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Falling through the cracks: AIDS and the urban "underclass"

Ayala, Victor A., Ph.D.

City University of New York, 1991

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300 N. Zeeb Rd.
Ann Arbor, MI 48106

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Falling Through the Cracks:
Aids and the Urban "Underclass"

by

Victor A. Ayala

A dissertation submitted to the Graduate
Faculty in Sociology in partial fulfillment
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4/25/91
date

William Kornblum
Chairman of Examining Committee

4/26/91
date

Executive Officer
Deputy

Professor Charles Winick

Professor Vernon Boggs

Supervisory Committee

The City University of New York

Abstract

Falling Through the Cracks:
Aids and the Urban "Underclass"

by

Victor A. Ayala

Advisor: Professor William Kornblum

This study addresses the AIDS issues concerning the urban underclass specifically through their interaction with the health care system. A myriad of factors are explored to highlight why this population is at high risk for the disease and conceivably will remain so. Limits on education (AIDS and otherwise), information sharing and dissemination and accessibility to health care and protective measures, have helped to trap this population in its high risk status. Further, cultural upbringing shape lifestyles to such an extent, it acts as a veil through which knowledge and information is received. This inability to receive, understand or be accessible to AIDS prevention information puts not only their own sub-culture at risk, but also those groups where interactions takes place, such as the urban poor.

The underclass remains vulnerable in the system, not

only to contract HIV infection and AIDS, but also to effectively negotiate proper medical care for their illnesses. The stigma of AIDS coupled with the stigma of underclass, as perceived by health care workers, can affect their treatment. The patient's inability to understand the illness gives rise to their inability to participate in their treatment. That is, to have effective discourse on treatment options, alternatives and side-effects. To further complicate the efficacy of treatment, health care facilities are understaffed and health care workers are sometimes untrained in the continuing complexities of AIDS care.

The study attempts, finally, to correlate the underclass population to society as a whole and underscores their right to proper and adequate medical treatment, regardless of lifestyles, stigmas and the perception of the health care worker. It reminds us of our own mortality and our right to die with dignity.

What exists in the following pages is a portal through which a journey will begin, one from which the reader can return, however not without knowing that he shares his humanity with these individuals. The desire for the quality of life, health and even death is universal.

Dedication

This transcript is dedicated to the one hundred sixty four people with AIDS who shared their lives and trusted me to tell their story. Their voices have had a profound impact on my life, and hopefully through their portrayals, we may begin to understand the suffering, pain of isolation and the need to reach out to our fellow man.

Acknowledgement

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Also, special thanks to my family and friends who, with their love, support and encouragement, have strengthened me to begin and continue this crucial work.

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CHAPTER I

AIDS IN AMERICA

Clinical Aspects

Since its discovery in 1981, over 139,064 cases of Acquired Immune Deficiency Syndrome (AIDS) have been documented in the United States. The Center For Disease Control, Atlanta, Georgia; reports that approximately 73,350 persons have died of AIDS related illnesses. Estimates of the numbers infected by the Human Immunodeficiency Virus (HIV) range between 1 and 1.5 Million people. It is projected that by the end of 1992, 365,000 American people will be diagnosed with AIDS [CDC; unpublished projections, The Essential AIDS Fact Book, Paul H. Douglas and Laura Pinsky, 1989].

AIDS refers to a complex infection which undermines the human immune system's ability to repel other diseases, thus leaving the body vulnerable to invasion by pathogenic organisms. Current research indicates that the syndrome is linked to exposure to a virus which has been known by several names: HTLV-III, LAV and ARV. In this dissertation, the writer will refer to the virus by its present scientific name- Human Immunodeficiency Virus (HIV).

HIV is a human retrovirus, part of a family of viruses scientists are just beginning to understand. As such it has RNA (Ribonucleic Acid) at the heart of its genetic composition. It can infect several human cell types, but shows a preference for the cells of the immune and central nervous systems. The virus primarily seeks out cells with a particular type of receptor molecule or port on the cell membrane. Once attached, the virus must transform its genetic make up to match the type encountered and then inserts the copy into the host cell. The virus may remain dormant for some time but when active eventually reprograms the host cell's Dionucleic Acid (DNA). This done, it reproduces within the cell, ultimately destroying the host cell. Before it dies, the host cell will have reproduced itself many times over, creating a multitude of new cells contaminated with the virus.

The virus's fondness for white blood cells known as T-4 lymphocytes is significant since it is these cells which are the immune system's first line of defense. The difficulty in fighting the virus lies in its ability to alter its external cell "armor," thus becoming a variant or mutant which is unrecognizable by the body's natural antibodies as well as artificial counteractive agents.

In addition to Kaposi's sarcoma (a skin cancer) and Pneumocystis Carinii Pneumonia (PCP), common opportunistic infections associated with AIDS are toxoplasmosis, a type of brain inflammation, cytomegalovirus (a relatively common form of herpes simplex causing inflammation in various tissues, including the retina, brain and liver), herpes varicella zoster (chicken pox virus which may cause shingles), tuberculosis, viral warts, chronic diarrhea (caused by Samonella bacteria), cryptococcal meningitis and thrush, a fungal infection of the mouth and throat caused by candida. Some disorders, like AIDS dementia complex (deterioration of the cognitive, motor and behavioral capacity), are caused primarily by HIV infection of the brain.

The HIV is fragile and not easily transmitted. But, upon infection it is found in all body fluids, both secretions and excretions. However, only blood, semen, vaginal secretions and possibly breast milk seem to be effective in the transmission of the virus. The nature and transmission of the virus implies that it can be communicated from one person to another in the human exchange of the aforesaid body fluids. Behaviors which seem most effective in the transmission of the HIV include: intimate sexual (vaginal, penis, oral or anal) contact, the exchange of used needles or syringes between drug users and perinatal transmission of the virus from mother to child.

Tests have been developed to verify HIV infection. The HIV test is an antibody test. It does not test for AIDS. Blood is drawn and tested for the antibodies which will be present if the individual was infected by the virus. Tests may be administered anonymously by public and private health care providers and institutions or organizations. The testing process, from decision to results, may be difficult for an individual. A host of concerns and worries often materialize. The return of a "reactive" or "positive" result often produces severe psychological stress. For this reason, nearly all testing sites provide some form of pre- and post-test counseling.

HIV exposure does not mean immediate experience of AIDS related illnesses. Neither sufficient time has passed nor has sufficient research been conducted in order to know precisely how much time lapses between HIV exposure and the manifestation of AIDS related illnesses. Current projections and predictions vary. A recent study notes that "...if left untreated, 14% of HIV infected persons develop AIDS within five years of the time of infection, 34% within seven years and 42% within nine years." [The Essential AIDS Fact Book, Paul H. Douglas and Laura Pinsky, 1989].

Upon the receipt of a positive test result, persons are strongly advised to seek medical care in an effort to monitor their vital signs and initiate treatment protocols which could prolong life and the onset of AIDS related illnesses. It is also at this point that the persons can make conscious efforts not to infect others. The initiation of "safe sex" practices and policies, drug treatment services are strongly advised. Here the medical evidence is unquestioned; the absence of symptoms does not preclude the transmission of the HIV.

Since the HIV destroys the body's natural immune system, infections must be avoided. Regular medical examinations, a balanced diet, exercise, adequate rest and stress reduction all help to preserve good health.

Demographic trends of people with AIDS

At this time it seems that infection is for life. In this country the greatest number of persons infected by the HIV are homosexual or bisexual males, intravenous drug users and the female sex partners of such men. Nearly 67% of all the people known to be HIV infected are gay/bisexual men and another 25% are intravenous drug users. The latter accounts for a growing proportion of the total. Although women were heretofore a relatively small proportion of the total AIDS population in the U.S., they are increasingly at increasing risk and therefore, of particular significance because of the risk of infection to a fetus during pregnancy and delivery.

To date, the vast majority of AIDS cases have materialized in the states of New York and California, although there are notable numbers in Florida, Georgia, Illinois, New Jersey, Pennsylvania, Texas and Washington, D.C.

At the start of the 1980's, virtually nothing was known about the syndrome or its transmission. "It was November 1, 1980... [when] single frames of tragedy in this and that corner of the world would begin to flicker fast enough to reveal the movement of something new and horrible rising slowly from the earth's biological landscape." "... a new virus [had become] well entrenched on three continents, having moved easily from Africa, to Europe and ... to North America." (Shilts, 1987). Young, gay men were the first of America's social groups in which were identified immuno-compromised infections. Between late 1980 and early 1981 Pneumocystis Carinii Pneumonia and Karposi Sarcoma were determined to be the direct cause of death for several men affected by the new virus. Later that year, the Center For Disease Control, Morbidity and Mortality Weekly Report released the first report on what would soon be called an epidemic.

During the last ten years, while the numbers of AIDS afflicted persons rose, the profile of the "average" people with AIDS (PWA) changed too. Initially, in this country, AIDS patients were predominantly white, middle class, gay males. The infection spread among this population primarily by way of sexual intercourse before the virus, related diseases and modes of transmission were understood.

By the mid 1980's the profile had begun to change. "The gay communities in major urban centers, pre-conditioned by many years of government indifference and supported by a healthy internal economy, sprang into action. The "San Francisco Model" of volunteer health care organizations, counseling groups and education programs was successful because the politically organized, empowered and well-funded gay white male community could quickly come together." (Mitchell, 1990). Their efforts were based on what had become known about the disease and its transmission. A recent study sponsored by CDC in a San Francisco City clinic cohort indicates that self-reported high risk behavior (associated with the transmission of HIV) among gay men decreased 90% between 1978 and 1985. Although AIDS is still "...the leading cause of death among gay men between the 25 and 44 years of age,..." (MWWR, 1987) the incidence of HIV infection is on the decline among middle class, gay, white males.

Since the mid-1980s the incidence of HIV infection and AIDS among African-Americans, Hispanics and all women has risen noticeably. "... of the reported cases of people with AIDS in the United States, ...26% were black and 15% were Hispanic" (MWWR, 1987). Facilitated by the exchange of infected body fluids during sexual encounters, shared needles, transfusions and perinatal status, the virus spread through those groups by way of bisexual men as well as intravenous drug users and their partners. "The percentage of all AIDS cases attributed to sexual contact between men and women has increased from 1.2% in 1982 to 2.3% in 1986 to at least 4.1% in 1987. By 1991 an estimated 5% of the cases (13,500) will have [resulted from such] sexual contact" (MWWR, 1987). Women now account for 8% of all AIDS cases in this country. They are the spouses or girlfriends of intravenous drug users or bisexual men, sometimes both. Nationwide, the incidence of AIDS among black or Hispanic women is about a dozen times higher than the incidence of AIDS among white women." Similarly, "among black children the incidence of AIDS is 15 times higher than among white children. In New York City, 93% of children with AIDS are black or Hispanic" (MWWR, 1987).

The quality of AIDS related information is better now than in the early 1980s and the educational response of certain communities, most noticeably the gay community has been significant. Yet, "By 1991, the United States Public Health Service expects to have a total of 279,000 cases of AIDS... If present trends continue, at least 108,000 of these will be among New York black and Latinos, most of them living in low income inner city areas." [<u>AIDS and The Third World</u>, New Society Publishers, the Panos Institute, 1989]. Also, "...blood surveys of military volunteers show that blacks are four times, and Latinos two times more likely than whites to carry the HIV virus." [<u>Morbidity and Mortality Weekly Reports</u>, May 15, 1987, Vol. 36, Number 18, pp. 273-6]. Information about transmission and treatment is not impacting everyone equally. This might explain the rising incidence of AIDS is rising at a dramatic rate among certain socio-economic sub-groups. "The spread of HIV infection among black and Hispanic needle-sharers has continued essentially unchecked: AIDS education and prevention [counseling] has largely been targeted toward the white middle class population and has only just begun to address the issues relevant to needle sharers" (MWWR, 1987).

The incidence of AIDS in intravenous drug users (IVDU) was first documented in 1984 [Selik, Haverkos and Curran, 1984]. "The route of transmission is presumed to be by parenteral exposure to contaminated equipment used for injection. Needle sharing has been reported to be a risk factor for these patients." [Harris, Cabradella and Klein, 1984]. "Needle sharing should be defined to include the sharing of syringes used for injection and possibly even the 'cookers' used for preparation of the drugs. Heroin and Cocaine are by far the most commonly used injected drugs among IVDUs who have been exposed to the HIV, but the particular drug being injected does not appear to play an important part in the spread of the virus." [Cohen, Marmor and Des Jarlais, 1985].

A 1986 report noted that "... 77% of these patients [were found] in New York and northern New Jersey. About 11% of the homosexual patients give a history of IV drug use, providing a potential mechanism of transmission between these two groups" (Flewis and Baker, 1986).

Of course all drug consumption, especially recreational use, expose the user to some measure of health risk. As one U.S. Department of Health publication explains: "...All drugs, including heroin, crack, cocaine, alcohol, marijuana and prescription drugs can put you at risk for HIV infection. When drugs and alcohol are consumed, the substances may impair judgement and lead one to have unprotected sex. Drugs and alcohol weaken the body's defenses and increase the propensity for illness." Suggestions about reducing potential infection are provided for people who use drugs intravenously and may share needles. They are advised to clean their needles by drawing chlorine bleach into the needle and the syringe, flushing the solution and repeating the process.

As in the connection of gay and bisexual men to IVDUs, women risk HIV infection if they have unsafe or unprotected vaginal, oral or anal sex with infected men. In New York City, AIDS is the leading cause of death of women between the ages of 25 and 34 years. AIDS is expected to become the leading cause of death among all city women of child bearing age by the year 1992. Of the 18,500 cases reported in New York City as of January, 1989, 2,300 (12.4%) were in women. It is estimated that by 1991, 9,000 women will be diagnosed as having "full blown" AIDS infection. Of the 2,300 cases, 51% are in African Americans and 32% are in Hispanic Americans. Nearly 90% of the affected children under five years old are either black or Hispanic. Almost all of these children acquired the condition from their mothers during pregnancy, whereas half of the white children with AIDS were exposed to the virus as a result of blood transfusions.

Now that AIDS has been introduced into mainstream American society, another deep pool of potential victims includes adolescents. Teenagers are particularly at risk. The number of abortions and cases of venereal disease have not declined significantly among teens, indicating that safe sex is still not being taken seriously by many young people. The Center for Population Options, Atlanta, GA., recently published a report on the behavior of teenagers that puts them at a high risk to contract AIDS.

Of particular concern are indications that only one third of sexually active teens use contraceptives regularly, and less than one quarter of those use condoms.

An estimated 200,000 teens of both sexes, frequently runaways, may become involved in prostitution.

A conservative estimate is that 200,000 teens have used IV drugs, some of them starting as young as 12 years of age.

Teens may also share needles for reasons other than drugs. For example, girls may pierce one another's ears; student athletes may exchange them in order to inject steroids or in tattooing each other.

Sociological factors in AIDS education and care of people with aids

While the use of narcotics is illegal and thus discouraged, health and other officials are practical enough to know that these substances will be used in spite of the high risk to users. In their article, (Faltz and Madover, 1988) point out that clinical and ethical issues are often barriers to treatment of IVDU persons with AIDS. Issues of care giver countertransference, education, denial, coping, interfamilial relationships, self esteem, intervention and treatment must be addressed to have any significant impact on the IVDU's willingness and ability to minimize risk for HIV infection, maximize healthiness and reduce the risk of transmission to others.

Specifically, the issues affecting if not undermining the treatment process include, denial of a HIV+ diagnosis coupled with addiction denial, difficulties in coping with pain, interfamilial conflict resolution, substance abuse relapse and coordination of social service agency care. "The patient and loved ones are often traumatized by the [HIV+ diagnosis] and the loved ones may be reluctant to confront the patient's substance abuse, too." In addition, "Because of the overwhelming nature of an HIV+ diagnosis, treatment providers as well as patients often feel the sense of hopelessness that precludes any possibility of major positive life changes." Further, "rationales for ignoring drug or alcohol abuse and the possibility of successful treatment for it include: 'the patient will die anyway,' that substance abuse treatment will take away the coping mechanism and that substance abuse treatment is 'too' stressful" (Faltz & Madover, 1988).

Despite the obstacles, the authors note that, "...crisis brought out by HIV+ or AIDS related illness diagnosis may provide an opportunity to make a powerful intervention in the individual's substance abuse, and the patient's quality of life may improve as a result... For the individual troubled by the chaotic life style that often accompanies drug or alcohol abuse, the crisis evoked by an AIDS diagnosis may generate a willingness to ask, "What will I do with the rest of my life?" The patient may choose either to get treatment for the abuse or to continue it. Many do choose to "Die High!"

A barrier to treating IVDU with AIDS often lies in the perspective and response of caregivers. "...Fear of the unknown, of contagion, of death and dying, of homosexuality, and the denial of helplessness, over identification with the patient, anger and the need for professional omnipotence" can undermine the quality of service offered to this special population. "... moralistic attitudes towards drug and alcohol abuse,... based upon the unreasonable assumption that an individual is in control of their excessive use of these substances [leads the caregiver to conclude that] the addict would stop if they really wanted. This may prompt the care giver to take a lethargic, passive approach to serving the patient (Faltz & Madover, 1988). Similarly, "In addition, drug or alcohol abuse may be considered a secondary problem of an emotional [nature] rather than a primary condition [causing] emotional problems. This view may lead the care provider to suggest mental health system referral rather than appropriate substance abuse treatment (Faltz & Madover, 1988).

It is an understatement to say that AIDS is a major public health problem; this cannot be stressed enough, particularly for women and children of color. These persons are increasingly and profoundly affected because of the marginal political and financial resources possessed as well as ignorance and poor socialization. Women may be afraid to ask their partners about their sexual histories. Some feel a strong need to fulfill their partners sexual wishes and so will not insist that the man practice safe sex.

According to Woman and AIDS Resource Network (WARN), Brooklyn, New York, evidence has been revealed to suggest that women with AIDS deteriorate and expire more quickly than their male counterparts.

The following table demonstrates these statistics:

Table 1. Length of Survival Time After Diagnosis

	FEMALE		MALE	
	No.	Time	No.	Time
California	128	40 days	6,946	1.0+ yrs.
Miami	111	6.6 mos.	N/A	12-14 months
New York City	552	9.9 mos.	5,281	12.5 months

Source: Woman and AIDS Resource Network, Women and AIDS: the Silent Epidemic. New York, 1989, p.3

Table 2. Female Deaths as Percentage of Total Adult Mortality From AIDS- U.S. and New York City

	Total Adult Cases	Total Adult Female Cases	Females as % of Total
U.S. Total Cases	86,656	7,523	8.7
U.S. Total Deaths	49,870	4,419	8.7
NYC Total Cases	18,504	2,301	12.4
NYC Total Deaths	10,036	1,169	11.6

Source: Woman and AIDS Resource Network, Women and AIDS: the Silent Epidemic. New York, 1989, p.3

Several theories have been suggested regarding the dramatic differences in the incidence of infection and the survival rate between the two sexes. One is that the figures suggest males may be diagnosed earlier in the course of their disease. Another possible explanation is that the data compare two very different social groups: informed, predominantly white, middle class, gay men, many of whom are professionals with access to insurance and two adult male incomes; compared with relatively uninformed, predominantly intravenous drug using, poor and minority women.

The differences in infection and survival rates are a reflection of the fact that poor women wait longer to get treatment because they have no financial access to the medical care system and also because they may be concerned that their children might be taken from them if they are diagnosed as HIV infected. Also, women who use drugs are less likely to seek medical help for fear of being forced into a recovery program. They are, therefore, diagnosed at a later stage of the disease process. In addition, they may be in poorer health due to other factors such as malnutrition, poor hygiene, abuse, poverty, etc. It is also felt that AIDS in women may be a different disease, perhaps exacerbated by female hormones. Moreover, pregnancy weakens the immune system, making women more susceptible to infection.

There is also a link between IVDU and children. "Of the 423 cases of AIDS among children reported through January, 1987- 53% had an IVDU parent..." (Des Jarlais, Jainchill & Friedman, 1986).

As the epidemic spreads, many of the infected persons have lost their jobs, homes and insurance coverage. Although Medicaid provides some assistance, funding is limited. Some pregnant women who have tested positive for the virus choose to terminate the pregnancy through proper abortion. But, without Medicaid many poor women have no such option. Some such women visit doctor after doctor in a vain attempt to secure the abortion. Most are unsuccessful and are forced to carry the child to term. Generally, all women labeled, "high risk" face the same kind of discrimination or potential problems, whether or not they have the virus.

A 1987 study conducted by the National Public Health and Hospital Institute found that the average AIDS patient spent 16.8 days in the hospital at an average cost of $680 per day. When doctor's fees are added the cost of AIDS related medical care totals $17,900 per patient per year. In aggregate AIDS care costs will reach $5.3 Billion in 1991 and could top the $30 Billion figure by the end of the decade, according to the National Center for Health Services Research.

The Health Care Financing Administration reports that federal funds pay for 70% of costs for IV drug user AIDS patients. In the public hospitals used by many blacks and Hispanics with AIDS, 52% of the patients admitted indicated that Medicaid was their only form of payment. Then too in 1987, the average public hospital lost $600,000 due to the cost of treating AIDS patients (drugs like AZT cost $7,500 per year per patient). Without some relief, many inner city hospitals will face severe financial crises forcing them to compromise the quality of care given these patients, reduce the number treated or close their doors completely.

This year, New York City will spend $250 Million of a $1.25 Billion budget on the medical care of AIDS patients. At current projections by 1995, New York City is likely to spend more than $500 Million for AIDS. "By 1991 one out of every four hospital beds in New York City will be occupied by an AIDS patient (Serwadda et al., 1985). "Caring for each person with AIDS will cost around $65,000 from diagnosis to death, and the direct costs of caring for the total predicted number of AIDS cases will reach an annual $8.56 Billion by 1991." [P. Dossier, AIDS and the Third World, The Panos Institute, 1989.] Some assistance may come by way of the Ryan White Comprehensive AIDS Resources Emergency Act of 1990 (the CARE bill);which will provide $600 Million nationwide, for case-managed services in community based outpatient clinics, hospital inpatient and outpatient treatment, and home health care to the poor.

Presently in the battle against AIDS, the scientific community has developed and tested many treatment options; Antivirals, such as Zidovunine (AZT), DDI-dideoxyinosine and DDC-dideoxycytidine which are designed to undermine the reproduction of HIV. Ddi boosted T4 cell counts and ddc has the most potent anti-HIV effect of any nucleoside. Immune stimulators Naltrexzone, Gamma Interferon, stimulation of Interluken-2 which is already found in the body, are used to strengthen the immune system. Recently developed and lately improved, Prophylaxis (Pentamidine) is designed to prevent opportunistic infections such as Pneumocystis Carinii Pneumonia.

In addition to these are other alternative treatments which are more or less grudgingly accepted by the medical community, including acupuncture, massage therapy, psychological visualization, mediation, nutritional, and urine therapy. These therapies, although relatively useful, are engaged for a select population and are not routinely made available or even discussed with the urban poor.

The work continues to develop a vaccine for the HIV and cure for AIDS. Experimental drugs are both in the developmental and trial stage. But, again, blacks and Hispanics are a disproportionately small portion of the trial population. An increase in AIDS among the minority, urban poor population coupled with a inconsequential number of minority clinical subjects in drug trial could be disastrous. An HIV vaccine or AIDS cure might be found that works well for whites but is ineffective for blacks. "Since 1929, it has been established that there are substantial differences in how blacks and whites react to a given drug.... black high blood pressure patients do not respond to the antihypertensive effects of Beta-blockers as well as white patients. Clearly under representation of blacks in hypertension clinical trials would lead to insufficient data to produce the kind of treatment best suited to both races" (Santiago, 1990).

According to the Journal of the American Medical Association, in over half of the clinical trials where race was a factor, it has been found that the percentage of black subjects was less than the percentage which lived where the study was conducted. This and other documented disparities prompted the National Institutes of Health last year to urge applicants for grants to include minorities in their studies. The Food and Drug Administration is also beginning to apply moral suasion in getting drug companies to be sensitive to the issue. But, getting African-Americans and Hispanics to participate in clinical trials is difficult. Given the rather dubious history of treatment involving minorities in past clinical trials, as well as the persistent rumor that AIDS is a laboratory created form of germ warfare against third world people, it is not surprising that minorities are wary of the trials and the clinicians.

Dr. Anthony Fauci, Director, AIDS Research, National Institutes of Health (Washington, D.C.), on June 17, 1990 said during the sixth international conference on AIDS:

> "The decade of the '90s will see some important advances that will have a positive impact on HIV infected individuals... Over the next several years, you will see a real acceleration of vaccine development..."

Taking clinical trials into the ethnic minority communities may be awkward, but if representation of white males is disproportionately high, the drugs developed may not be best suited or even safe in the long run for blacks and Hispanics.

Since a vaccine has not been developed, researcher's are focusing on AIDS education and its impact on HIV prevention in ethnic minority communities.

In <u>AIDS and IV Drug Abusers</u> (Des Jarlais) notes that:

> "Some of the most promising developments in limiting the spread of the Human Immunodeficiency Virus lie within the realm of health education. Such efforts undertaken by homosexual and bisexual communities... have lead to reductions in self-reported high risk sexual behaviors among sexually active homosexual and bisexual men as well as a reduction in the reported rates of other sexually transmitted diseases... AIDS education has become a growing

> concern among heterosexuals... being incorporated more often in sex education curricula in the public schools. Despite these trends, AIDS education remains controversial. It is not yet widespread."

Dr. Des Jarlais continues that AIDS education for intravenous drug users is even more complex. Because many of their activities are illegal and their political power base is non-existent, the governmental measures taken to address the specific needs of this group have been limited.

Ten years into the epidemic, some people seem to believe that they will not experience an AIDS related illness, that the "AIDS thing" is a disease of gay men and drug addicts. Many people see HIV infection and AIDS as the consequence of unnatural or antisocial behavior. Some even go so far as to say "they get what they deserve."

In Illness As Metaphor, Susan Sontag writes about the "mythologizing" of diseases, especially those of unknown etiology. She comments that such illnesses take on a symbolic meaning when the origin and causes are mysterious and unclear. Her thoughts are particularly relevant to this study. When AIDS was first identified, it was connected to the nation's gay community. Reports of this strange, new illness and the revelation that the suffers were homosexual, led to its being named GRID- the Gay Related Immune Disorder. Sontag writes:

> "Nothing is more punitive than to give a disease a meaning- that meaning being a moralistic one. Any disease whose causality is murky, and for which treatment is ineffective tends to be awash in significance... Feelings about evil are projected on to a disease (so enriched with meaning) it is projected on to the world..." (Sontag, 1977).
>
> "...Patients who are instructed that they have, unwittingly caused their disease are being made to feel that they deserved it..." (Sontag, 1977).

By the end of 1990, the Federal Government is expected to spend $1.16 Billion on AIDS research and may dispense $1.245 Billion in fiscal 1991. Despite the impressive sound of this dollar amount, there is controversy as to the commitment of the American people and the U.S. government in coping with and ultimately discovering a cure for the AIDS syndrome. An article in the April 25, 1990 edition of the New York Times, "Panel Says Government Is Not Leading the AIDS Fight," notes "The Federal Government's top advisory panel [The National Commission on AIDS] on AIDS policy told President Bush... that AIDS policy in the U.S. was like an orchestra without a conductor, because the Government had failed to lead the campaign against the epidemic effectively. All across the country there is a cry for leadership from the Federal Government and partnership between the various levels of government." Among the panel's recommendations were: the establishment of a cabinet level post filed by an official commissioned to devise a national strategy to cope with AIDS, provision of disaster relief for the areas hardest hit by the epidemic, enactment of antidiscrimination legislation to protect PWAs and the elimination of government restrictions as to the content of AIDS educational brochures."

