettering Cancer Center developed a model program to provide comprehensive services to AIDS patients within an acute care center. Their psychosocial intervention program begins with orientation to the center by a social worker. The orientation meets the client's need

for information and personal acceptance and the staff's need for information concerning the patient. The patient is prepared for what will happen that day. He/She is given information on services such as financial resources, community support services and counseling available to him/her. Referrals are made to appropriate community resources and the patient is invited to join a weekly support group at the center. This has proven to be an effective way of dealing with the patient's initial panic and mistrust of the institution. Ongoing psychosocial support activities include: (a) support groups not only for AIDS patients but for their lovers and families; (b) patient education; (c) instruction in relaxation and behavioral techniques; and (d) liaison with community resources (Christ, Wiener, & Moynihan, 1986).

Sloan-Kettering has recognized the need to provide educational materials and programs to sensitize staff to the gay life style. Among other things, they sensitize them to the extreme anxiety of many AIDS patients and their tremendous need for contact, encouragement, and reassurance. They have taken complementary measures to improve communication between staff and patients. This has helped alleviate mutual suspicion and unease (Christ, Wiener, & Moynihan, 1986).

CHAPTER 5

Family Issues

Family Communication and Relationships

In many instances, the families of AIDS patients are in need of supportive care. Parents, siblings, spouses and children of AIDS patients are invariably affected in some way. Because of their life styles many of the people who have contracted AIDS have had very little contact with their families. They have established a pattern of communication that creates confusion, ambivalence, and further isolation which can be an additional stressor at this time of intense emotional need. Family secrets are often held concerning who knows and who does not know about the patient's life style. This closed communication limits the family's ability to respond and provide the patient with the support he/she so desperately needs. Communication is typically most open with siblings and least open with the patient's father (Christ, Weiner, & Moynihan, 1986).

Frierson, Lippman and Johnson (1987), after working with the repercussions of AIDS on family members over a 4 1/2 year period, have become aware of many of the frequent sources of stress upon these families and interventions that help them deal with the crisis. They note that families who have had a closed pattern of communication simultaneously face the dual revelation of a homosexual or addictive life

style and a terminal illness. For families previously aware of the patient's sexuality, the diagnosis brought a sense of reality to a life style they had only intellectually accepted. To many relatives the diagnosis implied promiscuity, drug abuse or other behavior they disdain, whether in fact this was the case or not. Occasionally, a patient was rejected by the family and forced to rely on others. The ability to adjust to the revelation of the patient's life style appeared to be influenced by such factors as the educational level, religious preference, socioeconomic status and the quality of the premorbid relationships.

Marital partners seemed to be particularly ambivalent upon revelation of their spouses' diagnosis. Some wives complained they were unable to express their anger at their husband's homosexual liaisons because of the imminent prospect of their husband's death. Some wives expressed guilt that in some way they "drove" their spouse to homosexual behavior, thereby "condemning them" to death and disease. In most cases, spouses denied the emotional impact of the revelation on them and directed their efforts toward the more immediate concerns of caregiving and anticipatory grief (Frierson, Lippman, & Johnson, 1987).

The Stigma on Families

Families sometimes encountered the direct stigma of AIDS. Family members have reported losing their jobs after a relative contracted AIDS. Children have been ridiculed by classmates and/or dismissed from school after a parent or sibling developed the disease. There has been exclusion from organizational or religious meetings, insurance benefits have been cutoff and families have been evicted from their domicile. Fear of societal prejudice has driven some families to fabricate other diagnosis to account for prolonged hospitalizations. Disagreements arose in many families over which relatives should be informed. The ramifications to the family have served to intensify feelings of guilt and alienation already present in AIDS patients. Obsessive worry about disclosure has intensified the psychological stress for patients and families (Frierson, Lippman, & Johnson, 1987).

Coping in Families

Many families expressed a desire to create a supportive environment for the member with AIDS; yet, they felt this conflicted with their responsibility for the well-being or health of other family members. Frierson, Lippmann and Johnson (1987) found this to be the most common source of intrafamily distress. Although lessened, their fears of contagion were seldom dispelled by factual information concerning the routes of transmission. Even though they realized their behavior was not logical, they often became obsessive. Some relatives developed excessive concerns with cleanliness, limited their social activities and refused to have guests in the home. They abstained from sexual contact and felt a compulsion to have repeated testing for the AIDS virus.

Families, as well as AIDS patients, experienced a sense of powerlessness in the face of this fatal disease. Overcompensation for their feelings of guilt and helplessness were commonly expressed by domineering behavior. Overprotection and not allowing patients to perform tasks for which he/she was capable only served to aggravate the patient's sense of helplessness. Often a wife who had been dependent and submissive assumed a more dominant role. While some women relished this new found authority, most found it a burden. Maintaining the delicate balance of meeting the patient's legitimate needs while preserving his/her autonomy and dignity was difficult for the majority of these families (Frierson, Lippman, & Johnson, 1987).

Emotional Responses of Families

Many AIDS families described an emotional "roller coaster effect" associated with the disease's frequent relapses and remissions. Grief themes included unwarranted guilt, displaced anger, and denial of the emotional impact of the disease. In addition to the grief reactions of anger, denial and depression, family members engaged in bargaining. Usually this was expressed in a willingness to accept the patient's life style in return for his or her

survival. Grieving was noted to be especially intense among parents who had naturally expected their children to outlive them. Patients and families were frequently at different levels of acceptance. It was often observed that a spouse would be in an early phase of grief while the patient had developed some acceptance of his or her plight. The degree of family acceptance was generally related to the premorbid relationship between the patient and family, their previous exposure to the grief process and previous psychological health of the family members (Frierson, Lippman, & Johnson, 1987).