The American underclass

Since 1965, the changing economy, demographics and social welfare programs have altered the nature of poverty in America. The U.S. Census Bureau reports that in 1989, 32.5MM people (14.% of the population) lived on less than $12,070.- the defined poverty level for a family of four.

According to the Census Bureau, family income reached an historic level of $30,853. in 1987. Such prosperity meant little to people living below the poverty line. Robert Greenstein, Director of the Center on Budget and Policy Priorities, Washington D.C., said:

> "The recovery is... leaving the poor behind. While unemployment rates have returned to the 1978 level, poverty [is] higher than the 11.4% figure for that year... The gap between rich and poor families is... at its widest level in 20 years."

The House of Representatives, Budget and the Ways and Means Committees revealed that between 1967 and 1987 the richest fifth of the population enjoyed a 12% increase in income while the poorest fifth experienced a 23% decline. Census data confirms that the wealthiest 20% of the nation received 44% of all income in 1987 compared with 41% in 1967. The bottom 20% received 4.5% of cash income in 1987 compared with 7% in 1967. Exacerbating their poverty is the rise in inflation, stagnation of the minimum wage and the evaporation of many low skill jobs. The Congressional Budget Office estimates that in light of all federal tax revisions, families at the bottom tenth of incomes suffered a 46% tax increase during the 1980s, while families in the upper tenth benefitted from a 3% decrease.

For most of the nation's poor, poverty is not a permanent condition. Historically, immigrants overcome poverty within two generations. Temporarily unemployed adults are often gainfully employed within a year. Although sociologists, economists and government officials disagree as to why, roughly 8M Americans are not assimilating. Labeled 'underclass,' they experience long term, often times intergenerational poverty.

At the risk of generalizing, the underclass is composed of the: a) passive poor- usually long term welfare recipients; b) hostile poor- criminals, drug/alcohol addicts and school drop-outs allegedly responsible for much of the violent inner city crime; c) hustlers- living off the underground economy and d) traumatized poor- substance abusers, the homeless and the mentally ill. Demographically, the underclass is composed largely of female headed, public assistance dependent families and single, young, ethnic minority, unemployed males. In the North Atlantic coastal area the underclass is concentrated in Boston, New York, Philadelphia and Washington, D.C. Undoubtedly, the census understates the underclass populace because the homeless are nomadic and inaccessible.

The origin of the metropolitan underclass is traced to the migratory pattern of the 1920-1960 period. During that time the opportunities offered by urban manufacturing concerns were attractive to the urban poor since it allowed them to obtain entry level positions. Since then city life has changed.

Technological advances and changes in the global economy transformed many American cities from manufacturing centers to hubs of information processing, finance and administration. In the process many older businesses which provided jobs for unskilled and semi-skilled residents disappeared. These were, in part replaced by knowledge intensive, white collar enterprises with educational requirements and information networks that exclude most poorly educated, socially isolated inner city residents from employment.

The civil rights movement of the 1960s weakened social barriers, making quality education, lucrative employment and better neighborhoods more accessible to qualified minorities. The unskilled, least productive and most dependent were left behind. The population which moved to the suburbs or prime city neighborhoods were followed by merchants and corporations, thus further reducing the supply of service providers and employers. The women's liberation movement and maturation of the 'baby boomers' intensified job competition.

Such demographic and economic changes created a gap between the skills of certain inner city residents and the needs of modern urban employers. The population shift reduced tax revenues, providing fewer resources for inner city institutions. Accordingly, the unemployment rate of poorly educated urbanites has risen steadily since 1970.

Drug abuse, crime and isolation from the upwardly mobile, leave poor inner city communities with destructive role models and non-working adults. The validation of new gender options, the shrinking pool of marriageable males (undermining the creation of nuclear families) and the sexual revolution (destigmatizing unwed motherhood) reduced the incidence of nuclear family formation- society's basic building block. Cultural isolation, 'street' life socialization patterns and persistent racial discrimination prevent many inner city inhabitants from developing the interpersonal and academic skills necessary to participate in a post industrial state. Economic recovery cannot, in and of itself, enhance the quality of life for the urban underclass; they have become too detached from mainstream economic and social institutions.

The underclass live with poverty and despair. After two decades of efforts to erase poverty, the ranks of the underclass are growing. Their impact exceeds their number, for their plight is a cause and effect of America's most persistent problems. The culture is marked by teen pregnancy, single parent households, chronic unemployment, crime, drug abuse, welfare reliance and homelessness. In general, the underclass life cycle features severe problems in several areas:

Birth- 42% of all infants born to poor parents are illegitimate compared with 14% born to more affluent parents.

Childhood- Minors are the most numerous and fastest growing subset of the underclass population; representing 39% of those who live in poverty.

Adolescence- Nearly half of poor females are pregnant by age 20. The high school drop out rate exceeds 50% in many inner cities.

Adulthood- Less than 50% of inner city black men are employed. Sixth percent of poor families are headed by women. Black men constitute 6% of the population, yet account for half of the prison inmates.

Death- The leading cause of death for young black men is murder by another young black male. The homicide rate for black men is six times that of white men. Blacks and Latinos represent 12% and 6% respectively of the population, but 25% and 14% of the diagnosed AIDS cases.

Is underclass behavior adaptive or cultural, society's fault or the individuals? Whatever the cause, they operate outside the norm accepted by American society. Prolonged poverty, William Ryan wrote in <u>Blaming the Victim</u>:

> "...can produce stress... and... emotional disorder... They are set apart... by their antisocial behavior [and] bad habits, not just by their poverty."

Additionally,

> "The lower class individual lives from moment to moment. If he has any awareness of a future,... it is of something beyond his control..."

The "culture of poverty" thesis popularized during the 1950s and recently revived by President Ronald Reagan promotes the idea that the underclass, crippled by behavioral disorders, lead chaotic lives. Oscar Lewis wrote:

> "...the culture of poverty,... is an adaptation to a set of objective conditions of the larger society... it tends to perpetuate itself from generation to generation... children... absorb the... values and attitudes of their subculture and are not psychologically geared to take advantage of... opportunities..."

While the poverty culture thesis may explain ghetto behavioral patterns, it does not explain the spread or intensification of poverty. The association of increasing inner city social problems with the crystallization of a poverty culture obscures urban structural changes. The exodus of the middle class from marginal neighbor-hoods eliminated a crucial "social buffer" which could have deflected the impact of prolonged joblessness plaguing inner city neighborhoods in the 1970s. In earlier years, community organizations (churches, schools etc.) remained viable and supportive of poorer residents because the principal patrons were economically stable families. Such families acted as role models, extolling the merits of education, employment and diligence.

The exodus of stabilizing community members resulted in an exponential increase in related forms of social dislocation. The cultural and economic isolation of the underclass leaves it beyond conventional forms of outreach. Their isolation and concentration worsens the frustration, passivity and hostility characterizing their lives. Society, by ignoring the underclass confirms this sense of worthlessness.

In a medical crisis such as the AIDS epidemic, the availability and digestion of current, factual information is essential to avoidance of infection or for appropriate coping with the condition. Since the underclass operates outside the mainstream network its members are not receiving or processing this vitally important material.

The underclass experience incorporates four elements which were irrelevant for previous generations of poor people but which are pertinent to any discussion about AIDS:

Drugs- Substance abuse is commonplace in poor urban neighborhoods. The current "fashionable" drugs are more powerful and readily available than ever before. They obscure the drudgery of everyday life and provide illusions of freedom. The drug trade is financed by illegal and illicit activities.

Television- In 1988 Nielsen Media Research found the poor view 39% more TV than other households. Television has replaced books as the medium of choice for the poor. Using easy and seductive entertainment, it promotes counterproductive behavior; sex without responsibility, wealth without work and its purposeless but hardly inconsequential violence.

Welfare- Work is as necessary to life as food, sleep and sex. Yet, public assistance programs provide subsistence income and medical care, but little for the education, job training or career counseling which make healthy, independent living possible.

Homelessness- The recession of the mid- 1970s reordered government budget priorities, yielding cutbacks in low cost housing subsidies. The inventory of such housing deteriorated while the number of poor increased.

Homelessness has increased sharply and visibly during the past two decades. The 'old' homeless of the 1950s blighted sections of the city, but they stayed on 'Skid Row' and could be ignored. Today's 'homeless' exist on the streets, in abandoned buildings or in spaces meant for fewer people. The issue is more complicated than the supply of low cost housing, urban redevelopment and the decriminalization of vagrancy. Homelessness arises out of mental illness, arson and poverty. The symptom (homelessness) arises from an illness (poverty) caused by conditions (inferior education and minimal economic opportunities) which threaten the quality of American life generally and its urban centers specifically.

Homelessness may be rooted in a lack of economic opportunity but, there are often immediate crises which result in displacement. Typically, individuals deal with difficulties accumulated over time which combine with an urgent problem to leave them without housing. The factors contributing to displacement include interfamilial conflict, joblessness, underemployment, housing damage, mental illness and substance abuse.

The following are characteristics of the urban underclass which may affect their risk for HIV infection and AIDS: generational poverty, breakdown of family and neighborhood structure, the drug epidemic, teenage pregnancy, lack of adequate job training and skills and the lack of appropriate HIV/AIDS education and information.

Statement of the problem

The increasing spread of AIDS to those who were already among the nations's most stigmatized people severely strains the capacity of our social welfare and political institutions. While the world awaits a cure for AIDS infection there is a general agreement that the only routes to prevention hinge on mass education and, some will assert, more draconian measures such as contact notification (Bayer, 1989). Recent trends in AIDS epidemiology indicate that more affluent and more educated risk groups have modified their behavior and are experiencing increasing rates of infection, especially outside the major metropolitan regions. Low income members of minority groups who live in areas of high intravenous drug use and high incidence of crack use are among the highest risk groups in the nation. (Centers for Disease Control, 1989). It is with the latter population and those assigned to its care that this dissertation is primarily concerned.

The Ethnography

The rapid spread of AIDS among the underclass and the special problems faced by such persons warranted sociological investigation. The writer initiated this study to investigate the extent to which underclass status 1) is related to risk of HIV infection, 2) poses barriers to treatment and (3) presents any special or unique problems for the care providers of such patients.

The writer engaged in field study of the prevailing conditions affecting urban, underclass AIDS patients and their health service providers. The research was conducted in a large public New York City hospital (fictitiously referred to as Oremus Hospital) where the writer was employed as a social service case worker assigned primarily to patients in the AIDS wards. The research was conducted as a classic participant ethnography.

The wards to which AIDS patients and others were assigned was the setting for the research study. There were usually thirty patients in a ward, of whom twelve to fifteen were diagnosed as "full blown" AIDS cases. The conditions of employment required that the writer counsel patients, as fully as possible, regarding the onset of AIDS related symptoms to their discharge or demise.

The subjects of the study were recruited as voluntary participants and assured complete anonymity and confidentiality. This necessitated the development of a coding system and designation of aliases for each of the persons whose dialogues are used in the study. Special emphasis was placed on those who entered the facility via the emergency room and who were ultimately transferred to one of the wards in which AIDS patients were served. In selecting subjects for the research, the writer sought the following characteristics which confirmed a socio-economic background indicative of underclass status. During the course of counseling and interview sessions note was made of each subject's demographic profile, (age, sex, marital status), socio-economic status (income, employment, medical insurance, sexual orientation, familial ties and other interpersonal relationships as well as domicile). Specific questions were posed to gauge the patient's awareness and knowledge of AIDS and their particular AIDS related status.

Over a period of twenty two months (February 1988-November 1989) the researcher collected data and notes concerning 164 patients and the site. Field research methods including first hand observation, formal and informal interviews, the creation of case histories and field notes were used to compile data and other information. Such information was recorded daily.

The sex and ethnic distribution of the total population studied was 126 (77%) male and 38 (23%) female. Of these, 68 (41%) were black males, 58 (35%) Hispanic males, 15 (9%) black females, 19 (12%) Hispanic females and 4 (2%) were white females. The mean age of the group studied was x= 34.2 years.

Mode of HIV transmission was 126 (77%) intravenous drug use, 4 (2%) heterosexual male to female transmission, 10 (6%) homosexual transmission, 3 (2%) sexual trade; 8 (7%) revealed multiple risk activity and

10 (6%) claimed non awareness of the means of transmission.

The majority of the patient population, 147 (94%) entered the hospital via the emergency room. Only 10 (6%) entered the hospital with referral from the satellite community clinic or upon the recommendation of their personal physician.

Overall, 106 (65%) entered the hospital without medical coverage. This 65% of the total population received hospital sponsored Medicaid, which remained in force only during the term of the hospital stay. Just 53 (32%) had Medicaid prior to their hospital admission and only 5 (3%) had private medical insurance.

The investigation revealed that 85 (67%) of the male population had their hospital costs covered by hospital applied Medicaid as compared to 21 (55%) of the females. Only 5 (4%) of the males had private medical insurance as compared to 0 (0%) of the females.

The mean age distribution at death for males was x= 36.3 years and for females was x= 34.4 years. The mean age of the population which expired during the research term was x= 35.86.

Table 3. Population by Ethnicity

	Black	Hispanic	White	TOTAL
MALE	68	58	-0-	126
FEMALE	15	19	4	38
			Total:	164 persons

*"Black" refers to those of African American and Caribbean descent.
"Hispanic" refers to those of Puerto Rican, Cuban and Latin American ancestry.

Table 4. Medical Coverage

GENDER	ETHNICITY	Private Insurance	Medicaid prior to Admission	Hospital Applied Medicaid	
MALE	Hispanic	3	20	35	
	Black	2	16	50	
	White	N/A	N/A	N/A	
FEMALE	Hispanic	-0-	11	8	
	Black	-0-	4	11	
	White	-0-	2	2	
TOTAL		5	53	106	= 164
PERCENT		3%	32%	65%	

This table highlights the health insurance resource available to the individual at the time of admission to the hospital. A disproportionate number (65%) had no policy at the time of admission which prompted the facility to apply for Medicaid coverage for the duration of the persons hospital stay. Once discharged, the subject's coverage ceases. A smaller portion of the study group entered the facility with Medicaid, which may be because prior arrangement had been made with the social service system. Only a few (3%) of the sample, possessed private carrier insurance.

Of course the availability of insurance is tied to overall financial security. It is not surprising that the poor are unable to protect themselves in this fashion. Their needs are more immediate.

As concerns this ethnography, it is important to note the strong correlation between lack of insurance and the predominant use of the emergency room (ER) as the mode of hospital admissions. Very few (10%) of the population researched was referred to the hospital by a physician. Even then it is likely that the doctor or technician was on staff at the hospital's own satellite clinic located elsewhere within the community.

Table 5.

Modes of Transmission:

GENDER	ETHNICITY	BODY FLUIDS	SEX			MULTI-RISK		UNKNOWN	
		IVDU	Hetero/	Homo/	Trade	crack/	Crack-Sex	IVDU/ IVDU	Partner/Other
MALE	Hispanic	45	0	4	0	0	1	0	4
	Black	54	0	6	1	0	2	0	6
FEMALE	Hispanic	12	3	0	0	4	0	0	0
	Black	8	1	0	2	4	0	0	0
	White	4	0	0	0	0	0	0	0
TOTAL		126	4	10	3	8	3	0	10
% of Entire Population		77%	2	6	2	5	2	6	
% of Female Population		63%	11	0	5	21	0		0

The majority of participants in the study were Intravenous Drug Users (IVDU) and it is surmised with some confidence that they were infected with the HIV primarily by way of shared needles and secondarily via semen contact during unprotected sex. The most common means of transmission was through contact with infected blood during intravenous drug use. Individuals describing such a cause constitute 77% of the total population. Beyond this, it is noted that 8 (5%) of the population were women engaged in the sex oriented "professions" to, in part, support their narcotic addiction. Moreover, 4 (2.5%) of the population were women who traced their contact to unprotected sex with a IVDU friend or spouse. The latter group denied any history of IVDU or sex trade activity. The implications are interesting if these statistics are projected on to the broader community. For every 1,000 women, 105 could be at risk for HIV infection through sex with an IVDU sex partner.

The three men (2%) of the total population in the multiple risk category are defined as such because they admitted to both IVDU or crack use, bisexual activity or paid sex with prostitutes. No single, definite cause of their infection could be clearly discerned.

Table 6. Mortality Distribution: Age Distribution and Related Death Rate

GENDER	ETHNICITY	15-20	21-25	26-30	31-35	36-40	41-45	46-50	51-55	56-60	Unknown	TOTAL
MALE	Hispanic	1	4	8	13	17	5	3	1	1	4	
	Black	0	2	12	25	12	8	2	0	0	7	
												126

Table 6. Mortality Distribution: Age Distribution and Related Death Rate (continued)

GENDER	ETHNICITY	15-20	21-25	26-30	31-35	36-40	41-45	46-50	51-55	56-60	Unknown	TOTAL
FEMALE	Hispanic	1	3	7	3	1	2	1	1	0	0	
	Black	1	1	3	2	3	3	0	0	0	2	
	White	0	1	2	1	0	0	0	0	0	0	
												38
NUMBER of DEATHS	Male	0	2	7	22	17	10	3	1	1	4	67
	Female	0	3	5	2	4	4	1	0	0	0	20
% DEAD BY AGE	Male	0	18	22	49	52	56	50	50	100	31	
	Female	0	27	16	4	12	22	17	0	0	8	

Concerning the death rate among the population by sex and ethnicity, the following statistics were compiled. Eighty seven (53%) of the total population expired in the hospital and 64 (39%) returned to their neighborhood/community. A small number 13 (8%) left the hospital prematurely, against medical advice.

Table 7. Interfamilial Ties

GENDER	ETHNICITY	EXPIRED		RETURNED TO COMMUNITY		OTHER
		Family Support	No Support	Family Support	No Support	
MALE	Hispanic	17	18	12	7	4
	Black	10	20	16	14	8
						subtotal-126
FEMALE	Hispanic	9	1	5	2	2
	Black	2	8	2	2	1
	White	0	0	2	2	0
						subtotal- 38
TOTAL AS A PERCENT		23	29	23	16	9

The study reveals that 58 (35%) of the group was domiciled and could rely on some measure of family support while eleven (7%) of the subjects were domiciled but had no family support. Sixty (37%) were homeless and had some measure of family support, while 18 (11%) were homeless without family support.

William Kornblum (1984) argues:

> "Since it seems that we will have the term "underclass" in common parlance, let us restrict it to people who are clearly "below" the poor in that they cannot survive unharmed for any length of time by themselves, because they lack both material resources and the ability to organize their lives. They are people who are outside both the class system of capitalist production and any local community. An "objective social class" that is one without class consciousness or institutions: they would include the homeless indigent, severe alcoholics, drug addicts, runaway children, and at-large psychotics who are not stable criminals. Criminals from poverty areas or elsewhere should be thought of as part of the underworld, a shadow society that has its own class system, in which there are those who own or organize the means of production, those who sell their labor, and those who seem to remain small-time crook-entrepreneurs."

The impoverished AIDS victims in this study would seem to be ideal candidates for underclass status according to this definition. Most are drug dependent, poorly integrated into the labor force, relatively uneducated, and incapable of caring for themselves in that they were not able to avoid AIDS infection at a time when information on safe sex and needle sharing abounds. The dissertation will show the conditions under which their illness drives them even further into the depths of the underclass.

The issue of underclass status and what it means for indigent AIDS patients (and for those charged with their care) is especially significant if it helps us better deal with the changing epidemiology of the disease. Closer analysis of the cases this author has recorded will reveal a number of pathways to infection and a variety of "natural histories" of coping with the disease which both confirm and qualify the helplessness dimension of the restrictive underclass definition. In some cases, for example, we will see homeless individuals who became infected through homosexual contact on the streets and in shelters where sexual deprivation, rather than homosexual identity, seems to be the explanation. Indigence and sexual deprivation, even when the person's class origins are not necessarily those of the underclass, tend to set traps which themselves produce mental illness and disease (Orwell, 1934; Kozol, 1988). Intervention in such cases, especially in the form of stable shelter, a job and income, and community attachments, can reverse damages and propel such persons into working class status. It can do so, that is, if terminal illnesses like AIDS or events like homicide do not take their toll first. In other cases to be analyzed in this study, we shall see people for whom AIDS infection is almost a form of suicide and even, in a few instances, also a form of violent aggression and murder. For many women in this study we shall see that AIDS infection is the result of lives spent in the heroine and crack dens of the city. Claire Sterk of the Graduate School and the Centers for Disease Control first demonstrated this connection. She showed that young women are trading sexual favors for the drug and, in so doing, are vastly increasing their risk of contact with HIV infected males (Sterk, 1988). We are also seeing increased incidence of HIV serum positivity among women who are non-IV drug users but whose partners may have been in the drug world or who had become HIV positive through earlier sexual transmission. In this study we shall present cases of women and men who, once infected, may or may not receive support from the other inhabitants of the cocaine world. This will afford some evidence of patterns of mutual aid and community among people who are thought to be among the most atomized members of the underclass.

The disorganized poor are not usually reached, or are not often persuaded, by conventional educational messages. In consequence, they are most likely to become victims of the AIDS related diseases. Once infected, they cannot afford quality care, are difficult to manage and tend to receive substandard treatment. The degradation of already substandard care is demoralizing to patient and care giver. This further inhibits the treatment process. Unavoidably, therefore, the dissertation will devote attention to the problems of inadequate care of underclass AIDS patients.

CHAPTER II

THE UNDERCLASS AIDS PATIENT IN AN URBAN HOSPITAL

In the mid-1980s, health care analysts and urban sociologists began to speak of a new dimension to the AIDS crisis in the form of a large subpopulation of low income and 'minority' people who constituted the fastest growing segment of person with AIDS. Black and Hispanic community leaders were especially alarmed since their communities already experienced a disproportionately high rate joblessness, teenage pregnancy, female headed households, welfare dependency, crime and incarceration. Almost by definition the urban 'ghetto' neighborhoods were economically and socially isolated. The fear is that such isolation would facilitate the catastrophic spread of an incurable disease through an already handicapped population.

There have been educational and public relations campaigns, both national and grassroots in scope, to alert the poor, typically inner city Blacks and Hispanic to the dangers of and precautions necessary to inhibit the spread of AIDS in their respective communities. Despite such efforts, it is clear that the epidemic is taking a greater toll among those ethnic groups. It appears that many more will die and their experience will affect family, friends, neighborhoods and the greater community. Thus, the author begins his examination of AIDS in the ethnic community with a look at the routine experience of the underclass person with AIDS in a New York City hospital.

African Americans, especially women and children are among those hardest hit by the AIDS epidemic. The Centers for Disease Control, Atlanta, Georgia estimates that 25% of all reported AIDS cases in this country have been diagnosed in African-Americans. More than half, 52% of all women with AIDS are Black. Sixty one percent of all babies born with AIDS are Black, and Black children constitute 53% of all the children with AIDS. According to CDC statistics, every two hours a Black person dies of AIDS related illnesses. The U.S. Department of the Census, Washington, D.C. reports that Hispanic-Americans account for only 8% of the population but 15% of the reported AIDS cases. Because a large number of the persons with AIDS are heterosexual male IV drug users, Hispanic women are 11 times more likely to become infected with the AIDS virus than non-Hispanic women. Together African and Hispanic-Americans represent 19% of the U.S. population, but 38% of the AIDS cases. Their share of the AIDS patients is increasing rapidly according to the Centers for Disease Control. Intravenous drug use and heterosexual activity are at the root of 40% of the AIDS cases among Hispanics and 45% among Blacks, but only 6% among Whites.

Environment

In many ways, the quality of care for AIDS patients is determined by the physical structure and management policies of the hospital. "Oremus Hospital" [not the true name] is of recent construction, occupying an area approximately the size of one city block. The surrounding neighborhood is representative of the ethnicity of the study population. Many parts are abandoned buildings, shattered store fronts and littered alleys. Its design emphasizes the efficient and smooth delivery of care and maintenance services. The facility has operated twenty four hours each day, seven days per week and twelve months each year since opening.

Hospital policy is to provide care without consideration as to race, creed, color or financial resources. On staff are more than 2000 professionals supplemented by an extensive and varied pool of volunteers with diverse responsibilities. Turnover and absenteeism are major managerial problems especially in the emergency room, nursing and social services units.

Oremus Hospital is also a teaching facility, known for rehabilitative and psychiatric care. The ambulatory and outpatient care services units are considered exemplary. Although there are more than 500 bed spaces available, state law prohibits simultaneously filling each of these. At peak periods the hospital serves 1200-1500 outpatients daily in the clinics and emergency room.

There is no unique policy for the treatment of persons with AIDS. As with any other illness however, there exists a model for the delivery of health care services to the AIDS patient. It includes examination, diagnosis, treatment strategy and methods, nutrition, discharge and aftercare or outpatient service. The full implementation of the policy is undermined by human and material shortages as well as the counterproductive attitudes of the patients and staff.

Special teams are available to serve every aspect of a patient's needs. There is a strong connection between satellite clinics and inpatient services. In the neighborhood are a few clinics to deal with HIV+ and ambulatory persons with AIDS. Illiteracy and resistance to care guidelines are major difficulties. Preventive medicine is not generally practiced by clients. Often, the AIDS patients' primary use of medical treatment takes place in the emergency room.

The Study Group

Demographically, the persons whose experiences are chronicled herein are primarily African-American (of native and West Indian origin) and Hispanic-American (of Puerto Rican, Mexican and Cuban ancestry). Most are adult males between the ages of 18 and 45 years. Since the focus of the study is the 'underclass', the group includes only those persons who live in or close to the poverty level as defined by the U.S. Department of the

Census. They are relatively uneducated, unskilled, unemployed and mostly undomiciled.

The study group is fundamentally different from those who serve them within the context of hospitalization. The administrators of Oremus Hospital are primarily male. They are at least 35 years of age. The interns and doctors are also overwhelmingly male. Many are recent or potential immigrants who range in age from 30 to 55 years. The nurses are largely female. They are a racially diverse population ranging in age from 25 to 55 years. The social workers are equally as mixed racially but, their age ranges from 25 to 40 years. Although economic status varied, no one in this group currently lives in poverty.

Hospital Admission

Hospital administrators have established a policy and operating procedure for patient admission to the facility. It is designed to identify medical needs, gauge the facility's ability to provide relevant service and determine how care services shall be delivered. In this way the administration maximizes the efficiency with which care is provided, minimizes financial costs and demands placed on the staff, while optimizing the chances for patient recovery.

There are two ways in which patients are admitted to Oremus Hospital. The first is by request of a resident physician who is the personal doctor of a specific patient. This is not common for the population studied. It is however, common for the study group to be admitted by way of the second alternative. The emergency room (ER) is the usual entry point for people in crisis. A life threatening physical state materializes. They arrive at the ER alone, accompanied by friends, family, paramedics, social workers or concerned strangers. Medical attention is sought at this time because the person has become incapacitated by symptoms including high fevers, persistent vomiting, extreme pain or unconsciousness.

On a Friday evening in late June 1988 the Emergency Medical Services Unit receives an anonymous call reporting a motionless man lying in an abandoned car several blocks from the hospital. Paramedics are dispatched to a street lined with gutted buildings to find an unconscious Hispanic adult male. In urgent need of medical attention he is transported to the emergency room. Although the ER unit is filled to capacity, this patient is given immediate attention by harried doctors who check vital signs; stabilize his heartbeat and breathing. The physicians 'rule out' seizure disorder and drug overdose as the causes of the medical crisis. Care beyond this is limited for now because he [Miguel] has no personal identification or family present. For administrative purposes a patient number is assigned and chart prepared listing him as "name- unknown." Semi-conscious, he is left on a stretcher in an adjacent hallway with ten other patients in a similar state; all awaiting hospital beds.

Esperanza: On a hot August afternoon in the same year, "Esperanza" is brought to the emergency room by her mother. For several days she has had severe headaches, high fevers and today is unable to ambulate. She has been in poor health for the past year. [Two years ago] a Department of Health counselor arranged for tests which were returned "HIV+." Despite the gravity of this news, she was told there was nothing to do until she became ill. "So, I didn't do anything or see a doctor until I wound up in the emergency room because I couldn't walk;"... the current... diagnosis is CM (Cryptococal Meningitis).

Delores: In mid-November 1988, "Delores," a 43 year old Black female was living in a public woman's shelter. During the preceding two months she lost twenty five pounds. Over the past several days she suffered a 104 degree fever, vomiting and diarrhea. A concerned shelter staff member brought her to the ER.... As hundreds before her, Delores is examined by staff doctors who proceed through a battery of tests in order to discern the medical problem. For now, the physicians can only say what she does not have.

Canute: One early Spring morning in 1988, a 29 year old Hispanic male was found lying on the city streets. A medical service unit brings him by ambulance to the emergency room. Since "Canute" is unconscious, it is good that the staff remembers he had been here three days earlier, suffering with HIV related illnesses. Today's complications include a heroine/cocaine overdose, shortness of breath and high fever.

The mood of the ER is generally stressed. Obviously, the patrons are not here by design. Their urgent medical conditions are precipitated by accidents, violence or situations resulting from long ignored physical problems. The chamber is frequently filled to capacity.

After a wait which, depending on staff availability, may vary from minutes to two days, the conscious patient or accompanying party are interviewed by ER intake personnel. Now, formal medical record keeping begins. The purpose of this first of many interviews is to obtain general personal and demographic information including: original symptoms, name, address, employment history, insurance coverage and next of kin.

Again, depending upon the number of cases and staff availability the patient will wait for some time to see a physician. Those who were escorted by paramedics now wait alone. Those accompanied by friends, family or others may or may not wait alone. Upon the physician's arrival, intake data is confirmed and a physical examination initiated which encompasses assessment of the person's chief physical complaints, psychological, social and medical background. Clothes and other possessions are relinquished and replaced by hospital gowns and a plastic identification bracelet. A doctor decides whether or not the person will be transferred from ER and admitted for care in a medical ward. The decision is based upon a preliminary diagnosis rooted in the earlier examination.

Next, a process of stabilization and treatment is identified. Depending upon the availability of beds, the patient is transferred sooner or later to a medical unit room where a new set of doctors, nurses and social workers reassess his/her state of health and personal history. The goals of such communication are, the creation of hospital records for managerial, financial (reimbursement) and educational purposes. An effort is made to gauge the patient's understanding of the condition, the diagnosis and to elicit their cooperation in the treatment and healing process. But, in order for substantive treatment to begin the patient must be assigned a bed in the medical ward. It is not uncommon for people to wait days for this accommodation.

Miguel: An Emergency Room staff social worker attempts an interview, but Miguel is unable to answer the queries. Forty eight hours later, he remains unconscious and is transferred to the Medical Ward. But, here too, the general intake officer is unable to learn his name, availability of medical insurance or any other personal information. In one of the ward's twenty eight private rooms, his clothes are removed and discarded. Several hours later, his condition improved to the point he could talk to the medical ward staff. A more thorough examination is completed and he is diagnosed, ruling out PCP (Pneumocystis Carinii Pneumonia), TB (Tuberculosis) and anemia.

Enforcement of the hospital care policy is documented by way of the medical record. It is a major part of the care process. All personal and health related information discerned by the doctors, nurses, social workers and other health care professionals becomes part of this permanent record. It is the primary means of communication (lab tests results, daily vital signs, physician's instructions, medication type and dosage) among hospital personnel concerning individual cases. Cryptic comments and sentence fragments are used in recording pertinent information to minimize document length. Technical medical terminology defines and describes the patient's condition and progress.

The 'progress note' section of the record chronicles the specific actions taken by the staff. Because of the number and variety of persons whose work becomes the content of these records, the reporting style is standardized. A kind of boilerplate is used to construct the file for example, "Patient is a 35 year old, single, Hispanic male with history of IVDU (intravenous drug use); in good health until three days ago. Complains about generalized body aches and vomiting 3X (times per) day and fever."

Current medical records are inventoried at the nurse station located in each medical ward. At Oremus there are two wards on each floor. Here doctors, social workers and nurses converge to record relevant patient care and interaction data. Each successive care giver is introduced to a case by way of the medical record.

There is tremendous emphasis placed on documentation. All health care professionals are required to note instances of patient contact. Hospital administrators and government officials rely heavily upon these documents to assess the extent and quality of medical attention provided. The institution so stresses this medium that a physician states "...medical and health related staff spend about 70 percent of their time treating the medical record and 30 percent of their time treating the patient."

The social workers, I noted, were most concerned with the proper identification of patients, their understanding of a diagnosis, public agency referrals and appropriate discharge planning. They are concerned that each AIDS case be reported to the Human Resources Department, Division of AIDS Services (HRA, DAS), in a timely (72 hours) fashion, that Assessment Forms be completed, AIDS support groups be engaged, family actively sought and involved in the case and that a specific hospital release plan be determined. Uppermost in their minds was the extent to which the Department of Social Services adhered to the appropriate Policy and Procedures Manual guidelines.

The medical records have an effect beyond their intention. The subjective impression formed by the content, language and detail used to complete the report affects the manner with which a patient may be approached. The very mention of antisocial or deviant behavior patterns signals each care giver in such a way that may impact the quality of interactions and service. Documents including comments such as "...patient is an active drug abuser,... homosexual male,... homeless,... prostitute..." conjure stereotypical and stigmatizing images in the minds of staff. Such patients can now be distinguished from the 'good' patients who are ill through no fault of their own.

Patient Presentation

It has been noted that the population studied arrives at the hospital in a state requiring emergency assistance. If alert, they are distressed, confused and afraid, sometimes bewildered or incoherent and generally in pain. Whatever is happening to their bodies is beyond their control. Characteristically, long untreated conditions have become unmanageable to the point of incapacitation. They want the problem "fixed" as soon as possible if not immediately in order to return to a normal routine.

Prior to arrival at the ER, the vast majority of patients were autonomous. Now, they express discomfort with the unfamiliar environment, the strange hospital procedures as well as the partially unrecognizable language used by the personnel. They are reluctant to release personal information which reveals illegal practices (drug abuse, prostitution) or unconventional life-styles (homosexuality, homelessness). All this serves to inhibit them at a time when frankness and openness would be most beneficial.

Larry: a 39 yr. old Black gay male entered the ER in medical crisis. He is suffering from a very high fever, uncontrollable shaking, occasional memory loss and 'black outs.' He is evaluated and then transferred to a medical ward. Tests reveal CM (Cryptococal Meningitis). During the initial dialogue with doctors, nurses and social workers he denied practice of 'at risk' behaviors associated with HIV infection. It was during subsequent conversations that he admitted to sex with multiple male partners. He regularly "spent the nights cruising in my mother's car, looking for trade".

Once admitted to a ward the feelings of unfamiliarity begin to fade. Now, the manner in which the population relates to the facility, the staff and procedures depends more on the patient's personality and past social experiences. They cope with the current anxiety in a number of ways. Some are simply resigned to the situation and accept whatever is said or done for them. Others, accustomed to indifference, are pleased that someone is attentive. Still others reach out and connect to other human beings. They are engaging and even charming in a rudimentary fashion. They readily make friends of the staff. Much of this is genuine if partially self-serving. For instance, discussions with dietitians may be initiated regarding food in order to obtain larger portions or with nurses and doctors in an attempt to ensure immediate, appropriate care.

Santos: At least in here I get a few things; food, caring people ...a bed with fancy buttons, my own room. If I don't want to be bothered with anyone, I close my door."

Brunilda is a very special lady. She is an engaging personality, with a unique ability 'to draw one in.' She says "Gee, you're cute, if only I were younger." She has quite an inventory of dirty jokes, too. "Lighten up, it ain't the end of the world, ... don't worry I won't bite you, but I can teach you a few things."

Canute: ...Sometimes I think that the purpose of me coming into this world is to suffer. I've had a lot of bads and very few goods... And, that shit about Jesus, I doubt that He ever did nothing for me... My parents are very religious... They'd ask me to pray... For what? It never helped me. At least here I get help; warm, safe, I feel a little more secure. I'm surrounded by love and people that care about me... I got this fancy bed... when I scream, they come."

Anxiety causes other patients to retreat. They remain silent in their darkened rooms. Attempts to engage them in conversation are usually difficult and awkward.

Delores: A battery of tests reveal the presence of HIV, TB and PCP. Delores became withdrawn and depressed for three days. She kept the curtains drawn, lights turned off and refused to speak with anyone. Her appetite returned as the fever diminished and her condition stabilized. Gradually, the sullen state dissipated and she began to open to me.

A large segment of the population contend with hospitalization in an uncooperative, demanding, angry manner. Some become the staff nightmares; the ones who call out to passersby or scream at the hospital staff. They focus on their immediate surroundings and services, complaining about the food portions, pillows and blankets. Their requests are expressed impulsively, with anger and hostility. There is no regard or perhaps awareness for the normative rules of social conduct. They can be crude and rude. Their needs can not be filled fast enough or to their complete satisfaction. Operational malfunctions such as inoperative call buttons exacerbate the situation.

Esperanza: ...was not impressed with the hospital care. "You see, you call a nurse [and] they say that the station is too far away to hear the calls... sometimes the buzzer doesn't work so, I must yell for a nurse when I need one... If I could get out of the bed do you think that I would urinate in it? Damn nurses! Her mother has complained about the hospital care on several occasions.

Esperanza lodged a complaint with Patient's Relations and is waiting for an interview with a representative.

Arturo: ...There is harsh criticism of the staff and care received. He has recurring fevers and claims that the doctors have given him nothing for it. He threatens to leave the hospital, "I might as well, sometimes there's only two nurses here working... They don't do nothing about my fever... my whole body aches... How the fuck can I be nice to the staff, when they don't do nothing for me." Someone on the staff told him that he's "...going to die anyway!" "My doctor is never here... The psychiatrist ordered medication for him, but it hasn't arrived. "Me encabrono [I get furious]... you got to get loud with the motherfuckin' staff... You ain't gonna play with me like a guinea pig- I yell at them. I'll get these motherfuckers."

The staff reacts to these behavior patterns in numerous ways, depending on their own personalities, professional experience and social background. They are frustrated that the patients do not appreciate how hard the staff has to work, their long hours or the resource shortages. Only empathy diffuses this frustration before it becomes anger or indifference. The 'no fault' and gregarious patients are 'adopted' and treated attentively. The withdrawn sullen patients are reassured or left alone depending upon the demands of the day.

Esperanza: The nursing staff is most sympathetic to Esperanza's plight. One nurse said that, "... she was an innocent victim; not a drug user like the rest of them up here. Her husband was a drug user. I spoke with her, that girl never did drugs in her life. The doctors take a lot of interest in her case. They're attempting to arrest the Meningitis and provide her with the necessary care."

MIlton: "At least the nurses are nice to me,. You know they thought that I was a bum, I guess that's what I looked like when I came here. They changed. They treat me much better now." "...some have given me reading material, candy or just plain conversation. Others look at me as if I'm just a gay germ. They say... are you, um... homosexual? What you been doing, boy, putting yourself in danger."

The demanding or abusive patients cannot be completely ignored. The staff attempts to be accommodating but remind patients that the staff controls their stay and treatment process. Reasonable wants and needs will be met according to the established schedule. There is resentment. Among themselves, some of the nurses remark that the patients are better off now than they were on the street or in shelters. The implication is that these patients should be grateful for whatever the hospital can provide. In extreme cases, security guards are called to restrain or eject patients.

Delores: Certain of the nurses feel that Delores is entirely too demanding. "She wants this and that, wants me running with her medication, wants blankets, everything exactly when she wants it... She thinks this is a[n] hotel. The nurses are put off by her screaming, panhandling of visitors and 'grubbing' leftover food from the trays of other patients. She often refuses to wear the mask (a protective measure during the early stages of TB) and is often caught taking 'drags' on other people's cigarettes.

Miguel: Some of the staff feel that Miguel is uncooperative and demanding. A nurse complains that he wants his bed changed every day and routinely asks for more than his share of snacks. "He thinks that this is a[n] hotel... I've seen him on the street... buying drugs... How is it that he doesn't get thrown out of here... He's done it [AIDS] to himself. A doctor characterizes him as generally uncooperative and noncompliant with instructions especially regarding medication.

The difficulty here is that certain staff judge particular patients as if they were fully competent and completely responsible for their actions. But, some of these patients experience AIDS dementia which affects the central nervous system. It causes incoherence, blindness, severe weight loss, weakness in the legs, listlessness or loud, sometimes violent physical or verbal outbursts. Complicating the situation further is the fact that AIDS dementia 'comes and goes.' The sufferers need extraordinary help in completing routine tasks. With medication they may be stabilized. Only trained professionals recognize this phenomenon; the average nurse in Oremus was not sufficiently educated to recognize or respond to this ailment.

There are frequent patient complaints that the physicians do not spend enough time with them, do not provide sufficient care or that they do not understand the medical diagnosis. Substance addicted patients complain the physicians force unassisted detoxification. Some patients claim that methadone is not dispensed despite its prescription. If available, the amount is insufficient. Some of the IVDU patients feel the doctors want them to suffer. Many of the IVDU patients asked me to convince the doctors to give them Methadone. The doctors usual response was "...this isn't a detox[ification] center, let them wait!"

Alan: "Nobody came in to see me last night, I guess they gave me a break... I might be dead tomorrow evening, I need someone here to bear witness... I haven't seen my doctor in two days."

Michael: "...They come in, I want to talk but, they ask how am I doing and then run out." For many days now he attempted to talk with the doctors about the numbness in his legs... "But, the doctors just kept going, telling me just one thing at a time.

Orry... expected to be discharged today... But, earlier his doctor told him that he "... had the virus."

Without any further explanation Orry was left feeling confused and angry....

Testing and Diagnosis

In order for the Oremus to fulfill its mission as a medical service corporation the staff must determine the cause and nature of the afflictions which affect those who come for assistance. When this critical information is discerned the focus of the staff interaction with a patient becomes treatment or cure of the infection(s). It behooves the doctors to prescribe expeditious therapies so as to minimize costs and discharge patients as quickly as possible. The reality of death is not a serious consideration, for the time being.

When the ER examination indicates the need for hospitalization the patient is referred to a medical unit. Symptoms are treated, but the generalities of the ER exam must be refined in order to develop an appropriate care plan. The social and personal information obtained during the ER interview may suggest "at risk" behavior. If so, after medical ward assignment, the patient is introduced to a nurse clinician who obtains more specific information about the patient's social activities, HIV infection and AIDS awareness. The issue of confidentiality is discussed and the patient reassured. A consent form is signed before HIV antibody tests are administered. The simple test is given and the sample referred to an external laboratory for processing.

Patients agreeing to take the test remain in the medical ward for treatment of the symptoms observed in the ER. The wait for HIV test results can be from two to three weeks. The results are helpful to the medical treatment process. In the meantime the staff can do little more than treat symptoms and try to make the patient as comfortable as possible. If the condition is less than critical, patients may be permitted to check out of the hospital if they wish. They are instructed to rest, take the prescribed medication and are referred to an outpatient clinic for medical follow-up. Some patients do not associate HIV+ status with their present sickness. Others assume that HIV infection means that they have AIDS. Even without a positive test result the hospital now considers these to be "full blown" AIDS patients if two or more HIV related infections as defined by the

Center for Disease Control are manifest. When the test results are returned, they are referred to the clinic which is charged with informing the patient. There medical counseling services are provided.

Michael: Although tested twice, Michael never went back to the clinic for the results... To questions about the possible means of infection, he responds "... I've a questionable background... I was bisexual starting at age 15... I've had sex with women who were IV drug users..." He denies exposure to semen, insisting that he got it [AIDS] from women.

A segment of the population is already aware of HIV infection and so inform the staff. The staff knows that the current symptoms may represent the development of HIV related illnesses. Therapies are identified and initiated. If the resources are available, the medical staff begins treatment of the specific disease.

Miguel: The infectious disease doctor discussed with Miguel the results of a bronchoscopy. The diagnosis; PCP requires three weeks of specialized treatment; AZT may slow further infection and prolong his life. But the description and terminology are too complex and formal for his comprehension.

Esperanza: Two days later, Esperanza's condition worsens. She is scheduled for another spinal tap. The procedure is completed at her bed side and she signs the patient consent form after its completion. She complains of headache and other discomfort... curses at the physical therapist, "That bitch is supposed to see me three times a week, I've only seen her once a week. How am I supposed to walk again?"

The social work team provides counseling and identifies potential social services. Specifically, homeless patients are referred to Human Resources Administration, Division of AIDS Services in order to obtain residential referrals, financial assistance, supportive psychosocial counseling and, if necessary, outpatient care therapies or long term care facilities. HRA, DAS will provide housing if homelessness is confirmed by the hospital social worker and the medical staff provides test evidence of HIV related illnesses. For the most part, housing will consist of SRO hotels or private group homes anywhere in the municipality. The number of such accommodations is limited and patients can wait several weeks or months for appropriate housing. In the meantime, the patient must stay in the hospital since internal policy and municipal law prohibit the expulsion of a homeless AIDS patient.

Financial assistance arranged by HRA, DAS is in the form of Supplemental Social Security Income since the indigent patients are deemed physically incapacitated. The wait for such support averages three to six months. HRA, DAS arranges psychosocial supportive counseling, outpatient care therapies or long term care services on an independent or group basis through the existing public or private organizations operating anywhere in the municipality. Counseling may begin in the hospital, staff permitting. External services may take weeks or months to coordinate.

Canute: ... Sometimes he feels that the doctors are rushing him out of the hospital. "...They say that I have to leave because they need the bed; I'm told to go on

Welfare, they'll help me to find a place." Canute's application for assistance rests with HRA, DAS which is unusually slow in this instance. It is proposed that Canute be moved to another hospital, but the alternative is an inpatient facility for the bedridden.

Canute is eligible for SSI (Supplemental Security Insurance) but his dementia requires discharge to a permanent residence providing 24 hour supervision. A long term medical care facility is the only viable alternative for a patient with Central Nervous System Toxoplasmosis, TB, anemia, seizure disorder, Oral Candidnitis and Herpes 3.

Placement in such a facility requires processing numerous forms which may take at minimum one month to arrange. Interviews are arranged for the requisite case examiners and workers.

Patients refusing the HIV tests usually do so out of fear, distrust of the physicians or impatience with the wait for results. Refusal to take the HIV antibodies test results in a "HIV status unknown" medical records denotation. They are not forced to take the test, but will be treated for current illnesses and when stabilized are discharged. They are given HIV related information concerning transmission and exposure risk reduction practices. They will again be encouraged to take the test.

If a patient was admitted to the ER with TB or 'rule out' PCP - (pneumocystis carinii pneumonia) and refuses a bronchosopy or similar test which could confirm an AIDS diagnosis, it is impossible to arrange for HRA, DAS supportive services. These patients are treated for the current symptoms and discharged when the condition improves. Treatment consists of massive dosages of antibiotics (Bactrim and Augmentin) which should last three to five days. More often than not, they will return when other, progressively worse, opportunistic infections become manifest.

Deborah: ...was admitted to the hospital four months ago with the same symptoms and rejected the treatment because it involved the insertion of a long tube down her throat into her lungs. In time with antibiotics the fevers subsided and within a week she was released. The case worker encouraged her to stay with friends for a while and to take the HIV test. But, there is no one with whom she could stay. The streets and emergency shelters again became home. In time she took the HIV test and it was returned 'positive.' She has difficulty believing it.

One day, against medical advice she walks off the floor. Four months later, she returns with accelerated Bilateral Pneumonia complicated by alcohol liver disease, severe diarrhea, fever, night sweats and rule out TB.

This is her fourth hospitalization in one year. She left because she didn't think anyone wanted to do anything for her. She stays in the hospital long enough to get the situation under control. When the antibiotic treatment produces some improvement, she leaves again.

Patient Awareness, Denial, Coping and Adaptation

The lack of basic information about health care has dire implications for the patient's ability to cope with illness. Another problem is manifest in a historical lack of palliative care. Most of the patients have not visited a medical care giver in years. Previous medical problems were ignored or addressed by way of self treatment.

Miguel: ... Asked when he last was examined by a doctor, he responded "You must be kidding, it was back when I was 17."

Miguel: This is Miguel's first hospitalization. As he states ".. I have never been sick and ...have no need to see any doctors." He asked a family member to bring him Nyquil, (I watched him drink two bottles in 30 minutes), which he thinks will help since "...the doctor's ain't giving me nothing [for the pain]. I won't let them put the intravenous in my neck. I won't let the nurse take my blood... she's trying to collapse my veins."

Remingo: ...shows me a scar under his right arm. He had stitches there for five months. He did not return to the clinic to have them removed. "Do you think they'll take them out here?" I encourage him to ask the doctors. "Ah, no me voy a molestar- I'm not going to bother myself."

Discomfort and fear are heightened by the wait for treatment and information. After admission to a medical unit the patients become wholly dependent on the staff to meet their physical and emotional needs. Fear of the unknown and distrust permeate their experience. And what they really want is attention-- and to connect with the staff.

During my next visit, I found the feeding tube disconnected. Miguel said that it came out yesterday afternoon. This observation prompts a discussion about the care he receives in general. "I'm a junkie, nobody cares... I know how they are, they say, Oh! he's a junkie, let him suffer."

Social workers are called upon to convince the patients to be more cooperative. This may be accomplished by increasing the patient's understanding of the medical condition while addressing the myriad social conditions affecting their lives. The social worker takes on the role of an advocate for the patient, attempting to sensitize physicians and nurses to the non-medical issues affecting the patient's life. Although the social worker gains the trust and cooperation of the patient, the doctor/patient relationship does not necessarily improve. To some extent, an us vs. them mentality develops between the staff and the patients.

Patients' knowledge about AIDS is somewhat limited. A general impression exists that there is a "new killer disease" (also called "the Virus") spreading around. The information was circulated by word of mouth on the street or within family circles. None could define HIV, although there is some notion of infection or transmission. There is slight familiarity with the different possible diseases and their progression. I spend much time clarifying the issues of infection and transmission, differentiating the syndrome from the specific illnesses.

The dominant perception is that AIDS is a "gay man's disease". Its recent spread among drug addicts is sometimes attributed to the effort to "kill off" heroin users. "The Man" [white power structure] is getting us because we use manteca [heroin]." In this case ignorance is not bliss. More than a general awareness is needed. AIDS is something to be avoided, but how?

"I don't think I got it from sharing needles... I don't share needles, I'm diabetic... so I get new ones [needles] all the time... Maybe I got it through sex with 'those' women... I really don't understand."

Michael ...never felt that "...it would happen to me... Before I really didn't care [about AIDS], but now that I'm one of them, I think about it."

Arturo: He has not paid much attention to the "AIDS issue," even after learning [it was] the cause of his sister's death..."

The AIDS diagnosis came as a shock to Marlon, he has no idea as to how he might have been exposed to the HIV virus. He spends a lot of time trying to "make sense" of the diagnosis.

David: I know who I deal with and what I do... I wasn't thinking anything wild; like AIDS.... This AIDS thing is far from my mind. You gotta give me good proof about this AIDS shit. I don't know what it is I got. I'm very careful with what I do and who I do it with. ...AIDS is like a cancer. It spread by sharing drugs, sometimes, with homosexuals. I know what they do. ...The body can't fight off that bacteria, it weakens their body so bad. ...I've seen people who had AIDS, they were very built and lost it. AIDS is a cancer, you can't stop it, regulate it or control it. It will burn up your body. I ask do you believe that you have AIDS? ...No. no I really don't know. [A nurse enters the room dressed in surgical gown, gloves and mask]... "What's this why does she have that on? Who's she fooling?

Santos: AIDS... its a bad disease, its dangerous; they don't know much about it... people don't care... its out of control. AIDS is underestimated; people don't see the importance of knowing about this killer disease. It drops your hair, gives you lesions... It gets your body. Sooner or later you're back to a kid... I've seen people drop like flies...

Esperanza: Esperanza belongs to that small sub-group of AIDS patients; the non-smoker, non-drinking, non-drug addict. Her late husband was an intravenous drug user. "You know what that means..."I found out that Papo was HIV+ in March, 1988. The doctors wouldn't tell me what he had. On his death certificate it read 'Cirrhosis of the liver'."

Delores: Within hours of her room assignment, we met in my official capacity as hospital case worker. Delores blames the women's shelter for her illness. ...[She] first heard about AIDS in 1983. "I didn't think that it would happen to me. I thought that the disease was basically a homosexual disease. I never though that it would hit home the way that it has.

Even when the patient understands the meaning of the diagnosis there is little appreciation for the fact that they must change their behaviors or that past practices are linked to the current state. To achieve this, they must first have someone with whom to talk about their feelings. They already demonstrate a strong urge to engage the staff, friends, or family members. But usually, the latter relationships are so fragmented that relatives resist attempts at closeness. For now, patients focus on living as fully as possible in the hospital. Part of this necessitates the forging of contacts, if not bonds, with other patients or staff.

When the patients actively accept their HIV+ or AIDS patient status there is some difficulty in getting them to connect this knowledge to the general experience of the typical AIDS patient. They have difficulty believing that they will share the experience of the more progressed cases in the other wards. Moreover, established behavior patterns are not easily discontinued. The period after a death pronouncement is not to be expected as a time to give up drugs. Some see it as a time to party even more heartily; after all, what more can go wrong!

Very few of the patients accepted an HIV+ verdict or HIV related illness diagnosis without difficulty. Most reacted to the news without appreciation of the long term consequences. They nearly always focused on the immediate illness, not the condition of AIDS. They made every effort to discount the AIDS pronouncement by downgrading an AIDS related illness. Customarily, PCP becomes influenza or TB; more acceptable sicknesses.

Denial is also manifest in the patient's refusal to associate his or her specific behavior with their impression as to the profile of an AIDS patient. It is hard for any of them to see their past behavior as contributing to the current medical state. They perceive it as unjust, even tragic. Heterosexual male intravenous drug abusers reject the diagnosis, citing the fact that they had no sexual relations with men or never shared needles with someone who "looks sick." Ostensibly straight men with bisexual histories qualify their homosexual activities.

Santos: ..."I left home when I was young... I started using dope-- shooting Cocaine for three or four years... I just fell into a crowd... I shared needles... I'm healthy... not weak, my hair ain't falling out. You can look at a person and tell [if they have AIDS]. Thank

God I ain't caught no AIDS. The Lord ain't going to let me kick like that... I got luck, it stays with me."

Withdrawal is a common reaction. Since many of these patients have had poor experiences with community social service personnel in the past, they are distrusting and ignore instructions or advice. They resist intimacy or sharing. Invitations to reveal their feelings to hospital social workers are rejected or ultimately accepted only after repeated explanation or encouragement. They only want the staff to "fix" the medical problem.