Therapeutic Interventions for Families

Since many of the families had received much misinformation about AIDS, one of the most beneficial interventions was the provision of accurate, reliable information. This included the unlikelihood of transmission by casual contact, suggested modification of sexual behavior, available community support services and recommended treatment choices (Frierson, Lippman, & Johnson, 1987).

Therapists made concerted efforts to project a nonjudgemental attitude in their behavior and encourage its development in the family. Although family members were permitted to honestly ventilate their negative feelings, the therapists consciously avoided making moral judgments. The neutral attitude they protrayed served as a model, enabling

relatives to gradually moderate their stance (Frierson, Lippman, & Johnson, 1987).

The principles Frierson, Lippman and Johnson (1987) employed in dealing with the grief of AIDS families were much like those in dealing with other terminal illnesses. They found particularly useful the techniques of examining unrealistic guilt, not confronting self-protective denial, facilitating the overall emotional experience and encouraging participation in death rituals.

Frierson et al. (1987) found peer-group counseling to be especially beneficial. Hence, support groups for spouses, parents and lovers of AIDS patients were developed to combat feelings of isolation and allow opportunity for shared experiences. Realizing the universality of such reactions, the opportunity for catharsis of their fears and emotion proved to be mutually therapeutic. Since group members were at different levels of psychological adjustment, the more advanced members were able to model and offer hope of improvement in their emotional distress. The ultimate experience of the death of their loved one became a group experience for these individuals who formerly felt alienated and abandoned (Frierson, Lippman, & Johnson, 1987).

CHAPTER 6

Future Research

Issues Requiring Further Psychological Research

In dealing with the AIDS crisis, there are many facts and factors that will require the course of time to be decided or discovered. For instance, in the absence of a cure the inevitability that all HIV sero-positive individuals will eventually develop full blown AIDS will take decades to be determined. Much is yet to be discovered about effective prevention, treatment and control of AIDS. Whether AIDS testing should be manditory and if so for whom is another question that will require the crucible of time. Such social and ethical questions may prove more difficult to illuminate than the purely medical issues. The AIDS epidemic offers great challenges and at the same time opportunities for psychological research. Some of the issues that need further investigation are enumerated below. However, the order of their presentation is by no means meant to indicate their priority or relative importance.

 Determination of ways service agencies, governmental agencies, organizations servicing gays and drug addicts can collaborate more effectively.

2. Study and discussion of potential legal and public health policy issues.

3. Documentation of the psychological impact and

behavioral outcomes of AIDS testing and the effect of various follow-up counseling strategies.

4. Examination of the interactive influence of genetic, environmental and psychosocial factors on the progression of the disease.

5. Development of educational and social support systems which may contribute to the prevention of AIDS and/or improve the prognosis of AIDS victims.

6. As demographics change, further research on the diverse subgroups of the AIDS population.

7. Determining the feasibility of employing legalistic approaches to control the spread of AIDS among drug abusers verses the likelihood of hampering its control by such measures.

8. Determination of measures that could ethically and legally be implimented in an inpatient facility (i.e., state mental hospital) to prevent the transmission of the AIDS virus in its premises. Determination of the legal responsibility if any that an inpatient facility may assume for its transmission, especially from demented carriers.

9. Determination of ways individuals, families and society can extend resources to deal with the financial problems of this expanding epidemic.

10. Developing further refinement of psychological assessment and treatment of AIDS.

ll. Empirical observation of factors associated with

delay in seeking treatment.

12. Examination of adaptive coping styles. Examination of psychological variables or personality characteristics linked to progression of AIDS.

13. Studying the role of psychological stress in susceptibility to AIDS and its influence on the course of the disease (i.e., Does anxiety further exacerbate immunosuppression?).

14. Determining psychosocial factors that contribute to health promoting or health damaging behavior.

15. Studying the reliability of psychological factors in predicting the length of AIDS victims' survival.

16. Developing better understanding of the psychological effects of AIDS on family members. Developing more refinement in approaches to help families cope optimally.

Conclusion

Professionals within the mental health community have a tremendous challenge before them in making a positive difference in the AIDS epidemic. Mental health practitioners and researchers can potentially help AIDS victims to cope with their condition and within the limits imposed by their disease, live productive lives with a sense of meaning and purpose. They can help high risk individuals to control their anxiety and reduce their risks. They can help others significant to AIDS patients avoid unhealthy worry as they assist them in supporting the patient. Lastly, but perhaps most importantly, they can assist in educating individuals and the public in such a way that decisions will be made rationally, based on accurate information, with compassion directed toward the victims of AIDS.

Clinical	Symptoms	and	Laboratory	Findings	Indicative	of	ARC
or AIDS							

Clinical	Laboratory
Fever of 100 degrees F, intermittent or continuous for at least 3 months	Depressed helper T-cells (T4 cells) Depressed
Weight loss of 10% or greater	helper/suppressor ratio (T4/T8 cells)
Lymphadenopathy of 3 months or longer	Elevated serum globulins
Diarrhea intermittent or continuous for at least 3	Depressed blastogenesis
months	Abnormal skin tests
Profound fatigue Night sweats for 3 months or longer	At least one of the following: leukopenia, thrombocytopenia, absolute lymphopenia, or anemia
(Hennessey, N. P. & D'Eramo, J.	E., 1986, Update: AIDS-
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