Delores: Before Delore's application for housing was processed and the discharge planned, her fevers rematerialized. Another spinal tap was performed which revealed CM. The presence of another opportunistic infection terrified Delores and she grew sullen. She was transferred to a semi-private room and a few weeks to a later private room.

I want out of this place... [its] getting me disgusted. They take out blood every two days, but the doctor doesn't explain. I'm just so disgusted...

The most indigent of these patients are so overwhelmed by their daily struggle for survival that coping with the implications of an HIV related illness or HIV+ diagnosis is postponed. Their focus is continued existence on the street, public assistance, space in shelter or SRO and money for drugs. Hospital social workers find that counseling sessions rarely go beyond the patient's efforts to survive and to deal with external social service organizations.

James: "I don't even think about AIDS. There's so many other things [to think about]... I can't remember one minute to the next."

Esperanza tells me about a letter from her income maintenance center. Her case will be closed because she did not attend the hearing. I attempt to calm her, offering to inform the center of her hospitalization.

It was mentioned earlier that the patients verbalize disappointment with the care procedures and process. While some of the complaints are legitimate, some may be prompted to avoid discussions about their fear of the illness and of death. To this point, Miguel responds:

"I'm going to die and I'm so fucking scared... I can't talk about it, I can't handle the unknown. He mentions that during the past winter he bought drugs rather than coats for his children, "... during the time I have left I'll try to leave something for my kids." But, lately he has been giving money to the visitors of other patients so that they could buy wine for him. He's been drinking about a pint per day since the hospitalization. Occasionally, he'll buy heroin or cocaine.

Much of the denial and withdrawal is rooted in relatively low self esteem. The patients have troubled lives which in their own judgement have been disappointing. An AIDS diagnosis seems par for the course. While AIDS was not expected; death certainly was. This is no surprise. But, at least a disease is better than that which could happen on the streets. They really believe that their death will matter to no one.

Miguel: Me having AIDS... I'm a nobody. The rich having AIDS is a difference. They have money, I'm a nobody."

Santos: "Where do you think [that] they're going to put me when I die; in a 14K gold coffin? They'll put me in a bag and throw me in a ditch... [saying] he ain't nothing but a bum."

"...I'm never going to get anywhere... I've always begged. I'm always going to be a bum.

Cory: ...watched an episode of '21 Jump Street' which dealt with AIDS [and] reflects on his mortality. "I don't think I'm being punished... my diagnosis is a result of my life-style... I've been living the life of Riley. Really, I've never questioned my life... sometimes I [feel] punished, but I have to think about the difference between the virus and morality."

Another segment of the population adapts to the diagnosis and various illnesses by extensively conforming to the environment and regulations. Of course there are instances when they express anger or resistance, but overall they try to cooperate to obtain needed services and to allow healing. It would be an overstatement to suggest that they are pleased with the state of affairs, its just that they are trying to ease the pain, to survive, to normalize their lives. These are the hopeful ones.

Michael: "The doctors tell me I have AIDS. I'm surprised, shocked. Its a sickness that there's no cure for it. Ain't much that I can think about it. That's not an attitude, that's the truth. I have to accept it, I have to just go on."

Among these adapters are those who are too beaten to struggle any longer. They know that there is little time left to them and they simply wait. The waiting is sometimes tempered with anger, sometimes stoicism, sometimes fear.

Delores: ...crying fits grew in frequency and intensity. She searched for assurance that this was not the 'end.' "Why me?... I was doing fine. I almost got out of this hell, I was feeling fine a few days ago." One evening, it took nearly continuous care and reassurance by case workers and nurses to calm her. We took turns holding, comforting and encouraging her to rest in order to fight the Meningitis and maintain a positive mental attitude. To Delores, this new infection represented "...the plague" for which there was no cure. She repeated "...this is it... there is no cure."

Over the next few days, Delores tried her best to cope with the situation. Despite the persistent headaches, she responded to the new medication but was leery of it. The brown bag on the IV stand troubled her as did the burning sensation in her veins.

During the next few weeks, Delores rested in a darkened room; shades drawn, lights turned off, no visitors. Within three weeks she expired of respiratory failure.

Networking with Staff and Fellow Patients

The institutional environment of the hospital is a community which is layered first with the rules and regulations of internal and external organizations. These form the basis of normative behavior. To this is added the patient population whose interactions are affected by 'street' or neighborhood behavior patterns. The catalyst for crisis implicit in their is a condition of forced containment. The patients cannot leave because their bodies will not permit it. Within the wards patients share a common, albeit sometimes unspoken, experience; AIDS.

Individually, patients seek to maintain their separateness and make every effort to protect their privacy. They would prefer that no one be aware of unconventional life-styles or unorthodox behavior histories. They most certainly will not reveal to other patients that they have AIDS until forced or encouraged to participate in group sessions where coping with AIDS is the topic of discussion. A few maintain this self imposed exile because the other patients remind them of the "very people who probably exposed them to the virus."

Aloofness has its limits, which are reached usually at about the onset of extreme illnesses. The hospital would prefer that this approach be maintained throughout the patients term. Communication and interaction puts each patient at risk for opportunistic infection. The common cold goes through this ward like wild fire.

Cory: ...is angry at the staff and resents the infectious warning sign on the door to his room. He has ripped it down twice before, "...they have no right to advertise..."

Larry: ...becomes uncomfortable if we discuss AIDS or his homosexuality too loudly. He is ashamed, scared and feels isolated.

Michael: ...the 'precaution' sign on his room door is upsetting. (All persons attempting to enter the room must report to the nurses station). He has taken the sign down. (The hospital has since removed all such signs in an effort to protect the confidentiality of the patient).

It is not unusual for new admittants to remain distant from the longer term patients and staff. They are often the most uncooperative and rebellious. But, as the length of stay exceeds three months they begin to become a part of the community.

The stigma associated with AIDS has an impact on every patient in addition to the discrimination with which they lived because of antisocial or deviant life-styles. Each arrives at the hospital with a history or an identity that is frowned upon if not condemned by the larger society.

Society's viewpoint has been expressed so often and in so many ways that the patients experience labeling in that they identify themselves as drug users, homeless, homosexuals or prostitutes. The staff responds according to the socially accepted value patterns and often treat the patients with disdain if not contempt. Much of the intra-staff dialogue concerning specific patients is derisive. They speak of an individual's street activities or personal appearance in ways that serve to separate the 'good' patients from the 'bad.' The staff often express astonishment at the extent to which some patients are "so caught up in their perverted activities." These thoughts become characterizations of the patients as lazy, uneducated, dangerous, thieves, faggots and whores. The effect is generally discriminatory for 'good' patients hospitalized with acceptable illnesses are treated more attentively, gently and with more optimism than the 'others.'

Miguel: ...This observation prompts a discussion about the care he receives in general. "I'm a junkie, nobody cares... I know how they are, they say, Oh! he's a junkie, let him suffer."

Michael: ...complains that the doctors do not visit him anymore, "They make me feel dirty.... I feel guilty being in this bed... I feel so ashamed..."

Marlon: "I've done a lot of wrong things, I'm being punished ... something disastrous is going to happen... I will be destroyed, my body will be destroyed..."

The clash of social classes and values is not an issue for concern of hospital administrators. As the staff is in control of the patient experience, they are free to project their expectations onto the patient, who is powerless to do anything about it. So while terminal illness is pitied by the staff, they nevertheless limit the empathy or sympathy felt for the study group by blaming the victim. "They asked for it, ...they did it to themselves, ...they deserve it."

In a broad sense, the patient community consists of two groups: the 'conformists', have a vested interest in the smooth operation of the ward. They have come to realize that adequate care and supplies will not be provided easily without respect for and adherence to hospital rules and established procedures. It is interesting to note that the very persons who constitute this group are likely to be outsiders (drug addicts, prostitutes, homeless, convicts) in the general population. Now, they seek to 'fit in'.

The conformists will often intercede with the staff on behalf of patients who are experiencing difficulties. Likewise, they become a source of information for newer patients as to the whys and wherefore of hospital and other social service regulations, policies and procedures.

Conformists scorn the second group- 'misfits.' Few of the long term patients and many of the newer patients fit this description. These are the ones who import and maintain unwelcome 'street' behavior patterns. The conformists will exercise direct pressure or invite official sanctions against the misfit's actions (panhandling, robbery, fighting).

Both groups have a subset, the 'resourcers.' They facilitate connections to the external world; obtaining drugs and cigarettes, sharing gifts and unwanted food with those other patients they like.

Canute: Drugs come into the hospital by way of visitors and the staff. Sometimes the porter [sells]... cocaine and heroin. He doesn't have to bring the works [syringe]... that's easy to get here.

Delores: Delores met other patients and their friends. One of these was suspected of supplying drugs to a few patients on the floor. Suspiciously, her spirits improved. On one occasion, I walked into her room to find another patient and two male guests. She barely recognized me. The other patient hurriedly left the room. One of the visitors wanted to know who I was and why I hadn't knocked before entering the room. The other slid a small brown bag down the front of his pants and left the room commenting, "Damn, there's no privacy 'round here." Delores would not answer my question about drug use responding only, "... everybody leave..."

Regardless of the personal networking styles, nothing eliminates the underlying fear which permeates their lives. Nearly all retreat when faced with the physicalities of death. Few want to be in a room when someone has seizures or becomes violent with dementia. They do not want illness to disturb the tentative peace of this world or the illusion of recovery.

Delores: The candidness of certain other patients really bothers Delores. She withdraws when Allen says, "I won't be around forever, you better find someone else to grub cig[arette]s from." Delores is disturbed by the sight of other AIDS patients. "I see myself. I get sick to my stomach... Whenever I think about AIDS I think of something dirty... I think of my past with drugs... and with men... I'm worried that I won't leave the hospital this time."

Miguel: He thinks he's getting weaker, it's difficult for him to see the other AIDS patients across the hall. "Being in the hospital is too much... so much sickness... I just can't handle what I'm seeing, [but] nobody talks about it. Its as if nothing is going on..." On the death of another AIDS patient, "... I know I'm going to die. Its just a matter of time. I'm so alone. When I saw her [the deceased] swollen, sweating body... boy, she was bad. I'm just blank... just passing the day through. If I'm going to die, let it come."

Within this environment there are truly touching moments. It is not infrequent to see ambulate patients care for others who are not able to care for themselves.

A group of patients become supportive of one another. They spend time talking about their respective diagnosis and the ways in which they can raise money for their supplies [drugs, toothpaste, candy etc.] Sometimes they panhandle in the hallways or lobby and recruit the visitors to purchase things for them.

The networking does have its detractions. Gossip is a favorite pastime. But, in most cases it is counterproductive since it fosters unnecessary concern and embarrassment. Of course the staff officially refuses to share patient information with anyone except relatives, but that does not prevent the patients from prying or forming their own impressions. Generally, the gossip is petty in nature. It is unhealthy in the sense that the discussion revolves around superficial issues (body sores, hair loss) and obscures the real issues affecting their lives (pain, mental incapacitation, poverty, homelessness, substance addiction and death).

Staff/patient communication is often strained and deserves some attention. Physicians are technical in their orientation. That is not to say they are dispassionate; rather, they are primarily objective in their approach to medical cases. Their patient dialogues tend to involve a technical description of illnesses and bodily functions. Ordinarily, there are too many patients and too few doctors to permit lengthy visits.

Then too, the doctors are aware that most patients, especially this group are unable to understand the intricate details of their situation. For these reasons, physician explanations are necessarily terse. Complicating the matter is the fact that a majority of the interns and resident physicians are foreign born. They speak English with very heavy accents. Sometimes they do not understand the patients. When both patient and doctor speak English as a second language the problem is further complicated. But, when the patient speaks no English they must often wait hours or days for a translator to decipher the communications.

Depending upon the mental state of the patient, thorough, well rounded communication can be difficult. Most people are apprehensive with AIDS patients. The level of apprehension may be heightened by the patients' perception of the hospital environment and role of the staff. Terse, cursory, clinical dialogues with the physicians can leave the patient, especially those for whom English is a second language, feeling alienated, powerless and helpless. The result is often detachment from the staff as well as resistance to the prescribed treatment. Arguments, minor violence and passive aggressive behaviors are common.

Service delivery practices substantially affect the quality of staff-patient communications and relationships. In order to provide certain kinds of care for these critically ill people specific treatment and palliative methods are used. This the staff, patients and family must take as a given. From the staff's perspective, only they need to be concerned with the logistics of service delivery. The scheduling of vital sign checks, therapies and medication; the number of nurses, the time of 'doctor's rounds' and deviations from appointed times are not matters for patient attention or comment.

There is little effort to communicate the reason for certain practices, and standards or to explain hospital care fluctuations to the patients, or their families and friends. Problems may arise when patient feelings and perceptions are not considered in the provision of service or precautionary practices.

Canute: Being in the hospital, especially when restrained [to the bed] reminds him of prison. Canute spent two years in jail for burglary. "... you just can't walk out of here... Its like prison."

Allen: is restrained to the bed... He is conscious now and able to converse. ...he [comments], "... I am being persecuted... They're going to keep me strapped in here... I'm not going for that shit... Why are you strapping me down?" In fact the staff is afraid that in a disoriented state he might fall out of bed. He has exhibited somewhat violent tendencies in the past and has pulled out the catheter several times. He says that was "...defiance. What is this shit! If I'm going to die, let me die free. I don't want to be strapped down like some animal." [Earlier], a nurse said, "Don't worry, we won't strap you down, but don't you know when you've had it?" Allen: ...What's with this lady?"

Esperanza: ...a nurse enters the room dressed in uniform, mask and rubber gloves... she passes the thermometer to Esperanza so that she can take her own temperature. ....Esperanza adamantly refused to submit to a fourth spinal tap. She believes the taps are the reason that she can not walk. "If I'm going to die, let me die." ...Its difficult to wait, ...waiting to see children, waiting to go home, waiting for the food... waiting for medical treatment... waiting to die... The new medication (Amphitephrin) and ... weekly blood tests aren't yet having an effect. "I'm sick and tired of dealing with this..."

Delores: is ...left with a plastic jar into which she must deposit a saliva sample. Coughing and shaking she misses the jar for the most part. I tell her its important for her not to spit on the floor. Angry, she tells me to mind my own business." "...but, ...Some of the [nurses] give me a hard time... They won't let me smoke in bed..."

Cory: is angry at the staff and resents the infectious warning sign on the door to his room. He has ripped it down twice before, "...they have no right to advertise..." He's offended that the nurses and doctors wear gowns, masks and gloves when in his room, "They're not taking blood... just my temperature or the IV... why the fuck do they have to wear those masks and gloves?"

Milton: ..."But, every morning the doctors come in... How you doing Chief and then leave... I can't believe it, but at least their treating me...I don't want to cause trouble." A nurse came into the room to give him a shot. "But, I'm afraid of needles." "Great," she replied, "just turn over."

Michael: He planned to inform his wife of the AIDS diagnosis shortly after receiving it. He hesitated because of uncertainty about her reaction. Before he could tell her, an intern placed the telephone call advising her to be tested. This uncommon action left Michael irate. Later, I heard that the wife had inquired as to the cause of his condition and the doctor felt it unfair not to tell her the truth... He threatened to sue the physician for violating his confidentiality and requested another doctor. "As long as I am in this hospital I'll be depressed...

Most patients are impatient with the staff's ongoing quest for personal information, especially when the same data is reported to different people over time. Impatience often becomes resistance to interviews and the routine of the medical treatment. The intravenous apparatus, blood pressure checks and temperature monitoring seem to be the items of greatest patient resistance. These treatment practices require patient conformance. They seemingly have no choice. When they do not comply or participate in their treatment as expected by the staff, the patient is labeled as "noncompliant". Their apparent resistance is noted in the medical record, "...patient refuses treatment." This notation has implications for the manner with which successive caregivers relate to the patient. Chronic "resistors" or "troublemakers" tend to be avoided by the hospital staff, if possible or discharged at the earliest possible time with minimal assistance.

Conduct modification recommendations are often resisted as if the patient refuses to permit the questioning of their choices or activities. Such resistance may be an effort to control some portion of their lives, to hold on to familiar patterns.

Delores: ...in the early stages of TB walks the hallways... visits neighbors; 'borrowing' cigarettes or leftover food. An old neighborhood friend is in a nearby room. [He]...is in the last stages of AIDS. ...he and Delores smoke cigarettes together... Sometimes Delores has to hold the cigarette while he draws on it.

Milton: When the PCP pneumonia was brought under control, he returned to the YMCA and visited the local outpatient clinic for follow up treatment. ...at the clinic, he noted that accepting the diagnosis was "...the hardest thing..." He is still "...dibbing and dabbing with 'crack'." This helps him to "get it" under control or simply avoid thinking about the illness and death.

Brunilda: She's had a habit for twenty years but, "...I made my bed, now [I] sleep in it. "You know you hear about this AIDS thing, but I just turned around and did it [shared needles]; having sex without condoms. That drug is powerful... I'm going to die using drugs." She admits to bringing drugs into the hospital. About three months ago, a friend staying on this floor in the hospital said "Yo te voy a currar- I will cure you;" she cooked up some manteca [heroin] and 'hit' her. "Maybe it wasn't the right thing to do in the hospital, but when you're strung out or enferma [sick]; only a true user knows the feeling."

Within the middle class community are a number of persons who live with AIDS. They have housing, a means of financial support, health insurance, legal services and access to a variety of psychological supportive services. Medical treatment is limited only by their ability to pay and ask questions. This holistic approach to care may extend lives. It certainly can optimize the quality of life for the time they have available to live it.

The study group, given their underclass status is much less empowered to request or obtain such life extending services and tools. The disrepute and handicaps associated with their socioeconomic standing work against them to minimize the chance to live with AIDS in any meaningful way. They have little or no income, residence, family, friends, insurance, history of health maintenance or experience in negotiating for service in a capitalist economy. For the most part they have barely survived, eking out an existence through marginal jobs, the underground economy, public assistance or by panhandling.

They have been downtrodden, alienated and overlooked. Against this backdrop is placed a heavily stigmatized illness and the effect on their lives is inertia. In their despair the spark of life fades. They lose drive and passion. What is there to live for now: welfare, a SRO (single room occupancy) and care by people who presume that they are worthless?

Canute: ...traces his drug abuse to the abandonment. He has lived on the streets since his teens. When first hospitalized for what now seems to be an HIV related illnesses, the Human Resources Administration (HRA) placed him in a SRO (single room occupancy) hotel. He feels lonely there and dislikes the hotel. "I'm by myself and the home attendants won't come to the hotel..." If possible he leaves the hotel, returning when absolutely necessary. Now, he's concerned that a lengthy hospitalization may have led the HRA caseworker to halt the rent payments which would mean eviction.

Despite his discomfort and boredom, Canute was reluctant to leave the hospital because that would result in his living on the streets and return to drug dealing and usage. "... I don't want to leave the hospital... When I'm alone, I know I will go back to doing drugs... I want to be in a place where people understand me... Nobody listens to me on the streets... I'm by myself... I ain't got nobody to turn to, my [extended] family don't care, they got their problems... What makes me go back to drugs is, if they don't care, why should I? ...I'm going to die sooner or later, what's my choice?"

Delores: ...is responding to the medication prescribed for TB. Within a few weeks... there are no acute medical problems. Now, the doctors are eager to move her out of the hospital in order to make room for another patient. As her case worker, I must confirm her undomiciled status, contact the family in order to inquires as to their willingness participate in discharge planning. Since Delores has no supportive family network and has been intermittently homeless during the past four years, I referred the case to DAS. A case worker will be assigned to coordinate the necessary services.

Michael: ...is unemployed and has been homeless for two years. Presently separated from his common law wife, he has two children; boys age 3 and 1 years. It was not long before he reinitiated homosexual affairs. Michael: "I was living in the fast lane... I started using cocaine, then 'crack', ...I lost my job three years ago. My wife asked me to leave our home. After that I spent the winters sleeping on the trains, mainly because I couldn't stand the shelters." He visited the soup kitchens and stayed with anyone who offered him a place to stay or 'crack.' He has also had sex with "drug girls" while using 'Crack.'

"As long as I am in this hospital I'll be depressed. I can't wait for the housing placement. I got to get out and start living again."

He does not want to return to what he was doing before he was hospitalized... doing cocaine and 'Crack' occasionally, sleeping on the streets and living in the shelters or staying with other men for shelter. ...That cocaine and crack really did a number on me. I really went for it. Now look at me."

When we met at the clinic, Michael noted he " ...is still dibbing and dabbing with 'crack'." This helps him to "get it" under control or simply avoid thinking about the illness and death. He believes that he will "...go through this illness alone,..." even though there are places to go, he hesitates because he feels so ashamed and guilty.

Remingo: ...Presently homeless, has lived on and off in various men's shelters. He would prefer not to return to the shelters after discharge because he has been robbed, mugged and beaten by other shelter residents. He calls himself a drifter. When he does not stay in the shelters, he sleeps on trains or abandoned buildings, sometimes with women who take him in when he has drugs to share. Eventually, they kick him out. To survive he steals, mostly car radios, food or when possible he combs the vacant buildings for scrap metal or empty cans. "...when you got cash you got drugs, women and friends."

His family lives in Puerto Rico. He left because he did not want them to know he used heroin. He hasn't seen them for five years. Upon arrival in New York, he met a woman with whom he lived for a while. He and a friend started to deal heroin. In time his girl friend ran off with his partner. He started to use more of the drug as a way to cope with the betrayal. Now, there is no one in his life. "You know its been a while... I've gone from this one to that one... I just don't got no one to love me. I've never had that. I'm a loner, just surviving on those damn streets... It's hard in New York, people don't give you a chance."

Summary

Aside from debilitating physical effects and certain death, the factors which had the greatest effect on the experience of the study group are poverty and social isolation. In general, they have had little or no opportunity to make choices about their lives. They barely achieved self preservation. Self determination and self actualization were not options. It is not surprising therefore that underclass AIDS patients found themselves at the mercy of the institution during their struggle with HIV related illnesses. They waited passively, and sometimes angrily for any and all services. They had little input into the nature or quality of their care received. In fact, they had little understanding of the medical condition, let alone the treatment process.

Throughout their lives, the underclass AIDS patients had made short sighted or poor choices about their lives. Most coped with oppressive conditions by resorting to substance abuse or illegal practices which put them at risk for infection. The problem with the spread of AIDS within the Hispanic and African-American communities is that those who become substance abusers, especially I.V.

drug addicts, often infect their loved ones or sex partners. The escalating trend in HIV infection is difficult to arrest and the patients hard to treat because of poor education, social isolation and meager financial resources.

The fact that many of the hospital workers were members of the same racial or ethnic group really did not make the situation any easier. The class distinctions between these two groups or the homophobia of the staff aggravated the patients' acute sense of apprehension, isolation and helplessness. The relatively few shallow friendships or bruised family ties meant that there was no opportunity for real emotional support for the patients when they were most needy. But when family ties were strong and family members helped to surmount fear, they represented an enormous wellspring of hope and encouragement for the patient. They could also serve as catalysts, inspiring the staff to do everything possible to treat the patient. Strong familial ties made the difference between suffering in despair or enduring illness with dignity.

CHAPTER III

FAMILY AND SOCIAL CONTACTS

Arturo: ...has not paid much attention to the "AIDS issue," even after learning the cause of his sister's death. He has yet to tell his wife the truth about his illnesses. Perhaps she has an idea. "...I'll tell her when I'm ready." He's concerned that a hospital employee who resides in his wife's neighborhood will spread the word about his condition. Perhaps she will tell his wife. I encourage him to break the news personally. "I don't think I have enough time, I can't take the way life is treating me, maybe it's my fault. I'm just concerned that if my wife finds out, she just won't want me back."

The family plays a pivotal role in the healing process. The illnesses and hospitalization represent tests, opportunities for the family to cooperate in order to cope with complicated feelings about the disease and complex methods of treatment: solid, consistent, reliable and trusted support from loving family members and friends can significantly affect a patient's healing process. Such support constitutes a well of strength and hope upon which the patient may draw. There is no substitute for this emotional brace. No matter how attentive and caring the hospital staff and social workers may be, they can not replace the nurturing provided by friends and family. This is evident in the case of Esperanza, a 32 year old Hispanic woman who contracted AIDS as a result of her intravenous drug using husband, who never told her of his drug use, nor that he shared I.V. needles with her brother, who later was diagnosed AIDS.

Esperanza: Esperanza is visited by her children and other family members. She is in good spirits, "...you don't know how much I've prayed to God so that I can walk again... I want desperately to take care of my children again." Mrs. Rivera prepares to do her daughter's nails and talks of frosting Esperanza's hair.

Esperanza's mother arrives with a home cooked meal, (arroz con pollo) and pretty balloons. She's unable to go home for Thanksgiving, the hospital provides her with a food basket; turkey with all the trimmings. She hopes to be discharged before Christmas. Although she wants to leave the hospital, she's concerned about being unable to move about freely or care for the children.

A variety of family ties were represented in the study group. Relationships included the entire spectrum of parents, step parents, siblings, step brothers and sisters, spouses both traditional and common law, 'live in' lovers and 'special friends' as well as extended family members, family friends and neighbors. The intensity and quality of these relationships varied immensely. In some cases, the patients were close to their families and may have established bonds with mates or 'special friends.' Even in the best of family relationships, the patients felt bad about informing loved ones of their condition. They hesitated and postponed the revelation until they felt comfortable with speaking about it.

In many instances, the patients had strained relationships with their families. These were often long-standing antagonisms, precipitated by varied events or behaviors. It took great effort to overcome sour memories and infrequent contact in order to deal with the present medical emergency. Sometimes, the 'bad blood' could not be overcome no matter how much the patient might wish or need it. Typical is Deborah, a 28 year old white female who entered the hospital with a medical diagnosis of bilateral pneumonia, rule out Bacterial Endocarditis. She was found lying unconscious on a parked car. She has a history of IV drug use: specifically Heroin, Cocaine and 'Speed' and has an alcohol addiction.

Deborah: Homeless for three years, she will not stay in the women's shelter, "...You can get hurt in there... I don't like being with all those women." She spent the last five years on the streets, sleeping in subways or sometimes with a "friend," who sells drugs, tries to make her "walk the streets" and beats her. "But, [I didn't stay] that scene was too rough." She speaks of violence, the prostitution and drug use, "...I was trapped. I was sometimes locked up in that house, he kept me drugged."

Her father and brother were contacted. At first the father did not want anything to do with her "...until she enters a drug rehabilitation clinic... All she ever was was trouble. After her mother died, all she wanted was to hang out with the wrong crowd. Don't ever call this house again! Tell her to clean her act up... after that she knows where I am if she wants to come home. Let her get welfare and into a program, first."

She cried when I told her the things her father said. "He's a sick bastard... He's always given me a hard time... Doesn't he know that this time, I have nowhere to go...and I'm really sick!" Angrily, "...that sick bastard tried to rape me, that's why I left the fuckin' house. I stabbed him in the stomach. It took twenty stitches to close that gut. I guess he can't forget that. Well, why would I want to go back there... All he's interested in is what I can give him." In the past he charged her rent, since she was on public assistance. To make money, he would sell her his needles (he is a diabetic).

Later, I contacted her brother who resides with the father. After much convincing he agreed to see her. Deborah was surprised when he visited. She cried and asked his forgiveness. She asked him to speak with their father. "All I need is a place to stay!" His only response, "You know how he [father] is."

The majority of relationships fell somewhere in between the extremes represented by Esperanza and Deborah. Relatives sometimes demonstrated genuine care and indifference; now and then intimacy or estrangement. Attempted reconciliations may be rebuffed, tenuously received or fully accepted. The communication process is often an emotional roller coaster for the patient and family members, which sometimes affect the hospital staff. Take the case of Milton, a 32 year old gay, homeless, Black male. His diagnosis included Meningitis, brain abscess, Oral Thrush, Chronic Wasting Syndrome and severe Diarrhea. When we first met, he had the covers pulled over his head, but in time responded to me. He had difficulty answering my questions.

Milton: ...obtained an Associates degree in 1978 and since then, has worked at several odd jobs, most recently as a purchasing assistant for a local college. Nearly fifteen years ago he met and lived with a woman who later gave birth to a daughter, Kate, now twelve years old. He has not seen the child or her mother for about five years. During a three year period he maintained a domesticated relationship with a gay lover who died one and one half years ago. The death and reduction in household income forced him to vacate their apartment, leaving him homeless.

Milton: ...sister and mother are aware of his sexual orientation but, he has not informed his father. The mother and sister do not accept this life-style. Their occasional visits to him in the hospital surprise Milton since they will not permit him to move back home. "...It hurts, but at least they pay for the TV."

At present, he is staying with his grandmother... she has asked that he make other arrangements. But, the illness has drained his meager resources. He has been technically homeless for the past year. He has an application in process for SSI disability payments.

The family dynamic has a significant impact on the prospects of the terminally ill patient. The subject struggles with physical deterioration and emotional turmoil. The psychological states of depression, confusion and hopelessness affect the patient's will to heal and thus, makes the difference between tentative recovery and rapid decline; cooperation with the treatment and medical advice or a complacent succumbing to sickness.

Milton: ...is despondent about the family's rejection... He thinks often about how to ask them again, but is hesitant because of past reactions. Instead he asks to stay with another sister and an aunt but they declined noting spatial limitations. I'm asked to help Milton prepare yet another request of the mother, but his overall depression works against us. "I'm very depressed, I just want to forget all this AIDS stuff. I've been praying everyday. I wish a miracle would happen... I'd like to start a new life, I don't want to worry about where I'm going after the hospital... If only I could go home."

The last time Milton was hospitalized he attempted suicide. Someone stopped him before he could jump out of the window. He attributes the act to despondency concerning his mother's rejection. "...I'm tired of being rejected by her especially since I haven't seen my father since he left her."

Regardless of the closeness or distance between them, the relatives and patients were all affected by the social stigma associated with AIDS. The extent to which they internalized the communal perception seriously impacted their future dealings with the patient, the hospital staff and the broader community.

Milton: During a visitation, Milton's mother brings him toiletries and slippers. Later I was told, "... I talked with her... she says that she tries to understand this AIDS thing...doesn't want to change her life-style; she's not going to play nurse or disrupt my fifteen year old brother's privacy, since we'd have to share his bedroom.... she said that the hospital will just have to find a place for me... she says I'll make it, like I did before. He cries, " I can't believe how cold and insensitive that bitch is!... "

Gay Males - Family Ties and Friends

Gay males often dealt with simultaneous disclosure of their diagnosis and sexual orientation. The long association of AIDS with homosexuality made it difficult for them to divulge the medical condition to loved ones without revealing a closely guarded secret. Self preservation mandated that they maintain surreptitious even duplicitous lives. They grew accustomed to projecting one face to the family and another to a special public. The mask has been worn for so long, that its' removal now is frightening. Then too, there is an awareness that the family may quietly have known the truth all along. To destroy the illusion would shatter the uneasy silence and make everyone uncomfortable.

Larry: ...has not told his mother that he has AIDS or about his sexual preference and sexual activity. He does not feel that she or any other family members would understand his attraction to other men or the way in which he satisfied his sexual urges. Even in the hospital Larry becomes uncomfortable if we discuss this part of his life too loudly. He is ashamed, scared and feels isolated. He is most concerned about his medical condition and its future implications-- fearful that one day he will leave his mother all alone.

Societal condemnation of homosexual expression was sometimes intensified by unique sub-group cultural values and religious codes. This is particularly true for the Hispanic males. From time to time I encountered men who had so 'owned' the proscription against homosexuality, that they justified their same sex history as an effort to survive. These men were unable to accept their homosexual experiences and usually developed close relationships with women to 'prove' their masculinity. Of course, their bisexuality or homosexual activities were not disclosed to the women in their lives. But, the secret could not be maintained any longer, especially if they had no history of intravenous drug use.

Infrequently, I counseled patients who had long ago accepted their homosexuality and made it known to their families. These were the ones who had the healthiest relationships. However the families felt about their orientation, it would not prevent their support when it was most needed. The following is a case in point.

Ruben: ...is a 24 yr. old Hispanic gay male. Diagnosed with CNS (Central Nervous System) lesions, Toxoplasmosis and KS recently, he told me that he tested HIV positive one year ago. Ruben has a very good understanding of the diagnosis and prognosis. This is his second experience with brain lesions. They cause dizziness and blurred vision. This hospitalization is most difficult for him because the illnesses are getting more severe.

"I accepted it [having AIDS].. I know I'm going to die, that's it. I just want to have a good time now. I still like to go out and party with my friends, like go dancing and be with my ex-boyfriend. We were lovers for four years."

Later, I met Ruben's mother. She's aware of her son's sexuality and the illness. She's very supportive and wants to take him home. She is however, angry at the staff for not being attentive enough; making him feel dirty, just because he's gay. "Look, my husband and three other children understand Ruben's life-style. We love him no matter what... All we want ... is to take him home." When first hearing of his diagnosis, she didn't know what to expect, she just didn't understand AIDS. "I know it will be hard, be we want him with us... whatever time he has left, we want to be there for him."

IV Drug Users - A Dual Ostracism

Characteristically, the intravenous drug users had the most tenuous ties with family members. The criminal behavior often associated with drug use had precipitated strains and breaches could not now be reconciled. They had often robbed relatives or physically hurt others. They had proven unreliable. These were the least trusted of the members of the family's network. That fact often meant many years of estrangement. In some cases the patient had no idea of where to locate their families. Where the family was accessible, they would provide only limited support. There was a certain detachment on the part of family visitors, they perceived the patient's interaction as rooted in the same behavior pattern which had caused so much pain in the past. They were not willing to risk safety and possessions in order to care for someone who had willingly chosen to jeopardize his/her life. Their visits were irregular and became less frequent as time progressed. Typical is the situation of Arturo, a 31 yr. old Hispanic male, who was hospitalized with medical diagnosis of rule out PCP, a high fever and wasting syndrome. He had lost 30 pounds in one month.

Alberto: ...is an admitted intravenous drug user who prefers heroin and has a history of bisexual relationships. He has shared needles with his sister. She tested HIV+ three years ago. But, he did not know of her AIDS related illnesses until just after the recent funeral.

Miguel: Married with two children; an eight year old son and six year old daughter. Occasionally he lives with his wife, sometimes other men but, recently he has been homeless.

He was sentenced to Almira State Prison for three years. And, later one year in Rikers Island Prison. Inside, he was homosexually active. Upon his release in 1977, he met C. They were married and now have two children. He has never discussed his sexual past with his wife, adamantly explaining "...I'm not a fuckin' homosexual! I was doing the fucking. Can't you understand I fucked those men, sometimes I stayed over their apartments, for money and sometimes for a place to stay. I stole from them... to survive after my wife kicked me out.

His mother, wife and sister visited him in the hospital regularly. But, often arguments would break out, cutting the visit short. Miguel had told them that he has TB or pneumonia. They attribute his deteriorated physical state to "the hard life he has lived." They know of Miguel's "bicio [habit]".

Like their gay wardmates, some IVDU patients had been able to hide their lifestyle from relatives. To disclose AIDS related illnesses now would mean having to explain the probable causes of infection. The dual revelation was a source of great stress and anxiety. Even more complicated are the situations where substance abuse is practiced by more than one family member. The sense of punishment and failure is oppressive. In these cases, fear of rejection was a major issue for the patient. They had difficulty accepting the medical diagnosis and were certain that family members would have the same difficulty. Beyond this, they feared the family members would avoid their pleas for help, even now when death was imminent. In order to avoid disclosure, the patients might focus on less threatening illnesses. These would be used to explain their hospitalization to the family. But, family members often became very concerned or suspicious with repeat hospitalizations or cases described as TB produced extreme weight loss or skin lesions.

The family, too, experiences a state of denial upon learning about the true nature of the illness. Few want to accept that this could happen to one of their own. This was complicated by a general unfamiliarity with AIDS and uncertainty as to the manner in which the illness will progress. If they were willing to permit the patient's discharge in their home care, they often experienced a sense of community isolation from the broader community. This was true in Marlon's and Ruben's cases.

Marlon: On the next visit, she assures Marlon that she will take him home if he is discharged. She will try to do the best she can. "I must do this." She will take the [AIDS antibody test] and seek medical guidance on an outpatient basis. For now the rest of the family will not be told of the diagnosis. She is afraid of the possible reactions. Perhaps people will stop visiting her home. Perhaps the City will take the children away.

Ruben: ...family signed him out of the hospital in order to take him home for a few days. When I telephoned, Ruben wouldn't speak to me, according to Mrs. G. he was depressed, angry and did not want to speak with anyone. She however needed someone to talk to and asked that I call again. She expressed a feeling that the family is totally isolated. Despite the medical assistance of the hospital and staff, they feel all alone in caring for him at home. A gay men's support group assigned a 'Buddy' to Ruben, but he doesn't seem to understand the cultural values of the family. His case load does not permit regular visitations. "People [neighbors] just don't understand... sometimes I feel so ashamed."

Sometimes the isolation was self imposed. Relatives could not bring themselves to discuss the matter with neighbors or even extended family members. When they do, friends fade away, contacts are less frequent; dinner invitations are no longer extended or accepted. There is difficulty coping with the routine demands of at home patient care. They complain that the existing community resources are too meager to make a significant impact on their lives, which have become totally dominated by the emotional and physical care of a terminally ill relative.

Marlon's girlfriend found the HIV testing process very stressful. Even though she tested negative, she feels that she is not out of danger and waits to be tested again in six months. She is terrified that she has to go to that clinic again and worries about being HIV infected. "I can't tell my family about his medical diagnosis, I can't even tell anyone that he might die. I have no support and feel very alone, ...how much must I endure....

The Single Mother

The single mothers constitute a special subset of the population studied. It is important to separate the IV drug using woman from the female who's partner is or was an IV drug user. Some of the women in the sample claimed to have no experience with IV drugs, nor were they aware of drug use, or bisexuality on the part of the partners. They fell victim to their mate's negative behavior patterns. They were ill informed about the nature of drug use and similarly ignorant of AIDS.

The women who were in hospital care because of a history of IV drug use or prostitution exhibited the same strained family connections as the gay and IVDU males. They often reported that their drug dependency began as a result of a relationship with similarly using men. Once addicted they frequently traded sex for drugs. Delores contracted AIDS in this way.

Delores: ...education is minimal. After dropping out of high school she had a series of maintenance jobs. It became clear that pushing drugs and prostitution would pay more money.

After one month of hesitancy Delores finally spoke about her family. She has four children ages 10, 12, 15 and 18. Two of them live with her sister. The oldest is in Rikers Island prison for attempted murder. By her own estimation, she has been a neglectful mother. The past eighteen years are marked by drug abuse, prostitution, petty robbery and homelessness.

Her mother died in 1987 of a heart attack. A sister died at the age of 32 of a massive stroke complicated by intravenous drug use. An intravenous drug addicted brother who frequently shared needles with her sister, died during the same month from AIDS related illnesses. Delores used to share needles with her sister too. She learned that her husband, absent for five years, recently died from AIDS related illnesses.

Patients viewed as 'innocent victim' was treated differently by their families. They reacted with sympathy and compassion. Support was readily available in terms of regular visits, gifts and flowers, food, babysitting, homemaking or temporary residences. These "innocent victims" were those patients who became HIV infected by partners who withheld risk behavior activity, such as Intravenous Drug use, and/or bisexuality.

The Homeless, Displaced and Dying

The homeless patients had the fewest human resources upon which to draw. They were least likely to complain about the hospital facilities because they had the fewest options. There was no family to speak of, if they knew where they were the connection had fallen apart so long that this was hardly the time to expect a rescue.

Remingo: ...is 36 yrs. old, a Hispanic Male who entered the emergency room in medical crisis. He had diarrhea and a high fever, was seriously underweight and diagnosed rule out PCP pneumonia. He told me of his long history as an intravenous drug user. He prefers manteca, heroin; but when its unavailable he uses 'crack' or cocaine.

Presently homeless, he has lived on and off in various men's shelters. He would prefer not to return to the shelters after discharge because he has been robbed, mugged and beaten by other shelter residents.

He calls himself a drifter. When he does not stay in the shelters, he sleeps on trains or abandoned buildings, sometimes with women who take him in when he has drugs to share. Eventually, they kick him out. To survive he steals, mostly car radios, food or when possible he combs the vacant buildings for scrap metal or empty cans. This provides the spending money, "...when you got cash you got drugs, women and friends."

Patients with Family Support

For patients with solid, supportive family ties, the picture is much brighter. Strong family ties not only improved the patients ability to cope with the illness but also elicited more attentive responses from the staff. It's as if the knowledge that a concerned family exists inspired better treatment from the professional caregivers. Moreover, the closer the family ties, the more likely it is that the necessary life-style adjustments will be made in order to provide care to the patient. Even under the best of conditions though, the road is a rocky one. Marlon's case is typical.

Marlon: During a twenty three day hospital stay, Marlon processes the meaning of the diagnosis. He begins to feel more comfortable with his girlfriend and the family's knowledge of his condition. They make preparations for his return home and pledge more honest communication. He promises not to do 'crack' anymore or "other private things." His main concern is that which others may say if they find out he has AIDS. He forbids anyone to tell his friends or the rest of the extended family.

His case is referred to HRA for SSI and supportive services. A few days after discharge I called him at home. His girlfriend says she's having difficulty with him. He's very depressed and extremely concerned that people in the neighborhood will find out about his diagnosis. She found the HIV testing process very stressful. Even though she tested negative, she feels that she is not out of danger and waits to be tested again in six months. She is afraid to return to the clinic and worries about being HIV infected.

They don't have enough money to buy food or some of the other little things. "...The whole damn thing is up side down I'm just the house maid. He doesn't want to marry me now, I'm not going to leave him, I'm 46 years old do you think it will be easy to find some one else and now that I may be infected." After the phone conversation I contact a community group to get food and supportive counseling services for Marlon and the family.

A week later I spoke with Marlon: "... I haven't been keeping my appointments with the outpatient clinic and slipped back to doing a little crack." His relationship with M is strained and he's not so sure what's going to happen. He agrees to visit with me at the hospital, but never shows up.

The presence of children complicates the situation further. If the patients had children, they were most commonly in foster care or residing with relatives. They expressed love for the children and a wish to have been better parents. They hoped to see them again before dying. Many times this would not be possible. It may have been years since the last visit. Other times, the relatives could not tolerate the patient's presence in the home. Another tragedy manifest in these situations was the likelihood that their children would also be infected. Long after the mother's death, other family members, foster parents or state agencies would have to deal with the maturation and slow death of these children.

Summary

The writer spends a lot of time thinking about the silence of this disease and how it is so unfortunate that some of the patients are not fully known to their families or friends. While others are not accepted or understood before they die. The torment and inner conflict that some deal with regarding sexual preference seems to isolate them. I am troubled by the sheer weight of the pain and loneliness they feel.

Michael: "I think about dying a lot. I think about the kids. I think about the things people say if you're a junkie... they think you don't care about your kids or your family [if you're a junkie]. I'm scared of dying. I won't be able to take it. I'm scared of being alone." The thought that his wife may also be infected in troubling "... If my wife gets the disease, I will fuckin' kill myself... What will I do, who will take care of my kids."

The presence or absence of family members has a significant affect on the patient. They are a source of physical comfort both in the hospital and for the sometimes subsequent home stays, and they are providers of emotional support. The degrees to which they provide such support appears to correlate to the degree of well-being the patient experiences. Unconditional love and genuine bonding was a welcomed ingredient to the patient's mix of daily experiences. However, those family members who provided support, but with their own agenda, offered a more strenuous variety of support.

Regardless of the support, one issue ultimately prevailed, that the patient faced on their own: the reflection on their lives, such as it was, in the face of death, their own mortality. Thoughts of self-punishment, second chances and religious deliverance, all permeated their experiences. The various stages of death and dying, as described by Kubler-Ross, were applicable to these people as it would be to anyone of us.

The next chapter addresses the dying issue as it relates to the study group. The works of Kubler-Ross and others are highlighted to help define their experience.

These experiences, as well as their thoughts and feelings, remind us that death is a universal passage.

CHAPTER IV

DEATH AND DYING

Canute: "When is my day going to come? ...I don't know when I'm going to die... It's funny you know when you're gonna be born, but you don't know when you're gonna die."

"What's gonna be is gonna be... I'm gonna die [but] I just can't think about it."

As much as the word is used in everyday conversation, we do not know much about what happens during the dying process and nothing of what occurs after death. The poet, Emily Dickenson called dying "...a wild night and a new road." It is the unknown and implacable nature of death and dying that colors the experiences of patient and staff alike in the AIDS ward.

For the person with AIDS, death is a much too personal thing to treat abstractly. They knew it would come, but it was to be like walking through a mine field: instantaneous, without warning or time to react. They were not expecting to die because of such an illness nor under these circumstances. For the person with AIDS death occurs in protracted stages, by inches; through doctor's visits, restrictive diets, medical crisis, a multiplicity of medications, weeks or months in an hospital and then the worst; heart seizure, cancer ridden organs or respiratory failure. And most of this process occurs during a stay of several weeks or months in a hospital.

With hospitalization comes much time to think. The AIDS patients now dwell on the factors which contributed to their maladies (substance abuse, sexual practices, inadequate health care, exposure due to poverty manifest in joblessness, homelessness, etc.). There is more or less serious reflection on their lives; the decisions and choices made. In time they speak of their experiences, disappointments, achievements, regrets, triumphs and failures. For those with intact familial or other social ties, there will be some concern about how to 'tie up loose ends'; to bring closure to their lives. Zita's concerns are typical:

Zita: The illness, uncertainty about the future and possibly avoidance prompt her to make plans for the children. "... this is something I never expected... [it has] really knocked me off my feet." She wants the respective care givers to adopt the children. I am asked to contact a lawyer who can finalize her plans. Nevertheless, she speaks of wanting to leave the hospital in order to start a new life.

"I just want to know when I'm going to die; just let me know, so at least I can tell my son and daughter, at least speak with them.

Self-esteem, Stages of Death/Dying

Many of the patients progress through the five stages described by Dr. Elizabeth Kubler-Ross, in On Death And Dying (1969). The first stage is the biggest hurdle to overcome. Denial presents a formidable challenge in part because healthy self perceptions and definition are rare among this group. Dr. Kubler-Ross wrote, "Denial functions as a buffer after unexpected shocking news, allows the patient to collect [her]himself and, with time mobilize other, less radical defenses. "... No, not me, it cannot be true! This anxious denial following the presentation of a diagnosis is more typical of the patient who is informed prematurely or abruptly by someone who does not know the patient well..., without taking the patient's readiness into consideration.

Dr. Kubler-Ross continues,.. "Denial, at least partial denial is used by almost all patients, not only during the first stages of illness [but, also] following confrontation.... [It] is usually a temporary defense and will soon be replaced by partial acceptance." In this stage patients seem to be observing their demise, going along with the program and procedures, the doctor's judgement ("s(he) knows best.") and 'mother nature's decision as to their fate. They feel powerless to affect the quality or degree of care received because they believe the outcome will remain unchanged. Ostensibly, they agree death is a certainty. But, most convince themselves that they will recover from this in part, because they know so little about the enormity of the illnesses and because they have survived so many other trials. They want and expect to leave the facility.

Denial is understandable when juxtaposed against the pattern of their lives. Many of these AIDS patients especially the gay and IVDU persons have behavioral histories rooted in denial. In a book about addiction for gay men and women, the author wrote:

> "...we have been conditioned... everywhere in society to be victims and to deny what is, and to

> accept what is not. Under these circumstances, it is little wonder that gay men... are at such a high risk for addiction...a disease of denial. Becoming addicted was the only way to stay sane... [this] made it possible to put up with the cruelty and abuse, the hatred and discrimination, the distortions of truth that... gay men experience" (Cominars, 1989).

A few of the patients remained in the denial state throughout their hospitalization until death. Most often however, they cultivated and maintained a partial denial throughout the stages of death and dying. These were the ones who could not develop other defense or coping mechanisms. Again, Dr. Kubler-Ross: "I am trying to emphasize that the need for denial exists in every patient at times, at the very beginning of a serious illness more so than towards the end of life.

Like Dr. Kubler-Ross, I observed that, "Depending very much on how a patient is told, how much time (s)he has to gradually acknowledge the inevitable happening, and how he has been prepared throughout life to cope with successful situations, he will gradually drop his denial and use less radical defense mechanisms." Take Canute:

Canute: ...believes his state is the result of "...a maldicion [evil spell]. I can't do nothing...work, sex, no se me para [my penis doesn't get hard anymore], I don't have no feelings... I can't do what I used to do.... Everybody has to go sometimes. At least nobody killed me, nobody hurt me." But, he admits being afraid. "You never know when its going to strike, you know sickness and death."

"They're all going to leave me, I can't blame nobody, when its your time, its your time! ... [but], I hope it's later, I don't want to die here. This [hospital] is a motherfucker, these people leave you in your room and shit, they don't pay attention to you. Yeah, they bring the medication and food, but that's it..." "After I die, I don't care what happens."

I don't want to suffer... I ask God to take me, take me, let me know when. I don't want to suffer. I'm not scared. I'm tired of suffering... just get it over with. If I could find a way I would do it myself. I'm tired of this, wasting my time, wasting the doctor's time. I'm tired of all this shit."

Others talk about the futility of medical treatment, they are just going to deal with it. In their denial many focus on the current opportunistic infections or another disease with which they are familiar if it is deemed socially acceptable. Generally, they refuse to believe they have AIDS and work to convince themselves and others that they have only the present infection or a curable disease. Sometimes their focus is dissatisfaction with the hospital, even if it is better than homelessness. In many ways it is worse than incarceration, since their very bodies prevent release. It is difficult for them to acknowledge the closeness of death.

The second stage as per Dr. Kubler-Ross' work is anger. "When the first stage cannot be maintained any longer, it is replaced by feelings of anger, rage, envy and resentment... This stage is very difficult to cope with from the point of view family and staff. The reason for this is in the fact that [it] is displaced in all directions and projected onto the environment at times almost at random."

Within the population studied, disappointment or dissatisfaction may be represented in negative, 'acting out' behaviors. At the root is fear of abandonment. They lash out with anger because parents, society or spouses have failed as all benevolent and perfect sources of order or nurture.

Patient experience in the anger stage is tied up in the image associated with AIDS. The stigma of AIDS impacts each patient. There existed prior to diagnosis a preconceived notion as to the 'kinds' of people who contracted AIDS. Although their appreciation for the complexities of transmission and progression is limited, they nevertheless view AIDS as a plague and persons with AIDS as pariahs to be despised, feared and rejected. This prejudice and that associated with their poverty, addiction, homelessness, homosexuality or prostitution serves to prevent them from distinguishing between the syndrome and their life-style. The perceived and sometimes actual indifference, insensitivity or contempt of hospital staff reinforces negative stereotypes and further isolate the patients from each other while undermining the possibility of a patient's acceptance of their own mortality. The patient is left to handle the anger. If it is not accommodated within 'acceptable' limits psychiatric referral are made the appropriate medication provided.

If the anger and denial become too much, too tiring or ineffective ways in which to address their situation the patients entered what Dr. Kubler-Ross defines as the bargaining stage, "...an attempt to postpone; it... includes a prize... for good behavior [often assuming] a deadline and... includes an implicit promise [not to] ask for more if this postponement is granted... Psychologically, promises may be associated with quiet guilt [such utterings are particularly significant cues for case workers since behind them lie issues which deserve to be addressed.] The patient needs trained facilitators who can help them to resolve irrational fears or the excessive need for punishment." Delores, for example, has consistently denied the veracity of her diagnosis. Each time we talk about her condition she concentrates on a particular illness such as TB. Anger is directed at her experience with drugs. She is now in the negotiation stage, talking about her family and a wish that she could be different with them. She negotiates the ability to care for herself. At the same time, she asserts a seemingly conflicting drive to survive. "I'm going to kick down to the last of it [breath], with God's help maybe I'll be here for ten years.... When I get out of here I want my own room. I don't want to be with anyone. Shit, I refuse to go down. I want another chance."

When the terminally ill patient can no longer deny the truth of the illness and the certainty of death (s)he is nearly consumed by dread. Anger, rage, stoicism, carelessness or indifference all fade in the face of a sense of great loss. This is the fourth stage, depression. But, the depression types vary. Dr. Kubler-Ross writes, "...one is a reactive depression,... the person has no difficulty eliciting the cause.... the second type is a preparatory depression... it is rooted in sadness about impending losses,", these are opportunities which will be denied.

In the depression stage, most patients react to the diagnosis as if in receipt of a death sentence. With the shock comes emotional and physical withdrawal. They are less communicative and keep to themselves in darkened rooms, lying listlessly in their beds. Withdrawal turns into anger, then depression, both of which are rooted in nonbelief.

In time there is tentative recovery from the emotional distress. If physically able they sit up in bed or begin to venture out into the hallways. They engage other patients finding similarly diagnosed persons with whom to discuss the medical situation, to commiserate. Occasionally they invite these new found friends into their rooms.

Others never really achieve this transitory emotional recovery. They internalize the diagnosis remarking that there is nothing they can do about it except to wait for what happens next. A few believe that they deserve such an end. As their medical conditions deteriorate they become weaker and revert to hiding in their rooms. It becomes clearer that death is near. The new friends who may not yet be experiencing such physical declines are put off by the sight of their decline and visit less frequently, then not at all. The specifics of physical decline is too difficult for most of the healthier patients to watch. They express disbelief or repulsion. There is a wish that the same will not happen to them. Others become curious but still do not want to see or know too much. Perhaps by turning away from it, they can put it off or avoid it altogether. As Canute puts it:

A few close friends have died from HIV related illnesses three of them in this hospital. "That hurt me... I used to [come here to] feed him... tell him that he was not going to die... I think its bad... I don't want to get to that moment... You know, die..."

Anne's reactions illustrate the trauma experienced as death approaches:

In time as the disease progresses she begins to have more difficulty. On two occasions she passes out. This is frightening and increases her feelings of depression. Anne begins to withdraw. I find her laying in bed in the fetal position. She prefers to leave the lights turned off and the door closed. "I want to be alone..." When she speaks to me, she appears confused, unfocused and disoriented. "What's gonna be is gonna be.... I'm gonna die [but] I just can't think about it." Beyond this, Anne will say nothing of her feeling about death and dying.

Sometimes, there are thoughts of suicide. Is this so that they can choose the time of their death and avoid the wait and suffering or is it the ultimate act of despair and hopelessness? Canute says, "Sometime, I think of 'cutting up,' you know like cutting myself or some stupid shit." He remembers attempting suicide when he was eighteen. During previous discharges he has attempted suicide by way of overdose and was readmitted when opportunistic infections left him unable to care for himself.

... When I was 18 I jumped out of a second story window... because I was depressed."

Don't get me wrong, I have had ideas. But, I don't care no more. I don't want to live. I've lived my life. I'm exhausted. I'm bored, disgusted. I feel like giving up." This train of dialogue prompts me to refer the case to an in-house psychiatrist. Upon consultation with the attending physician, the psychiatrist prescribes Cojenten and Haldol.

He is not planning to hurt himself yet. But, by his own admission if he were to do so he would "...jump out the window and other crazy shit man. When I get crazy thoughts like this, I go to sleep and relax my mind."

The last milepost is acceptance. Dr. Kubler-Ross comments, "If a patient is to die in a state of acceptance and peace... [they must have] been able to work through their anguish and anxieties..." Only with "... enough time... and some help in working through the previously described stages [will] he reach a stage during which he is neither depressed nor angry about his 'fate.' S(he) will have been able to express ...previous feelings,... envy for the living and the healthy, his anger at those who do not have to face their end so soon. ...S(he) will have mourned the impending loss of so many meaningful people and places... contemplate the coming end with a certain quiet expectation."

A few of the population studied, with higher levels of social skill, intact family relationships and perhaps with religious beliefs reach the acceptance stage. They achieve a level of freedom which seems rooted in profound trust. These are the ones who are victorious over the disease and death. The greatest achievement in life is to face yourself as you really are, to face what others have said and done and to believe that you are worthwhile anyway. Those who reach acceptance have found the courage to be who they really are, without apology.

Alberto: ...was uncustomarily frank and open, "I know what I got.... La Sida [the AIDS] ... I got my days... I'm going to try and take care of myself.... How long do I have to live?" He knows that he will not recover from this disease. And copes by remaining very still in his room, alone and in prayer. There is a calm, quiet strength about him. He walks the corridors carrying the Bible which his mother left during an earlier visit. A new set of Rosary beads are proudly worn about his neck.

Within the population studied the most popular mechanism for achieving acceptance requires a turn or return to religion. Faith does not wash away the tears, but they begin to live with new integrity, trust and hope. Dying, when faced, apparently can be a great liberation. Part of dying is letting go; throwing down the burden. They are free from the injustices and betrayals experienced, from the sickening smell of their own wasted bodies, minds, spirits, from their own cowardice.

Jerome: ...was fully conscious of his near demise. He spent a lot of time talking about his faith in God. He sometimes asked that I read to him passages from the Bible. He liked to listen to religious music so I secured tapes from his church and the hospital loaned a tape player (which was later stolen from the room). But, the arrival of death was not so much a topic of conversation ("[That's] in God's hands...") as the recollection of what life had been like for him. In his frame of reference life was finished.

During our last visit, Jerome began to fade, slipping into death. He asked that I have a minister visit him. Jerome was Protestant but I was only able to get a Catholic priest to pray with him. He died some time later; alone and unattended.

In some cases consolation is obtained from drugs in conjunction with religion:

Remingo: ...During my visits, I attempt to focus on the diagnosis and prognosis. He resists talking about the illness or the prospect of dying. But, over the next few weeks his condition declines. During our time together I held his hand and tried to make him comfortable with the process of letting go. In these last few days he "... started to take care of things." He asks that the Pentecostal witnesses spend more time with him. Even now however, there are rumors that he has also been keeping time with visitors suspected of supplying drugs to patients.

The Protocol of Death

At the demise of a patient the staff assumes a purely utilitarian function. When the physician pronounces death, a team of nurses aids (two or more) prepare themselves outside the room; donning masks, gowns and latex gloves. I have been granted permission to observe the process, so don similar protective garb.

The room is just as I had left it. The machinery is still there and the room is in disarray. There is dried blood on the floor. David's motionless body rests on its back, the blood stained gauze pads scattered about the bed where they had fallen when he last struggled to breathe.

First, the life support machine(s) if any, are disconnected. They are very careful. It is important to avoid any body fluids which might ooze from points where catheters or other tubes had been inserted. Such tubes and other disposable machine parts are discarded in a red plastic bag. This color is an indication to all staff persons that hazardous, infectious waste is contained therein.

One of the nurses began to remove the IV tube from his upper arm, then the ING tube from his nose. She pulled back the top hospital sheet and removed the catheter from his penis saying, "...hey, you got to be careful with how you remove these tubes... this stuff is dangerous [a prick with the tip of a tube or catheter might expose one to the highly infectious body fluids]. The tubes were disposed in the specially marked bags.

Together, we pushed David's body forward so that one of us could remove the sheet which rests beneath him. Next, his hands were crossed, secured with surgical tape and placed on his chest. The ankles were similarly secured.

The team is careful to guide me, the novice in the handling of the body. "just do it this way, we won't have no seepage.... We got to be careful with body fluids.... Just do as I tell you. ...Stop being so nervous! Let's just get it done.

We rolled his body to the right hand corner of the bed and rolled a new sheet under the mid section of his body. A similar move to the left was completed to spread the sheet completely under the corpse. A mortuary tag is tied to the toe and beginning at the head the torso is wrapped in gauze. Next, the body is neatly wrapped in the sheet. All is ready for the next staff person who will take his body to the morgue.

There is something bitter and ironic about death in a hospital. The mission of the facility and endeavors of the staff are directed toward recuperation and the extension of life. Despite all the training, experience and resources, death happens. It occurs at random. Some patients will die under circumstances from which others recover. The inevitability of death is an occupational nuisance; the joker in the card deck to be drawn at anytime. Yet, the staff tries to beat the odds.

Isolation and Internalization

When a patient is near death and the staff has decided not to artificially prolong life, there are visible cues which are observed by the other patients. The sight of patients dying unattended is traumatic for the others. Their situations are so similar that they believe their death will be same. Towards the end, fear is a constant companion.

Canute: A few days later, Canute began what would later be called the 'final stages.' He floats in and out of consciousness. There is no one to cut his hair and the beard has grown long and unmanageable. His face is distorted by pain; one eye is nearly closed. He cries incessantly and often yells for help. He had to be restrained.

Over the next few days, he grows weaker. In a barely audible voice, he complains about the pain. It was difficult to watch Canute's slow dissent into death. We sit quietly together for awhile, then he'd ask, "... what do you think is happening?" As I responded, he would close his eyes as if he did not really want to know.

The obvious physical decline and pain was not enough to initiate a confrontation of his dying. The fear of death prevented him from talking with me about his feelings. There were few questions or comments about his perceptions.

The routine of the hospital went on all around him seemingly oblivious to his dying. During the last few days I stopped by his darkened, silent room to find him laying in the unlaundered sheets, starring blankly at the ceiling. His face unshaven, hair uncombed and meal trays untouched.

Alone and in pain, the dying patients are at the most vulnerable and helpless point of their lives. The fear and hurt are difficult to express, especially since there were so few people who listened to them in life. Coping takes on many forms. Some revive their drug use in order to escape.

Delores resumed drug usage. While the staff supposed this, the issue was not pursued because they could not prove it.

Isolation is intensified by the fact that most of this population have very strained if not broken family ties. Relatives had little reason to contact them when they were in good health. There is little incentive to be supportive now at the dawn of death. Since a large portion of the population studied were homeless, they had few if any friends in the community who could offer support. In general this population is alone and unsupported at their death.

Canute: ...resisted the hospital chaplain's visit because he felt that it was not "... time yet." There is no one to hear his struggle. He is left alone, except at meal and medication time. On March 24, Canute died wearing rosary beads.

The singularity, aloneness and isolation of the AIDS patient in this study continues even after death. Often unclaimed bodies remain in the hospital morgue for days or weeks until relatives are found and come to claim them. Others are simply interred in municipal paupers graves.

Weeks later, no one has come to claim the body. Attempts to reach the family are in vain. The body lies in the morgue for some time. He is eventually buried, probably in Potters Field.

Although my observations support Dr. Kubler-Ross's paradigm for death and dying, I do not wish to give the impression that each patient flows through the process systematically. There is ebb and flow, a cyclical movement here, within these stages are roller coaster like mood swings; hostility, withdrawal then extroversion; almost as if nothing is wrong; next sadness and melancholy.

Most of the group studied remain in the denial, anger, bargaining and depression stages throughout hospitalization. The denial is manifested in complaints and resistance. This generally involves blaming the doctor(s) for not making their condition clear to them. Many genuinely could not understand the specific terminology used to describe or define the AIDS syndrome. Others interpreted the staff's inability to express their conditions in lay terms as hostility or a 'holier than thou' attitude. I believe that the staff truly avoided telling them of the likelihood of death. The significant demands of serving their bodies do not permit much time for addressing the patient's emotional needs. Unfortunately, the staff's avoidance gives the impression that recovery is assured.

Most patients demonstrate a real interest in knowing what will happen, at least abstractly, as the disease progresses. The unknown is probably the most unsettling issue. The staff and family are reluctant to answer such questions, in part because there are so many permutations and in part because they are afraid to scare the patient. The rationale is, perhaps its best that they do not know. In any event, the doctors and nurses expect that someone else will address this issue (clergy, family, friends or social workers).

Waiting to die is a very difficult thing to do especially when they have so few opportunities for distraction or resources to increase understanding. Escape from the hospital is a familiar theme. Most want to live as they were accustomed until "their time comes." The medical ward is often viewed as a prison death row. They express feelings that might be expected from a convict who has exhausted the last appeal. Reprieve has been denied. They must simply endure the pain and discomfort until it is time.

Anne: For the most part, she appears resigned to her demise. "I know all about it [AIDS]. I'll leave it in God's hands. I know I don't have much time. I know what's happening. I know I'm going to get sicker... I'm a fighter, I'm a Cancer. I leave it in God's hands. If it ain't my time. I'm not going no where."

Days later Anne remains on the respirator. The edema has worsened. The doctors expect renal failure. We spend time together quietly. When I hold her hand her eyes open and she winks at me. She struggles to breathe even on the respirator. The doctor thinks she may need to be suctioned "...but, perhaps this is it."

She tries to raise herself from the bed which angers the doctor. She's terribly afraid and I tell her it's okay to let go if she wishes. I wiped the tears from her eyes. She winked again and clasped my hand. Moments later, she died.

In contrast to Anne, Delores reverts to denial of the dying process, wishing to leave the hospital so that she could resume her 'life.' She refuses to see that her 'days are numbered.' The hospital staff relate to her as if it were business as usual. The doctors treat each symptom separately as the occasion arises; "treat the acute medical condition." Their aim is her eventual discharge. The issue of her death is never really discussed with her. Towards the end; the last two weeks of her life, Delores is surrounded by other AIDS patients in various stages of demise. She believes there is time to live before she goes through the same things.

Only those patients who reach the acceptance stage entertain thoughts of refusing artificial life extension methods. They are tired of this ordeal and have ratified death. The questions and fears have not been eliminated; but they have achieved a wholeness and ability to face the situation as it is. Ruben’s case is typical:

"I don’t want to die.... I just don’t want to... I’m afraid of dying alone ..." There is a fear of the unknown. He asks "What will it [death] be like, how will it happen?" He does not want to expire in the hospital. I’m afraid that I’m not going to have a chance to be with my parents and ex-lover again."

I am asked to review the ‘do not resuscitate’ policy. [He] disfavor[s] artificial life support. Ruben wants to die at home. He is discharged again but, within hours developed breathing complications and is returned to the hospital. The family is confused as to what to do next. Since they are not in the room during the exam, he is placed on a respirator. Despite best efforts, Ruben expired within a couple of hours.

When an HIV+ person is admitted to the ward with AIDS related illnesses the technicians focus on specific problems, addressing causes and cures. The treatment strategy assumes the dual goals of recovery and discharge.

Canute: I ask Canute to tell me what he thinks about. "When we talk about all this death, I think its bad. I don't want to get to that moment, you know die. I think if the hospital can't do nothing, they shouldn't supe me up [make him believe that he will recover].

He does not discuss his feeling about death with the doctors. "They don't care, they just act like they're treating me. They give me all these pills, then come into my room and say; Canute, how you doing? Sometimes, they don't wait for an answer. They treat me like a bum." ... They need to tell the truth...

Under 'normal' circumstances (advanced age, premature birth, accident) death is understandable. The death of an AIDS patient is perceived as tragic, yet it is also something "they brought on [deserved] themselves or asked for by way of "inappropriate behavior." In addition, the generally working or middle class administration most often views the AIDS patients as long since doomed to self-destruction by their dysfunctional behavior patterns. The fact that they were drug users, prostitutes, gay, illiterate, homeless means, in the abstract, that there is little reason to go beyond basic care in addressing their medical conditions. There is an undercurrent to 'blame the victim', and it is manifest in the wording and tone of official documents as well as staff-patient interaction. Canute complains:

...I don't hardly leave my room anymore. Most of my friends left or died. That's why you see me laying down. I feel sad. I say it this way, we all going to die, But, let the man prove himself. We don't need to be treated like dogs. Some of the people [staff] in here ignore us. The doctors, nurses don't really care. At least they should let us die like human beings. They should listen to us once in awhile, that's all. That's all my friends wanted.

You feel lonely in here, it's damn boring and depressing in here. I think it's important that people listen to us.

... there were others who made Jerome's experience difficult. These were the tourists, who called on him only to view his facial disfigurement. They'd say "... that's what AIDS can do... you see, he's a homosexual. If he weren't doing those things he wouldn't be here. God don't like ugly.... God don't like that anti-man [the West Indian equivalent of faggot] stuff."

In addition, the underclass status of the population implies that they are a drain on hospital resources. Without a doubt, when they are released there will be others to fill the bed.

As it is these patients are left to cope with the disease(s) and their mortality by themselves. Here, they flounder and the sight is pitiful. They are anguished and their cries just to be heard go unheeded. Again Canute:

"They're all going to leave me, I can't blame nobody, when it's your time, it's your time... [but], I hope it's later, I don't want to die here. This [hospital] is a motherfucker, these people leave you in your room and shit, they don't pay attention to you. Yeah, they bring the medication and food, but that's it..." "After I die, I don't care what happens."

This is not to say that the nurses or physicians are unfeeling or careless. In fact I witnessed many herculean efforts to circumvent death. I also observed much compassion in those serving the people. But, in the end, the patient is left alone to die quietly. There are situations when the patients could be revived, their lives extended or their passing made easier. But, physicians and nurses have the discretion to use or withhold these measures.

Delores: As the 'end' approaches, people avoided her room. There is less and less staff-patient interaction. The doors remained closed, lights turned off. It is important that the staff apportion its efforts among those patients who can potentially be saved.

The application of new and modern technologies to prolong life was not regular. Some physicians hesitated to initiate such protocols on behalf of IVDU and or homeless AIDS patient who were expected to soon die. At times a 'why bother' attitude was evident. At other times I would walk on to the medical ward and find that two or three people with AIDS intibated, (breathing assisted by a respirator). In these cases the physicians had chosen to aggressively prolong life in the face of a terminal illness. Some of these intibated patients, 'bounced back;' their lives were temporarily extended. Others expired despite the effort.

While working at Oremus Hospital I noticed that the 'do not resuscitate' (DNR) policy and the related use of cardiopulmonary resuscitation (CPR) were sensitive, complicated issues. In general the communication between patient and physician regarding this matter was quite limited. It seemed difficult for the doctors to speak of this procedure with the patients. Since many patients were in a state of denial or had some misunderstanding or misinterpretation of the diagnosis, they were reluctant to discuss this issue with their physicians. Planning or preparing for death was not something they seem ready to handle. Most often, the institution of such a policy was a decision left to the house and or attending physician.

The instrument by which extraordinary measures are exacted is the blue telephone located in the nurses's station of each medical ward. Upon witnessing an emergency or being alerted by the alarm of a life support apparatus, the staff person will use the phone to contact an operator. The operator calls for urgent assistance using special code words and the public address system. Within minutes a specially trained medical team is dispatched to the specific location. Routinely when patients demonstrate critical difficulties the staff sounds the ‘code blue’ alarm. At times a ‘slow code blue’ is expressed among the physicians which means although an emergency exists, there is literally no need to run to the patient’s rescue.

Occasionally, no code blue is sounded. The reasoning in such cases seems to be that the patient’s medical status is too severely deteriorated. There is no reason to take extraordinary measures to prolong life. They will die sooner or later. This is the silent, mutual understanding between the attendant physicians, intern(s) and nurses.

The professional staff shortage also affects the extent of life prolonging measures exacted on behalf of these patients. Sometimes there may be four or five respirators running in a 28 bed ward attended by two nurses and three aids during a specific shift. The extent of emergency care provided under those conditions is necessarily limited.

Helplessness and Acquiescence

Patients who resist or argue with the prescribed treatments in ways that are deemed antisocial or ignorant by the staff find their wishes or requests denied or ignored. At worst, an unacceptable manner widens the gap between health care worker and patient so that actual services decline or diminish in quality. There are now fewer opportunities for the patient to be educated, for understanding and acceptance to be enhanced. Ultimately they are penalized for this behavior by being denied access to specifics or avoided by the system. I think the great demand for medical attention results in an overload of cases beyond the limit that can be served by the staff. In such a situation, they simply have no time to spare and perhaps little patience for the client who creates 'unnecessary' behavioral problems.

The staff may also have difficulty dealing with the people who struggle to live. As Dr. Kubler-Ross points out, the health care staff "...can do this only when [they] have faced [their] own fears of death,

...destructive wishes and become aware of... [their] own defenses which may interfere with ...patient care." The achievement of such empathy or compassion would be a monumental one, for most of the staff seems so overwhelmed with the nature of these terminal cases that they erect psychological barriers to block the horrors thus stifling most chances for real introspection. Yet, the staff is given no supportive service to help them to cope with their own fears of death or the routinely or occasionally difficult patient.

Perhaps more than any other social class of terminally ill people, the population studied needs much professional assistance in coping with the inevitability of death. But there is no significant help for them. In Oremus Hospital the medical staff is too overwhelmed by the sheer numbers and the facility too burdened by the cost of care to provide the necessary psycho-social counseling. In the best case scenario the medical staff too, would receive counseling and guidance in coping with their own fears of dying and their perceptions of the population served; thus reinforcing the emotional support provided earlier to the patients.

In her most recent book, <u>AIDS The Ultimate Challenge</u>, Dr. Kubler-Ross asks, "Will AIDS patients ever reach a stage of acceptance and peace [in the dying process]?" "Yes," she responds, "...if they receive and give themselves enough permission to express their anguish and their tears, their sense of impotence against a vicious killer and against a society that discriminates, judges, blames and... enjoys the fruits of the[ir]... unhealthy life-styles... If they have enough of a support system with people who simply love and accept them and give them the natural nurturing that all human beings need, especially when they are sick, then... they develop the stage of peace and serenity that makes the transition we call death a quiet slipping over into another... existence."

Summary

No one dies completely whole, with all their issues resolved, all their questions answered and all their fears assuaged. But those who are indigent, with no support, alone and isolated go to death beaten, shattered and broken. They die ignored or unaccepted in part by family, friends, the hospital staff and for some time now, by a society and culture that does not value their lives or talents. The fact that they contracted a disease associated with immoral or illicit practices was somehow used to justify hardened hearts, abandonment and the collective death wish harbored for this population.

Their hospitalization and death presents the health care staff and indirectly all of American society with a challenge. Their medical treatment can be a duty numbly done because we are 'civilized.' Or we can choose to treat more than the body in serving terminally ill people. Medical care providers are human beings beneath the white lab coats and they personally know addiction, divorce, bankruptcy; have been estranged, promiscuous or suffered illness, they know the pain and so might reach out in real empathy to others. My observations suggest that these professionals need counseling to cope with their own fear of mortality and prejudices toward the underclass. More than this, America, as a society includes people each of whom have known some measure of failure and betrayal. As a nation, then we should reach out in compassion to help these people resolve the defeats of their lives and even the "fear of the wild night and the new road" we will all one day face.

CHAPTER V

DISCUSSION AND ETHNOGRAPHER'S FIELDWORK EXPERIENCE

This chapter is devoted to the ethnographer's experience as a case worker, and an experience which is rooted in circumstances arising in 1985. At that time a friend I will call 'Bill' was diagnosed as HIV+. Bill, a white male, was a well educated clergyman; a member of a religious order who was dedicated to serving God as the pastor of a local church. He lived alone in a solidly middle class neighborhood in Brooklyn, New York.

Not too long after confiding his HIV+ status, Bill developed what I would come to know as commonly experienced AIDS related illnesses. From time to time I helped him to keep his medical appointments, visited him in the hospital, assisted with household chores and provided emotional support.

The most troubling thing about my experience with Bill was the way he coped with the illness in near isolation and silence. He told only a select few about the diagnosis. No one in his family or congregation was aware of the nature of his illness or his impending death. I was unable to understand why he chose not to tell more people about the situation. When hospitalized, he spent much time alone, with only a few visitors. On many of the occasions when I visited, find him lying in his own waste, confused, seemingly uninformed about his medical condition or prognosis. After each of the several hospitalizations and discharges, he returned home in a weakened state; virtually unable to care for himself or his two Abyssinian cats. In time, a close friend moved into the apartment to help care for him.

Six months after his diagnosis, Bill died. There was no funeral since the body was cremated, but a memorial service was held one month later in the church where he served as pastor. Publicly, his death was attributed to cancer. I attended the memorial and was struck by the fact that Bill died in isolation, too. At his death there seemed to be few questions, no real attempt on the part of the flock he shepherded to discover the real cause of his demise. I wondered how many other people experienced AIDS and death in this circumstance.

In 1986 I took a part time job with the New York City Department of Health, AIDS Hotline. As a telephone counselor, I received an education about the nature of

HIV infection and AIDS-related illnesses. I was responsible for providing information on the subject to anonymous callers. Beyond dispensing the latest news regarding the epidemic, I was exposed to the diverse social and sexual activities of the New York City population. I was confronted with ignorance and fear in those who were concerned about being tested, who had tested positive for exposure to the HIV or were related in some way to someone who were HIV+ or had developed AIDS related diseases. All kinds of people called the hotline: gay, straight and bisexual, married and single, men and women, adolescents, young and mature adults, blacks, whites, Hispanics- all at various stages of curiosity, misinformation, concern or panic.

One caller telephoned me every Wednesday night. She was considering taking the HIV test because her husband and the father of her teen age children had developed AIDS. Knowledge of the disease came with disclosure of his bisexuality. In addition to the worries about her health, she was coping with the issue of public disclosure. It was important to this middle class, Italian woman that her children, extended family and neighbors be kept ignorant about the nature of her spouse's sickness. Yet, in the face of fear, resentment, feelings of betrayal and potential public humiliation, she cared physically and emotionally for her husband.

My experiences with 'Bill' and the special Hotline caller coincided with the near completion of my graduate Sociology studies. I decided to devote my thesis to the unexplored issue of the urban ethnic minority poor and their experience with the expanding AIDS epidemic. Of particular concern was the apparent lack of information and social support possessed by the anonymous callers I counseled as a hotline worker.

Curiosity about the lives and circumstances of this special population prompted the choice of an ethnographic research methodology. To facilitate this approach I took a part time (20 hours per week) case worker, position in an hospital. The job required that I provide direct, personal, one-to-one supportive counseling services to AIDS patients. The location of the facility was such that the majority of the patients would be poor ethnic minority persons. My ethnicity and Spanish language skills would be especially useful.

The first day on the job I was shown the medical ward where I would spend the next twenty two months of my life. I met five patients in various stages of HIV diagnosis and AIDS related illness. I wondered into what kind of situation I had gotten myself. At first, the level of suffering was overwhelming. During these early days, I would have to leave the sick rooms in the middle of a counseling session in order to regain composure. There were to be many sleepless nights as my rest was invaded by the memories of the sick moaning, complaining and physical struggling with illness and death.

[Author's Notes]...I didn't want to be there- felt astonished, saddened, heartbroken...the magnitude of illness there. I hated the smell, the sight of people so distorted... they move so slowly and that stare, the look of death in their eyes.

Some of them won't talk to me, I've got to be persistent. Keep moving, I'll get through the night, get out of the hospital.

The initial shock dissipated and I focused more on the duties and responsibilities of the case worker. After gathering the necessary demographic and family history information for the case record, I assessed social service needs and helped to identify the hospital discharge plan for each patient. To do this required interaction and discourse, an assessment of the patient's understanding of the diagnosis or medical condition. This was not usually an easy process. It often took much time to engage patients. My questions about personal life-style matters were often perceived as invasions of privacy and viewed with great suspicion. It became clear that I needed to find ways of establishing trust and confidence with people whose lives were often characterized by desertion, betrayal and dishonesty.

It was not uncommon during the initial meetings, for patients to refuse to speak with me ("What the fuck do you want?" "Who are you?" "I don't want to be answering so many questions!") Some people ignored me, simply pulling the sheets over their heads, hoping that I would just leave the room. If they spoke, it was to ask that I turn off the lights and close the door on my way out. When I reached the point where I no longer took this rejection personally, I would take a seat in the patient's room, remain silent and wait until they spoke.

This might take several tries to be effective, however. Other times, I attempted to buy the patient's confidence by doing little favors for them- purchasing cigarettes, candy, clothing or making telephone calls, sometimes taking their requests to the doctors or nurses. This would circulate among the patients and in time I cultivated a favorable reputation ("...that Ayala is OK, you can talk to him, he listens... respects our type of people...").

As a caseworker I was exposed to the factors with which these, the disenfranchised of the city community, dealt on a regular basis: homelessness, drug addiction, loneliness, chaotic life-styles, and now the unfamiliar routine of hospitalization and the uncontrollable developments in their bodies. Much of the counseling time was spent encouraging the patients to speak about their lives and understanding of AIDS. It was important for me to be genuine, empathic and honest about caring for them and wanting to make their hospital experience easier. Since most were homeless, intravenous drug users, sex workers, assorted criminals or homosexuals and sometimes various combinations of these, they were unaccustomed to sharing their experiences with anyone who listened in a non judgmental fashion. Even if they believed that I was there to help, there was often curiosity as to my real motivations. I always revealed myself as a case worker and sometimes as a graduate student of sociology, especially to those whose experience seemed pertinent to my research.

There is a thin line between empathy and over identification and being 'tested' by patients readily clarified the issue. I was always at risk of being used or manipulated by patients into actions which would sometimes prove harmful to them in the long run. This was particularly true of the substance abusers who routinely tried to badger, beg or cajole me into obtaining greater and greater doses of methadone for them from the physicians. In the beginning of my hospital experience, I would rush to the nurses station in order to accommodate the patient. Fortunately, the more experienced members of the staff and certain situations with individual patients made me realize that such patient behavior was manipulative and really a reflection of poor impulse control or pain intolerance. My lack of experience in this area created friction with the medical staff. Some of the doctors and nurses perceived my intervention on behalf of the patient as interference or an attempt to impose my judgement on theirs.

Regardless of the patient's stage of the dying process, it was difficult to cope with their emotions surrounding their fears of the illness and their mortality. The counseling sessions were often intense and physically draining and as both case worker and researcher, posed a serious commitment. Being available, both physically and emotionally, to the patient and their families was a challenging and a spiritual awakening. It became clear that the connection between my reflection on the issues of death and dying was necessary, indeed unavoidable, in order to facilitate the patient's dying process experiences. Crossing the line from caseworker to fellow human being and back, was less mechanical each time, as it should be, although never easy.

Some of what I experienced highlights current hospice movements as described by Kubler-Ross, Levine and Ram Das in their writings.

> "...This new hospice movement focuses on providing a warm, supportive, and open environment for the individual undergoing the dying process...
>
> ...The most important contribution this movement makes, however, is that it supports the acknowledgement by all involved that dying is indeed the business at hand..."
> (Ram Das, 1982).

The health care system as it is, prevents us from getting in touch with these feelings which facilitated the nurturing of the patient's dying process and the healing of their spiritual being.

In workshops provided by Kubler-Ross they...

> "...share ...everything we have learned from the dying patient who has been our teacher for the last twelve years. We allow the participants to share their own griefs, search for their own unfinished business, for their own fears and guilts, and we help them to relive and externalize their negative feelings in order to find peace and to do away with the drain of energy required to repress all these negative feelings. We help them to free themselves of guilt and fear, and we try to teach them unconditional love and service to their fellow man so that they can return to their homes, schools, hospitals, or places of work and do those things that your dying patients learn to do in the final days of their physical life..." (Kubler-Ross, 1978, p. 149)

Confronted by a number of patients exceeding the ability and resources of the facility or neighborhood social services kept me in a state of continual frustration. There was a strong feeling of uselessness in the face of their deteriorating health and death. The magnitude of psycho-social, medical, financial, political deficits brought to the landscape of my interaction a sense of powerlessness. Simply knowing that my 'shift' would soon be finished was a help. At other times absenteeism was the only way I could cope with the situation or my anger and depression with it. As my tenure in this job lengthened I had to make a concerted, conscious effort to distance myself emotionally from the patient's pain in order to minimize my own. Objectivity was the only way to deliver the best possible service with the least personal cost. I wrote the following after a discussion with a fellow social worker:

On this ward I deal with 28 patients. It's difficult. I have to document everything that I'm doing with them. Hey, we're short staffed, could you imagine, trying to be on top of the histories, personal circumstances of every one of these patients. I mean, this one is homeless, that one is a drug addict, the other one has AIDS and won't face it. You have the doctors always pushing you to find housing for patients... they want them OUT. So, they see you in the halls and yell, "hey, did you find housing for so and so. We're just so short staffed; sometimes, I just can't handle this. I don't know how I do this.

Boy, so many people are dying up here... it's like a dying club. Sometimes I can't believe it. I just need to get out of here. I'm transferring to the ER. At least in there, the patients keep moving, they come in and move out."

Eventually, it got to the point where I had to find and make a mental note of individual, specific ways in which I helped specific patients in order to feel good about this job. I focused on simply being present, listening, providing emotional support, touching them physically as concrete ways of easing their pain and transition to death. Acknowledging their lives, encouraging them to cease dwelling on the past, encouraging them to live each day as best they could was difficult but essential to their well being and mine. I made a point of observing the demonstrations of commitment, even heroism on the part of co-workers. It was important to celebrate the fact that the 'glass was half full' rather than 'half empty.'

Time proved to be a finite resource. I was never sure that there would be enough of it to uncover the needed research information or to adequately serve the patient's needs. It was not uncommon for the patient to become incapacitated or to die with my work unfinished.

Two issues, patient denial and counterproductive behaviors, posed particular challenges to my work as researcher and case worker. From the relative security of my middle class status and education it was difficult to accept the fact that these individual would often interfere with their healing process. But, to remain objective as a researcher and to be effective as a counselor it was crucial that I respect the manner in which each person coped with their situation. At times this meant accepting the patient's insistence that PCP (Pneuocystic Caranii Pneumonia) was influenza or their determination to leave the hospital in order to resume drug use.

Over time, I grew more angry about the limitations of the patient's response to medical care and the facility's ability (or willingness) to serve these distressed persons. I grew angrier still at the social conditions which led many African Americans, Hispanic Americans and women to this state of suffering and degradation. The lives characterized by meager education, poverty, discrimination, low self esteem and violence and neglect made me question the genocide theories and wonder about my own safety and stability in contemporary America.

> "Access to advanced technology is only one of the many needs of persons with AIDS. They also need a full spectrum of services ranging from tertiary care to home health, nursing and hospice services. These services, described by Carol Levine of the Citizens Commission on AIDS in New York and New Jersey, are sadly lacking. Adequate subacute services and housing, in particular, can make a vital difference to the well-being and dignity of persons with AIDS." (Gostin, 1990).

The increasing physical weariness and occasional depression forced me to disassociate myself emotionally from the job and the research from time to time. I concentrated on being more professional in the execution of my duties.

In time, I became savvy to the maneuvering of "hustlers" disguising their requests as real expressions of need. Growing to understand the background and nature of the study group enabled me to discern a patient participating in a bona fide methadone drug treatment program from one simply wanting the drug.

Doctor's and nurse's attitudes were, at times, condescending and felt in two directions. One was toward the patient, adopting a "blaming the victim" attitude and distancing themselves, believing that the illness was their fault, ("...if they didn't do what they're doing, they wouldn't have AIDS... if they'd follow my direction, they'd be outta' here!"). Another direction in which poor attitudes were aimed toward the caseworker and their work with the patients was expressed when, often to initiate an examination, the doctor would interrupt a counseling session, discounting my presence and invalidating my work, as if perhaps I were not there at all. One intern interrupted a session, telling me not to allow the patient to cry and "get out of control". He insisted I focus on helping the patient understand the medical procedure and the diagnosis. Ironically, I was doing just that, but with his clinical blinders on, he was not able to see emotional expressions could be the vehicles to physical awareness. Another incident occurred at a time when a patient was near death. As I held her hand and connected with her to assure her and comfort her passing through this fearful of moments, a doctor abruptly came in to draw blood and, even in his awareness of the moment, could not separate himself from the clinical procedures even for one moment to experience the humanness of bonding with the patient.

Despite the staff posture, I was usually able to convince them of the need for more attention for those who were truly in need. I learned how to approach the staff with extraordinary requests. I learned as well to respect the staff work habits and accepted the fact that it is the doctor and or nurse who decides when patients are seen and how they are medically treated.

Conversely, the physicians and nurses relied on me to identify the patient's social service needs and services. It was my function to clarify the medical issues for the patient and family, if any. I was responsible for the development and implementation of discharge plans so as to avoid unnecessarily long hospital stays. In the best of circumstances, this proved advantageous for the patient and the facility. But, in too many instances the inadequate availability of appropriate housing, supportive counseling and community based referrals, or other services would leave the patient to fend for themselves once discharged from the hospital.

Discharge proved especially difficult for the undomiciled patient. Confirmed AIDS diagnosed patients were not accepted by local shelters. Such resistance was a source of great friction between the hospital administrators and doctors and the case workers and neighborhood social service organizations. Battles over turf or areas of professional responsibility could easily leave the patient without adequate care or provisions.

> "Case managers in hospitals may be the most appropriate persons to design discharge plans for inpatients but may lack the information and resources to assist several months later when the client needs help with housing, employment or other problems. Community based case managers may, in contrast have the ability to deal with these social and personal problems but may lack authority and expertise to manage care when the patient is hospitalized. The ideal system would permit flexibility and cooperation among case managers. (Levine, 1990. p. 49)

One of the more difficult issues was that of substance abuse in the hospital. There were times when I or other staff persons uncovered illegal drug use which would ultimately be ignored by those in positions of authority with the facility's security force. On one occasion I had learned that a patient used a syringe to inject Heroin into the IV bag. Angered and disturbed, yet understanding the patient's addictions and their social circumstance, I knew there was little I could do to effect a change in such behavior.

Security personnel were reluctant to confront the patients involved or the non-patient traffickers. The latter were sometimes neighborhood persons or even employees. But unless security personnel actually witnessed a transaction, they claimed there was nothing to be done. There were occasions when patients left the hospital to buy dope. The lack of surprise on the part of physicians, nurses or security was remarkable. If the patient's "excursion" was too lengthy, the nurses were authorized to strip the room and assign another patient to the bed. In the meantime, the patient's disappearance was reported to security. If the nurse mentioned that the missing person was an AIDS patient, that usually meant the end of Security's search. Usually, the patient returned by way of the emergency room anyway.

Ironically for this population, their experience with illegal drug use proved convenient from time to time. More than once, I witnessed a doctor's difficulty with injections because a patient's veins had collapsed after years of drug abuse. Almost without fail the patient would say "Let me do it, geez...". It might have been more humorous if it were not so tragic.

Drug addiction complicated the patient's recovery process. Methadone and other substances counteracted the licit prescriptions, sometimes further weakening the patient's physical condition. Recovering addicts were a special challenge. Some doctors viewed them with suspicion, thinking that they entered the hospital with 'fake' symptoms only to secure free Methadone. As a case worker, I had to confirm the patient's participation in a recognized treatment program.

At times when such treatment was verified, doctors dispensed what the patients felt were inadequate dosages. Since specific dosage amounts could not be disclosed by the drug treatment provider, doctors were left to prescribe treatment based on their own medical and moral judgment.

The issue of confidentiality was a potentially explosive one, but always an ethical dilemma. Early in my employment, all patients who were suspected of being HIV+ or of having AIDS, had such status noted by the prominent display of red signs on their room doors which instructed the entrant to stop at the nurse's station before going in the room. In time this practice ceased because of patient or relative complaints, but the more subtle use of red trash container liners in the appropriate rooms persisted. The effect is the same for those with the awareness to recognize that red trash can liners are used for the disposal of hazardous, infectious waste.

Similarly, the staff was placed in the awkward position of withholding information as to HIV+ or AIDS position status from family or friends if the patient so wished. Many of the patients willingly informed friends or family of their diagnosis But, in most cases this happened only after several counseling sessions. In some instances the case worker was requested to be present at the time of revelation. There were too many cases where wives, lovers or pregnant girlfriends could not be told the truth about a patient's status because of the latters refusal to reveal it. Fear of rejection, embarrassment or simply irresponsibility kept the patient from sharing this information with those who had a right to know. In potentially life threatening situations, moral suasion was applied in order to prompt the revelation. In too many instances, the news was revealed after the patient's demise. Then, the medical, nursing and social service staff was left to cope with the family's or friends outrage.

A patient I am working with introduced me to his wife who has recently had one child and is two months pregnant. He doesn't want her to know that he is HIV+ and has AIDS. During my conversation with her, she said that he told her he has pneumonia.

Despite much dialogue he resists telling her the truth. The doctors and I confirmed that if he doesn't tell her, we will.

Later, the wife was informed and has initiated HIV antibody testing. Although pleased with this development, I am struck by how much control over the situation the husband had.

An interesting observation during my research was how dominant and controlling men in this underclass group, proved to be. They exercised tremendous power and control over women and/or "passive" men. They not only controlled them, but also subjugated women and others to achieve their means. At times, violence, prostitution, crime, drug addition, withholding important HIV/AIDS information, sex without condoms, etc., were tactics to control them.

Despite the difficulty represented in the aforesaid situation, it must be remembered that the American medical profession has a long tradition respecting informed consent, confidentiality and privacy. The potential risk to the patient of unilateral disclosure of their AIDS status is real and significant. The public's widespread and general lack of empathy, sometimes even hostility, towards infected persons is widespread and well known.

> "A positive HIV test result is important clinical information that should be part of the medical record. That record may be viewed by many people, ranging from other health care professionals and administrators to insurers and possibly employers. The overriding need, therefore, is to prevent discrimination against a person purely because of his or her serological status." [AIDS and The Health Care System, Preface: Hospitals, Health Care Professionals and Persons With AIDS, Lawrence O. Gostin, Editor, Yale University, 1990. p. 11]

Given the perception (of researchers) that this population would not comply to protocol schedules or to follow-up procedures, at the start of this research I observed that few of the HIV+ or AIDS diagnosed patients participated in treatment protocols. Specifically, AZT, the primary antiviral drug known to slow the HIV virus growth, was only sparingly dispensed to these patients. Aerosol Pantamadine, a prophylactic used to treat PCP was scarcely available for these patients.

Towards the end of the research it appeared that the hospital used such treatments more aggressively. Still not every AIDS patient was treated with AZT. Then too, medical care follow-up is limited for this population. Little effort is made to assure that the patients, once discharged, comply with the prescribed regimen. Customarily, patients using AZT are requested to see a physician every two weeks in order to have their white (blood) cell count checked. Patients complained that they could not keep such a schedule because the waiting list at their neighborhood clinic permitted appointments well beyond the two week recommendation or that when they kept their appointments the volume of other patients was such that they had to wait hours in order to see the health care provider. As well, there were medical and other health care staff shortages that impaired the ability to cover this volume.

There is no known cure for AIDS nor a vaccine for the HIV. Only the AIDS related illnesses are treatable and over time the virus weakens the immune system to the point where even AIDS related illnesses do not respond to treatment. Thus, physicians have a number of options in determining treatment methods for the opportunistic infections. Over the past ten years much information has been made available to help patients decide how and when they will be treated. Adult Gay males and educated, middle class AIDS patients have been most assertive and thus, most involved in their treatment protocols. This was not the case for the population observed during this research.

The socio-economic background of most of the population was such that they had no regular contact with a physician that did not involve a medical emergency. There was little experience with preventative or palliative medical care. Their modest education and meager medical experience precluded real understanding of the health issues much less any informed basis upon which to make decisions about their care.

Second, most of the patients arrived at the host in a state of physical crisis. Some were admitted to the facility in more or less advanced stages of AIDS related illness. By the time they coped with the psychological problems, particularly denial; there was little emotional strength left with which to ask questions or make rational, objective decisions about medical care.

This fact served to further complicate the patient's hospital experience. They had tremendous fear about being treated by strangers who now controlled their lives, apprehension about treatment processes they could not understand and thus anger about being 'forced' into therapies, such as intubation and resuscitation, which seemed to prolong their lives but, also their suffering.

Because of the limited knowledge and experience demonstrated by most patients, the medical staff readily assumed complete control of the treatment process. They saw little reason or benefit in trying to educate the patient at this 'late' stage. It is unclear that this had a detrimental effect on the quality of care or the sensitivity with which services were delivered. But, it was sometimes observed that patients, no matter how poorly informed, received better, more extensive care when concerned family or friends were regularly present at the hospital. Such family members were able to intervene as patient advocates, questioning medical services and negotiating better results.

The 'clash' of cultures also impacted the staff /patient relationships and medical care delivered. As noted, most of the patients were of Hispanic, African or Caribbean origin. Sometimes english was not their primary language. This was not the case for the facility's care givers who were of East Indian, Middle Eastern, African or Hispanic origin with varying degrees of english language proficiency. Cultural biases, conflicting perceptions, misunderstandings, even the need to simply wait for translators all served to postpone, delay and hamper the quality of care given to these people. So, again in their effort to simply deliver medical care, there is little interest to move beyond the culture and language barriers. The health care provider moves on, content in the thought they've done their job and the patients withdraw a little more, knowing they are not understood.

Fear of contagion was a subtle and sometimes obvious impediment to treatment. Doctors, nurses, administrators and others as well as the researcher worked with trepidation in this regard. The principal concern was about being accidentally pricked by needles used to make injections in HIV status unknown or HIV+ patients. When such accidents occurred the hospital worker had to deal with the apprehension and anger about infection and the routine of being tested every six months until they felt safe again. The following comments, obtained during conversation with a surgery resident, are representative:

> I'm afraid, scared during surgery... Do you know how many needle 'sticks ' I've had? I've even had an eye wash of HIV juice! I was doing surgery and it flew into my eye... Everybody should be tested. It's not right for me to face this risk. HIV test should be pre-operation, Hey, I'd like to see my 22 month old son grow up.

A discussion with a surgery intern:

> Hey, we have a right to refuse treatment of a patient, especially if it's not for an acute medical distress- something life threatening. If the person refuse HIV testing, why should I have to treat them? Why do I have to be put at risk? AIDS should at

> least be treated like other communicable diseases... there must be mandatory testing!

Such feelings seem pervasive in the medical care community.

> "In the long run, many argue, we will end up with routine (possibly mandatory) screening in health care settings. The presumption favoring testing is fueled by various professional concerns, including reducing the occupational risks and achieving clinical benefit for the patient. Physician training to use available medical technology to illuminate clinical decision making regarding testing diagnosis, prognosis, and treatment leads inexorably toward wider use of HIV antibody tests. As the technology of testing achieves greater accuracy (culminating in an antigen rather than antibody test) so, too will the pressure to use the test increase. After all, for many years physicians have ordered lab tests to be performed on blood without getting specific informed consent for each test."
>
> "...many health care professionals believe that their occupational risks are unacceptably high, particularly if they practice invasive medicine in hospitals with a high serological prevalence. The concerns are understandable when one considers the frightening high seroprevalence levels in maternity wards and emergency rooms in such major urban areas as the Bronx, New York. The cumulative risk to a health care professional working over many years with infected patients is not trivial." (Gostin, Editor, 1990. p. 5).

I was able to contain my fear of exposure by keeping in mind the information circulated by the CDC about HIV transmission modes. My concerns were more about susceptibility to live, 'air borne' bacterium expelled by patients with rare, more or less contagious diseases such as Salmonella, Tuberculosis, Meningitis, chicken pox and Herpes Simplex. Complicating the issue further was the observation that neither the patients nor hospital staff always abided by established, published precautionary guidelines. I began to fear contagion from less than vigilant co-workers. I took precautions, but the longer the research project lasted the more concerned I grew that the statistical odds of infection were increasing.

Interestingly, the need to continue overshadowed the fear of contagion. These people needed someone, some connection between their desolate existences and those who can provide some comfort in these times of stress and pain. Even the health care workers entrenched in medical procedures and detailed relationships, continued to serve. Perhaps one can assume it was to support their own existences, to maintain their livelihood. But when pregnant nurses came in day after day and donned protective clothing, caring for patient after patient, one cannot dismiss that perhaps even they felt the pangs of humanity and did their jobs because they felt the need and the rewards of merging medical treatment with human understanding.

Summary

Given the emotional upheaval felt, the moral or ethical questions raised, and the professional adjustments experienced, my findings as researcher, counselor and case worker, underscored an awareness that the American society is at an impasse in its experience with the AIDS epidemic. If the disease and its treatment are to be addressed effectively and its 'victims' served adequately, our government, schools, social service agencies, churches, health care industries, scientific researchers and families must work together to develop a comprehensive response. At risk is the certain loss of a vital resource: human life.

CHAPTER VI

REVIEW AND IMPLICATIONS, THEORY, POLITICS AND EDUCATION

The demographic findings and socio-economic backgrounds of the subjects interviewed for this ethnography coincide with what has been described by many sociologists, political scientists and journalists as the "underclass" or disadvantaged and or disenfranchised poor.

In his book <u>The Truly Disadvantaged</u> (1987) William J. Wilson, the author gives a clear and concise example of the people he believes populate ghetto neighborhoods. His theory states that the ghettos are made up of:

> "...that heterogeneous grouping of families and individuals who are outside the mainstream of the American occupational system. Included in this group are individuals who lack training and skills and either experience long term unemployment or are not members of the labor force, individuals who are engaged in street crime and other forms of aberrant behavior, and families that experience long-term spells of poverty and or welfare dependency." (Wilson, (1987), pp. 7- 8).

Wilson continues:

> "...the term underclass suggests that changes have taken place in ghetto neighborhoods and the groups that have been left behind are collectively different from those that lived in these neighborhoods in earlier years. It is true that long term welfare families and street criminals are

> distinct groups, but they live and interact in the same depressed community and they are part of the population that has, with the exodus of the more stable working and middle class segments, become increasingly isolated socially from mainstream patterns and norms of behavior..." [p. 8]

In conducting research for his book Underclass (1982), author Kenneth Auletta, over a two year period, interviewed participants in the Manpower Demonstration Research Corporation Project, a Manhattan based nonprofit entity, which conducted work programs, supportive counseling and training sessions for ex-convicts, ex-addicts, long term welfare recipients, school dropouts and delinquent youths.

At the start of his research Auletta asks: "...who are those people behind the bulging crime, welfare and drug statistics and the all too visible rise in antisocial behavior- that afflicts most American cities?" (Auletta, 1982, p. 13).

Auletta determined that among the impoverished people inhabiting urban communities, that there is a distinct underclass among blacks and whites. In my research I found a common thread among the interviewees which concurs with Auletta's theory:

> "...that this underclass generally feels excluded from society, rejects commonly accepted values, suffers from behavioral as well as income deficiencies. They don't just tend to be poor; to most Americans their behavior seems aberrant." (Auletta, p. 13).

He continues:

> "...There is some dispute over whether the term underclass is the right word to describe this group of Americans." "...First critics of the phrase say it leaves the impression that the problem is intractable, that criticism would carry more weight if the phrase was 'permanent underclass." (Auletta, p. 13).

Auletta correctly notes that the phrase sounds insensitive and tends to ignore the fact that such individuals can be helped out of the category. In the end, Auletta dismisses the debate on the term underclass and turns his focus to the problem as he states "The problem is more important than the phrase... and the problem is real."

> "...neither traditional left or right wing dogma fully explains the growth of what threatens to become, perhaps for the first time in American life, an intergenerational underclass..." Further, "...a guaranteed job, as we shall see, may not lure a hostile or fearful person back into the mainstream of society... A tax break or suspension of government regulations, may not induce private business to locate in the South Bronx or to hire unskilled or belligerent people." (Auletta, p. 16).

He cites that:

> "...for 25 to 29 million Americans officially classified as poor,... poverty is not a permanent condition...[but] an estimated 9 million Americans do not assimilate."

These Auletta calls the underclass.

In a forthcoming article by William Kornblum, Ph.D., to be printed in DISSENT (Spring, 1991), he reviews current thought and literature on the underclass credited to authors such as David Ellwood, William J. Wilson, John Kasarda, Kenneth Auletta and Christopher Jenks.
Dr. Kornblum remarks, "...the concept logically ought to refer to people who have been pushed into a world of suffering they can escape only with help from others in the larger society." Kornblum continues "...the underclass includes those people who are trapped in a nether world at the bottom of both the legal and illegal class system. The major traps are addiction, homelessness, mental illness, destitution and usually a combination of these conditions."

Rodrick Wallace, Ph.D., utilizes mathematic models to demonstrate the correlation between "contagious urban decay and population shift" with HIV exposure, infection and AIDS. Dr. Wallace states that AIDS in the Bronx, New

York and similar areas, "...seems increasingly a marker disease of extreme poverty, ... which may well form an important reservoir for further spread or resurgence of the disease." (Wallace, 1988). In previous works he clearly makes the case that the "...disruption of personal, domestic and community social networks and structures increased social disintegration and intensified a nexus of behaviors likely to be associated with rapid transmission of HIV." (Wallace, 1990). Dr. Wallace infers that unless political, social and economic stability is brought to New York City's minority areas, AIDS will continue to spread and take its devastating toll on people of color.

> "Prompt and considerable investment to improve the living conditions of the poor seems more than just good public health practice. It may be an absolutely essential underpinning to the nation's health, particularly to the control of AIDS." (Wallace, 1988).

Many of the study group could specify no regular, means of financial support. Money was primarily derived from either government social welfare programs (public assistance, supplemental social security) or the illegal, underground economy.

As discussed earlier, 106 (65%) of the subjects included in the researcher's ethnography entered the hospital without any medical insurance. Approximately 77 (43%) of this population were homeless. Then too, 75 (48%) had not completed high school, 11 (7%) graduated from high school while only 3 (2%) had some college education and 34 (22%) did not respond to the question about educational background.

All of the respondents had some experience with substance abuse, 24 (15%) used cocaine, 25 (15%) admitted to using crack, the more addictive cocaine derivative, 118 (72%) indicated current and or past intravenous drug use,and 45 (27%) admitted to an alcohol addiction.

Such characteristics confirm the study group's inclusion in the underclass as defined by Auletta, Kornblum and Wilson. In extreme situations most barely survived on economic resources well below the accepted poverty level as defined by the U.S. Department of Labor. Their economic resources and coincident life-style facilitated labeling by the general public and the hospital staff in particular. Such labels were affixed according to the individual's predominant social behavior. Emergency room attendants, nurses, etc. defined these people as homeless, an IVDU, criminal, homosexual or prostitute.

This population suffered from the stigma associated with their perceived low socio-economic status. It was seen as proper to fault them for an HIV+ or AIDS related illness condition. The participants were aware of their public image, their underclass status; even if they did not articulate it in those words. They spoke of their frustration with unemployment and the difficulty in trying to cope, day to day, without real money. Their family lives, many now long since fractured or broken, were plagued by domestic violence, sexual abuse and absentee parent(s). Education was not a priority in their upbringing. Most dropped out of school or accomplished the bare minimum necessary to be pushed through the system until graduation.

Once out of school they attempted to live according to their perception of what the term 'adult' meant. But, lacking the normative life skills, their endeavors soon produced disappointments, failures or disaster. Young and free of the constraints of school attendance most of the study group "hung out" in the neighborhood and formed relationships of one sort or another. With or without the sanction of marriage they often produced children and were suddenly faced with the responsibility of parenthood. Again, lacking the normative life skills and substantive educations they had great difficulty obtaining and maintaining gainful employment. As a rule, they had no concept of or were unable to cope with the pressure of getting to work on time, relating to coworkers in a professional setting or dealing appropriately with job or interpersonal pressures. This coupled with the added pressures at home, soon prompted most to abandon job and or family or to be abandoned by a mate. This disappointment and the resultant sense of personal failure, coupled with the lack of economic and social opportunities often led to alcohol abuse, drug use, public assistance (if available) or homelessness.

Existing literature documents that not every individual who faces economic and social deprivation succumbs to drug use, crime, homelessness or other antisocial behavior. Researchers, such as I. Chein, B. Lander and D. Glass, examine issues of vulnerability.

They concur that a significant person in the life of someone exposed to social poverty, and a positive vision or expectation for the future can make the difference.

In summation, the life-styles of population studied appeared adaptive, cultural and environmentally stimulated. The lack of adequate education and social preparation facilitated their slide into antisocial behavior and isolation. They could not be rescued from this decline because family and community resources were severely lacking.

Alcoholism and or drug abuse is such a prominent feature in the lives of the population observed that it deserves special attention. It was interesting to hear from the participants that such self destructive behavior was the only known method for coping with boredom, a sense of worthlessness, the violence in their lives or irresponsible, unresponsive family members. Others spoke of being introduced to drug use by relatives or trusted friends. Once familiar with drug usage, they found it became a recreation, then a preoccupation, and finally the focus of their lives.

Drug addiction interfered with everything in their lives. Whatever glimmer of hope remained in familial ties or developing employable skills was destroyed utterly. At that point most saw it as the needed cure, others as an illness- a weakness.

Drug use was financed by petty and then major criminal activity. To get money, most stole money or property from family, friends; employers, neighbors or strangers. Arrest, trials, police records and sometimes prison soon followed. The latter meant physical removal from familiar surroundings and further isolation from family and community life.

During this ethnographer's interviews, many IVDUs displayed a understanding of HIV transmission modes. However, most indicated that their drug habit was so profound and extended over so long a period that despite the knowledge, they made conscious choices to share needles and to continue using IV drugs. Most often the client indicated that it was hard to enter drug treatment programs because of the shortage of treatment slots and the resulting wait for admission. Many expressed a preference for doing drugs as opposed to facing the realities and the implications of the diagnosis. Others felt that the people with whom they were sharing needles "looked clean," which implied that they could tell if someone was AIDS infected.

As the epidemic unfolds, AIDS cases involving IVDU is expected to grow dramatically. "Care providers are becoming aware of the multiple connections between AIDS risk and substance abuse... These include sexual transmission of HIV to partners of intravenous drug users, neonatal transmission by infected mothers who are IV drug users or partners of IV drug users, increased risk due to disinhibition under the influence of drugs or alcohol, increased risk due to immuno-suppression caused by drug or alcohol use." (McGregor, 1986: 1474-9)

"In the U.S. IV drug users form a link to two other groups at increased risk for AIDS: heterosexual partners and children. Of the 423 cases of AIDS among children reported through January, 1987- 53% had an IV drug using parent. Of the 1,111 cases reported where heterosexual transmission appears to be the route of exposure, 73% involved transmission from an IV drug user." [Des Jarlais, Jainchill & Friedman, 1986].

Many of the intravenous drug users expressed some understanding of AIDS prior to learning of their HIV+ status. But, most were confused about the subject especially issue concerning transmission. In recent years information that the virus could be transmitted via shared needles or "works" had circulated among this population. But, few of the respondents believed that they would be infected. It is a common practice for underclass intravenous drug users to share needles, but a notable portion of the population made comments such as "...yes, I shoot drugs, but I have my own works and I never share with anyone." or "...but, I know who I share with... and they don't look like they have AIDS..."

In some cases I observed a resignation on the part of IVDU to their illness, "...hey, you have to pay the price... I've spent so many years chasing drugs that I just can't stop... its a way of life for me... AIDS is the consequence." Perhaps this reaction is a reflection of the acquiescence with which they have accepted so many other disappointments in this life.

In a state of denial, it was not uncommon or even surprising that some people continued to use drugs. Among substance abusers, denial was a defense against dealing with the consequences of the addiction. Patients needed to discuss specific symptoms associated with drug or alcohol use including withdrawal, tolerance, "black outs" and use alone.

Beyond this, I observed resistance to stop drug use even when the patient accepted the fact of their AIDS diagnosis. "I've been doing this all my life, I'm just not ready to stop now..." Others used their hospitalization as an opportunity not only for treatment of AIDS related illnesses but, as an occasion to seek help for their drug addiction. Scarcely available drug rehabilitation programs and the lack of suitable housing undermined this effort however. Then too, if the patient had prior experience with rehabilitation programs, they perceived such facilities as having very limited affect, "...They take you off one drug and put you on another one [Methadone]." They also did not feel comfortable with the overcrowding and restrictive rules or regulations in force in rehabilitation clinics.

Those expressing such views said that they wanted to manage their own addiction through continued albeit "safer" use. They believed that getting off drugs would have minimal effect on their lives. They still would have marginal job skills and fragmented links to the community. "What will I do with myself when I'm clean [drug free]?"

The health care workers demonstrated predictable reactions towards the drug use or addiction of the patients. While many understood it as an illness, they had little patience for the problem in the face of the diseases they had to treat in full blown AIDS patients or the acute ailments of HIV+ admittances coming through the emergency room. Doctors viewed with disdain and suspicion requests for Methadone, even when the patient's participation in a rehabilitation program could be documented. Some acquiesced and prescribe the drug. On occasion, physicians denied such requests forcing the patient into withdrawal, "cold turkey."

The issue of drug addiction had special implications for the duties of case workers. Communication and thus, cooperation was poor between drug treatment facilities, community based operators and the hospital. It was difficult to discern what type of care was being provided to the patients both, before and after their hospitalization. Certain information was not obtainable from other facilities because it was held confidential by custom or law. We had to rely on the patient for information and their lack of communication skills or knowledge made it difficult to provide comprehensive medical or social service. The fact that patients might go from one clinic, drug treatment program or hospital to another heightened the confusion and resulted in fragmented, sporadic care.

A certain amount of righteous indignation was observed especially among the interns who were frustrated by the approach and reaction of the AIDS afflicted homeless and or drug addicted patient. The latters relative lack of discipline and control prompted frustration and anger, "...we're wasting the tax payers money... we weren't trained to practice medicine under these conditions... how does society benefit from any of this?... They're [patient] disrespectful and very nasty... careless and noncompliant... they don't deserve treatment. They're killing themselves... AIDS is God's punishment, look at the way they live, they have no values." In these comments is little appreciation for social circumstances which helped to produce these counterproductive, antisocial, even self destructive patients.

Faltz and Madover (1987) note clinical and ethical issues as well as barriers to treating this population especially counter transference and minimal educations. Denial of HIV related diagnosis coupled with denial of substance addiction, difficulties in pain management, with family or loved ones. There is a need for on going counseling to prevent substance abuse relapse and the coordination of care among agencies. The essential information must be conveyed to the patient even if they do not seek substance abuse treatment. Early intervention and treatment are essential to minimize the risk for HIV infection and transmission.

The authors continue, "...crisis brought about by AIDS diagnosis may provide an opportunity to make a powerful intervention in an individual's substance abuse, and that the patient's quality of life may improve as a result." "For the individual troubled by the chaotic life-style that often accompanies drug or alcohol abuse, the crisis evoked by an AIDS diagnosis may generate a willingness to ask. "What will I do with the rest of my life?" The patient may choose either to seek treatment for the abuse or to continue it. Many choose to die high." The authors note that too often those providing care for patients with HIV related risk or infection are not working in coordination with substance abuse providers. As a result they sometimes over look the importance of both kinds of treatment.

> "The patient and loved ones are often traumatized by the diagnosis and loved ones may be reluctant to comfort the patient's substance abuse in the person diagnosed as having AIDS or ARC...They may perceive the disease to be their most immediate concern and the substance abuse an ancillary issue for which a referral may be offered" [p. 144] This "why bother" attitude is common thread in my observation during the ethnographic study, "Because of the overwhelming nature of an HIV related diagnosis, treatment providers as well as patients often feel a sense of hopelessness that precludes the possibility of major positive life changes... Rationales for ignoring drug or alcohol abuse and the possibility of successful treatment for it include: the patient will die anyway, that substance abuse treatment will take away a "coping mechanism," and that substance abuse treatment is stressful. [These] rationales imply the question, why bother treating substance abuse in patients with AIDS?" (Faltz & Madover, 1988, p. 145).

In the hospital the observer was exposed to the ideology asserting that a person must "hit rock bottom" before effective intervention can take place. Helping professionals as well as laypersons requires reminders about the dynamics of addiction and the need for motivation in recovery.

It appears that another barrier to substance abuse treatment among HIV infected patients is the transference of the treatment provider's fears and perceptions onto their patients.

> "...fear of the unknown, fear of contagion, fear of death and dying, fear of homosexuality, denial of helplessness, over identification with the patient, anger and the need for professional omnipotence." (Dunkel & Hatfield, 1986: 114-17).
>
> "Moralistic attitudes towards alcohol and drug abuse is based on the unreasonable assumption that an individual is in control of their excessive use of these substances. The notion that the addict would stop if they really wanted to, can easily be used as a rationale for not aggressively encouraging treatment." (Faltz & Madover, p. 147).

Health care workers were notoriously impatient with the IVDU clients pleas for pain medication. But, in their weakened state, these patients had unusually low pain thresholds.

> "...average doses of opiates or psychoactive medication may not be successful in relieving pain." (Faltz & Madover, p. 152).

No matter how dysfunctional the IVDU, AIDS patients may appear to some observers, I observed a clear interest in self preservation.

> "There is a common stereotype that IV drug users are not at all concerned about health and are not likely to change their behavior in order to avoid exposure to human T-Lymphotropic virus type III. Much of the stereotype appears to be based on observations of the very unsanitary "shooting galleries" (Califans, 1982, Des Jarlais, Friedman & Strug, 1985).

Despite this stereotype, there is consistent evidence from a variety of sources to show that IV drug users in New York City have changed their behavior in order to reduce the chances of exposure to the AIDS virus.

> "Approximately 60% of the subjects reported efforts to reduce the chances of exposure to the AIDS virus, primarily through increased use of sterile needles."
>
> "This self reported increase in sterile needle use was confirmed in our interviews of persons selling needles, who reported an increase in demand for sterile needles as a direct result of the AIDS epidemic. Limited availability of sterile needles was also noted as a major constraint on risk reduction in our studies of IV drug users not in treatment." (Des Jarlais, Jainchill & Friedman, 1986 p.54)

My findings support those of Des Jarlais:

> "All of our present evidence, however, does indicate that efforts to reduce transmission of HIV are occurring as a result of knowledge of AIDS. IV drug users should not be considered unresponsive to the threat of AIDS." (Des Jarlais, 1986).

But, one must begin to understand the life of the drug user and the power of the addiction. This activity has become the focal point of their lives. Until that power is dispelled, they will do whatever is necessary to get the drug. The attraction, drive to get drugs can not be broken altogether until the other deficiencies in their lives are addressed. During the course of this research, the refrain "Me voy a curar!" was heard. "I'm going to cure myself," meaning that the person needed the "fix" to deal with their life circumstances; addiction.

To go even further, those individuals interviewed in my sample, many times denied knowledge of AIDS, and at times were unwilling to confront their risk behavior or comes to terms with the diagnosis. The denial was so great that people would not even tell their mates or family for fear of rejection.

The enormity of the AIDS condition not acknowledged; they wanted to deal only with the immediate medical crisis. The IVDU members of the study group demonstrated very little knowledge as to the progression of the AIDS status and related illnesses. They had particular difficulty comprehending the correlation of coincident factors in their life-style to the disease. It was difficult to convince these persons that homelessness, malnutrition, drug abuse, insufficient medical attention, "unsafe" sexual practices and cigarette smoking had any relationship at all on their health or chances of recovery from illnesses. Thus, in general, they would not take medical advice very seriously.

The female relatives and lovers of male, IVDUs are seriously jeopardized or terribly affected by the association.

> "Women make up approximately 7% of the total number of AIDS cases in the United States." "AIDS also affects a lot more women of color; 50% are black, 23% Latina and 26% white (at January, 1987)." (Richardson, 1988).

Richardson notes,

> "... That 73% of the women with AIDS in the United States are black or Latina, is clearly disproportionate to the percentage of the population which they represent. According to health officials, this reflects the more widespread use of injectable drugs among black and Hispanic women... It may also be because the social conditions of many black and Latina women's lives- poverty and poor access to health education and care included- put them at greater risk... All too often researchers ignore the wider social conditions, including poverty, racism, and sexism, which are at the roots of the spread of AIDS in the black and Hispanic community." (Richardson, p. 29).

Thirty eight women were interviewed during the course of this ethnographic study. All of them entered the hospital by way of the emergency room. None had private medical coverage but were insured by Medicaid. As concerns educational background, 19 (50%) had not reached the high school level, 7 (18%) had some high school and 6 (16%) dropped out of high school. Only 6 (15%) did not respond to the question.

Twenty six (68%) admitted to active intravenous drug use, 7 (18%) used Crack cocaine and 5 (13%) did not respond to the question.

Seven (18%) indicated active participation in the sex trade to finance their drug use. Eighteen (47%) of this group were homeless.

The sample of 38 produced 20 children; 10 (26%) had more than one child. Most were cared for by extended family members or were in foster care.

Interviews uncovered four (10%) who believed that they were infected with HIV by their sex partners. None had any knowledge of their partners sexual past or drug usage. They confessed that they had had great difficulty in getting their partners to discuss their sexual pasts.

Negotiating condom use was fruitless. Few of the women seemed to own their sexuality. The male partners were in complete control of the sexual activity and there was often violence (rape) or the exchange of sex for drugs or money. A few spoke of being locked in "crack houses" for days or months during which time they were forced into sexual acts.

Homeless women were the most vulnerable of the sample subgroup. They related stories of great degradation and subjugation as they sought means of survival on the streets. As such they led nomadic and violent lives. Many witnessed the death of boyfriends, lovers, husbands and friends from AIDS.

None of the group were particularly concerned about AIDS or the inherent risks prior to the HIV+ determination. Now, they express disbelief at the diagnosis of AIDS related illnesses. All of the diagnoses were the result of hospitalization because of acute medical crises. They cited family responsibilities or the lack of time as the reason for postponing examinations at the first sign of illness.

Few of these women achieve the two or six year life expectancy of HIV+ diagnosed persons. Most died in short order because their HIV seropositivity was determined in conjunction with the onset of relatively advanced AIDS related illnesses and in part because they were already in a state of physical decline because of minimal health care and exposure due to life on the streets.

The presence of children in the lives of study group had some significance. There were psycho-social issues which would impact the lives of the children. The confusion and sometimes fear in the eyes of children visiting sick parents was notable. This resulted in limited visits, especially since the care givers did not always want to bring the children to the hospital. It was thought that the hospital environment and the sight of an AIDS suffering parent were too much for these young eyes and minds to handle. The children were rarely adequately prepared for the death of a parent, in fact they seemed to be intentionally insulated, left ignorant of death or these specific causes. When older children were informed as to the AIDS related causes of a parents death, there was little opportunity for them to discuss it with anyone, especially peers because of the stigma associated with the disease or the antisocial life-styles led by the deceased parent.

For a few children, this would not be the only parent or relative to struggle with or die with the disease. In some cases this meant that the child became a ward of the state in the worst case or a guardian of another relative, usually a grand parent. The long term implications of such abandonment are unclear.

The population's disclosure of sexual preference was somewhat limited and at times restrictive. Just 10 (6%) members of the total sample described themselves as homosexual (4 Latino and 6 Black men). Half of this group openly discussed their homosexuality. They appeared to be relatively comfortable and somewhat proud of this identity. The other half was less at ease with disclosure. Only after several interviews, when they began to trust me, they were able to speak freely about the issue.

Despite their sexual preference and the particular relevance that has for AIDS, this group tended to attribute their HIV+ status or AIDS condition to intravenous drug use. Family ties among the group varied.

Four of the gay respondents indicated some form of family or significant other support. Six respondents claimed no such support. Similarly, six of the respondents had housing in the community, living alone or with friends or family. Four reported being homeless.

Unlike any other sub-group within this ethnography, gay men were more likely to have friends involved in their health care process. This gave the hospital staff something else to talk about! More open-minded staff welcomed the presence of significant others in supporting and caring for patients. Others, impaired by their own prejudice, ridiculed such a network and presented obstacles to its effective functioning.

Those gay men without family or friend support made special mention of the fact that their friends or lovers had abandoned them. They felt this was because some gay men did not want to be reminded of their own possible exposure or risk. The ethnic minority members of this study had not been reached by the broader Gay community's AIDS education programs. They speculated that the message and support mechanisms were intended for white men and thus, they didn't hear the warnings or were not invited to take advantage of the support systems.

Like the IVDU AIDS patients, gay AIDS patients were seen by most of the hospital staff as responsible for their condition. More than this they were perceived and treated as moral degenerates, something less than real men or as traitors to their gender. I heard staff members refer to these patients in prejudicial terms such as "anti-man,", queer or "butterfly."

The so-called bisexuals had the most difficulty discussing their sexual histories. Most of those who made a special point of characterizing themselves as the "top man" (during the sex act) or aggressor. There was often a history of exchanging sex for drugs or money. They did not consider their same sex behavior as really homosexual, ".. I just stood there and let some fag blow me." So, during the early risk assessment interviews these men omitted or attempted to dismiss their same sex experiences. About half of the gay or bisexual Latino or Black men who identified themselves as such were open and indeed proud of their orientation. The other half of the Latino and Black men who I would later come to label as gay or bisexual resisted, vehemently such a characterization. To uncover the information, I stopped asking the respondents to identify themselves as Gay or bisexual, and asked only if they had ever had sex with other men.

Existing literature confirms the sensitive issue that homosexuality represents within the Hispanic culture. "Bisexual behavior among men within the traditional Latin American culture is not always an expression of sexual identity; it is often the result of culturally polarized perceptions of masculinity and femininity... many heterosexual Latino men engage in same sex activities with homosexuals... they are often convinced that they are not having sex with other men, at least not with men who conform to the definition of M-A-N as they would use to describe themselves. Thus, same sex practice in the Latin culture are often numerous, anonymous and shrouded in an atmosphere of denial that the invention of a "third sex" allows." [De La Vega, 1989].

The most vulnerable of this subgroup were the minors (less than 21 years old), recent immigrants, runaways and/or prostitutes. They were aware that their lovers and roommates put them at risk of HIV infection by an insistence on unsafe sex or disregard for safe sex practices. But, they felt powerless to protect themselves because money, housing or even citizenship depended upon their cooperation with this or these persons.

EDUCATION

The American public is informed and educated about health issue using a number of vehicles including audio and visual media, newspapers and magazines, specialty pamphlets, direct mailings and the school systems. The language and style of such communication is geared to reach the broadest number of citizens, mainstream America. Thus, social and economic sub groups are not considered in the design and distribution of such materials. It is not surprising that these groups do not react or respond in great numbers to such messages, no matter how important.

The interviews conducted during this study suggest that the underclass receives health education principally, by way of mouth. Many of the patients in this ethnography learned of AIDS through community contacts and friends. Community based health outreach programs and clinics play an integral part in that communication channel. The article <u>How Black and Latino Community Organizations Respond To The AIDS Epidemic</u> states:

> "...Blacks and Latinos have a long tradition of using community organizations to address social problems... In communities that are often economically disadvantaged these groups are a critical resource for progress. In New York City, for example the Citizen's Committee of NYC estimates that more than 7,000 volunteer neighborhood groups are organized in minority communities. Many are addressing survival issues such as housing, crime, drug abuse, teen pregnancy and access to health care... Thus, one potential control strategy in Black and Latino neighborhoods is the integration of AIDS prevention activities into existing work of community based organizations...
>
> ...the community organization's credibility with their constituents, knowledge of the relevant channels of communication and their familiarity with cultural values and beliefs equip them to play a significant role in stopping the further spread of this epidemic." (Freudenberg, Lee & Silver, 1989).

A disturbing similarity between this epidemic and most others is the disproportionate effect on the poor. Because education is critical to controlling the spread of HIV and AIDS, the ability to reach across class boundaries is vital. Yet, those who must design and provide this education sometimes have little knowledge of the culture or conditions of the poorest people.

> "Differences of languages, values, and life-style can make effective collaboration and communication difficult." (Freudenberg, Lee & Silver, 1989).

> "Complicating these factors is the additional element of stigmatization, the phenomenon of marking individuals or groups as warranting exclusion from human society. In its sociological meaning, stigma is the set of ideas, beliefs and judgments that the dominant group in society holds about another group that it has selected as deserving scorn or blame. "These beliefs are not merely negative; often members of the stigmatized group are characterized as dangerous or as deserving of punishment for some vague offense or moral impropriety, a pattern of thought that has led throughout human history to the blaming and persecuting of minorities as the cause of plagues or scourges... "the HIV epidemic has led to stigmatization since its beginning. The fact that the disease has been largely confined to male homosexuals and IV drug users has made stigmatization almost inevitable, for these groups were already the object of some degree of deprecating judgement that constitute this phenomenon." (<u>Aids Sexual Behavior and Intravenous Drug Use</u>, National Research Council, National Academy Press, Washington, D.C., p. 26)

> "Fortunately, even though stigmatization has occurred, the public thus far has repudiated the worst for of stigmatization punishment; calls for quarantining those infected with HIV have been rejected, and some protections for ensuring confidentiality have been erected in areas of antibody testing. The role of the health professional is in part to dispel myths or false notions about illnesses, medical conditions, transmission, contagion.

> The white, Gay male community in this nation has from the beginning been featured prominently in the AIDS epidemic. The first "victims" were Gay white males. The country's first grass roots response to AIDS in terms of epidemiological education, political lobbying, fund-raising, public relations, treatment protocol education came from within this subculture. The Gay Men's Health Crisis Center and similar organizations have become models for such community based outreach in the face of this health crisis." (<u>Aids Sexual Behavior and Intravenous Drug Use</u>, National Research Council, National Academy Press, Washington, D.C., p. 27)

To a certain extent, gay, ethnic minority males who traveled in the same social circles as white males benefited from the efforts of groups such as GMHC. But, in general, people of color who are becoming the bulk of AIDS casualties lack the social, political and economic resources to insulate themselves from the epidemic's effects. AIDS is yet another issue magnifying the deficits of a community already suffering from second class citizenship.

> "Of the more than 24,600 known cases of AIDS in this city (New York) since 1981, nearly 15,000 of those with the disease were black or Hispanic as of January, 1990. Eighty five percent of the children with the disease are black or Hispanic. Of the known deaths from AIDS, as of December 8, 1989, 5,043 have been white; 4,821 have been black; and 3,721 have been Hispanic. Projections indicate that by 1993, new AIDS cases involving whites will have decreased, but there will be an increase in the case load of blacks and Hispanics. Indeed, by 1993, it is expected that 73% of the new cases in the city will

> be diagnosed in minority men and women." (VILLAGE VOICE, Hentoff, 1990).

At the onset of the epidemic, the education programs were developed by and for white, gay males. Despite the fact that the AIDS demographic profile began to change in 1985, it is only very recently that education programs have been targeted towards the ethnic minority population. Even so, very few of those programs are developed by ethnic minority professionals. The significance of this fact can not be minimized. The contrast in the education, social and economic backgrounds of Gay white males and ethnic minority persons calls for very different approaches to education. Comprehension of technical medical information is certainly one issue but, the cultural significance of "safe sex" issues, condom use, bisexuality, homosexuality and drug use are also important.

Several writers have noted several obstacles to AIDS prevention by community based organizations including the lack of resources (space, equipment, personnel and money), inadequate day care facilities and the work for which the organization was commissioned consumes all its resources. How could they possibly manage to providing comprehensive AIDS education and services. Authors are saying that community base organizations are already experiencing a lack of resources and are overwhelmed by their existing mission. How could they possibly now move to provide comprehensive AIDS education and services?

> "Many of the constituencies they serve are also overwhelmed by other problems: "Outreach into the community where there are no human services at all desperately needs to be done. And you have to do it before you expect people to care about AIDS. AIDS is one more thing, part of a whole lot of other things which can go, which are going wrong." Similarly, "... organizations hesitate to become involved in AIDS prevention for fear of arousing political opposition... This fear of political opposition needs to be distinguished from the moral objection that other groups may raise to certain aspects of AIDS prevention." (Freudenberg, Lee & Silver, 1989)

These points are confirmed in the article: AIDS, Sexual Behavior and Intravenous Drug Use, National Research Council, National Academy Press, Washington, DC, 1989.:

> "AIDS education efforts provide a number of examples in which potentially effective prevention activities have become entangled in social conflicts that cause delays in their implementation or weakening of their message. Specific controversies have involved restrictions on the use of explicit language in educational material, conflict between providing scientific information or promoting particular moral values in AIDS prevention messages and prohibitions against condom advertising on network television..." (National Research Council, p. 26).

> "Advocating the use of condoms would offend some segments of the community and turn them against us... Another fear, that of stigmatization, kept some groups from active involvement in AIDS prevention. The leader of a group serving recent immigrants noted that he was concerned that there will be a scapegoating of immigrants because of AIDS." (Freudenberg, Lee & Silver, 1989).

The authors noted that:

> "...While our respondents were concerned about the larger issues that are frequently cited as barriers to AIDS education in minority communities; racism, homophobia, sexism, certain cultural or religious issues, their immediate problems were more prosaic." (Freudenberg, Lee & Silver, 1989).

The authors also found that:

> "Many community based organizations have already defined a role for themselves in AIDS prevention. Those groups with previous experience in a variety of issues and specifically those with experience related to drug abuse and sexuality are most likely to become involved in AIDS education. Some neighborhood groups may need help before they are able to become involved in sexuality or drug related issues that challenge the religious or cultural values of the constituents they serve. AIDS related organizations seeking to involve community based organizations can not assume that these groups are ready to make AIDS a priority with out outside support. Neighborhood groups even when they understand the threat posed by the epidemic need training, administrative and staff support as well as financial resources." (Freudenberg, Lee & Silver, 1989).

In my opinion, public officials looking for how to best allocate funds for black and Latino community-based prevention initiatives must look for institutions that have not only the technical expertise in medical aspects of AIDS but also credibility and the trust of the community. Yet,

> "If someone has the wherewithal to get some grant money, they should know that any AIDS program should be one component of the larger program that provides some of the other things the community needs, the concrete services needed. Holistic, multisectoral approaches are needed." (Freudenberg, Lee & Silver, 1989).

The current method of reaching the underclass is ineffective in conveying the risk of AIDS infection and convincing these people that they are vulnerable by their acts of commission or omission. I interviewed too many individuals who did not or still, do not believe that they are at risk for AIDS because they are not homosexual or do not "shoot" drugs. In particular the women were under the misconception that people who have AIDS must "look" sick or been obviously, stereotypically homosexual. Even though some participants of the study had an awareness or some information about the disease, their knowledge fell short especially in the area of co-factors which may influence the progression of the disease or types of treatments available. Unlike that which the adult, white, Gay male population became circa

1984, the underclass population is passive in its search and use of information or resources with which to deal with the AIDS epidemic. They are totally dependent upon the dominant society for whatever information or services are available with which to deal with this crisis.

Community based clinics and neighborhood hospitals are the major vehicles through which the underclass receives medical care. Most of the sample had some experience with local clinics but 94% of the patient population received most of their medical care in hospital emergency rooms.

Health Care For the Urban Poor

The AIDS education efforts in the minority community highlights the poor health status of ethnic minority Americans, especially African Americans. From an article in AMERICAN HEALTH, November 1990:
"... It's been a stark reality of American life for centuries; Black people suffer from illness more, get poorer medical care and die younger that white people do..." From an article in the LANCET, spring 1990 commented that the crisis in Black health care has

become "...a scandal of such long standing that it has lost the power to shock." From an article in THE NEW ENGLAND JOURNAL OF MEDICINE, New York, January 18, 1989: "...that mortality rates in central Harlem are so high, men there are less likely to reach age 65, than men in Bangladesh. Death rates for Harlem residents under 65 are nearly triple the rates for whites of the same age, due mostly to cardiovascular disease, cirrhosis, homicide and cancer. Inner city areas such as Harlem are analogous to natural disaster areas."

One recent study in JAMA found that about one third of the racial difference in death rates for middle aged adults could be attributed to six well established risk factors: high blood pressure, high cholesterol, obesity, diabetes, smoking (cigarettes) and drinking (alcohol). These are factors largely determined by life-style, with some input from genetics. Some Blacks may have a genetic predisposition towards diabetes and hypertension." That's only one third of the explanation however. Another third is due to low income and the final portion is "unexplained."

That "unexplained" factor may be the effects of racism. Some psychologists suggest that the epidemic of Black hypertension is partly or wholly due to the stress of living in a society where race is still a major barrier to achievement and healthy living. Beyond all the speculation there is one clear fixable dimension of American medicine's color gap: the lack of good medical care for all citizens, regardless of race, creed, color, financial status, sexual orientation, religion or national origin. At every socio-economic level, Black Americans get medical care inferior to that available to whites."

Dr. Harold Freeman, Director of Surgery at Harlem Hospital (New York) and co-author of the NEJM, Harlem study sums up the situation: "About one third of the deaths that occur in Black Americans would not occur if Black Americans had the same health status as white Americans..."

From an article in THE NEW ENGLAND JOURNAL OF MEDICINE, Washington, D.C., March 22 1989:

> "...While the life expectancy of whites is rising, that of Black men is falling says the Department of Health and Human Services. Based on 1987 statistics, whites can now expect to live 75.5 years; Blacks

> only 69.5 years and Black men only 65.1 years. The infant mortality rate for Blacks is now nearly 18 per 1,000 live births, just over twice the rate for whites. One reason is that only 61% of pregnant Black women receive prenatal care in the first trimester, vs. 79% of white women... Nearly one third of all people with AIDS, and more than half young children with AIDS are Black."

From an article in THE NEW ENGLAND JOURNAL OF MEDICINE, Chicago, May 2, 1989:

> "...The Council on Ethical and Judicial Affairs of the American Medical Association [reports] that a range of studies and statistics indicate that Blacks are more likely to require health care but, less likely to receive health care services. The gap shows up especially in cardiology and cardiac surgery, kidney transplant, internal medicine and obstetrics... These disparities in treatment ... are unjustifiable and must be eliminated."

From an article in THE NEW ENGLAND JOURNAL OF MEDICINE, Atlanta, March 12 1990:

> "...The number of low weight babies, after dropping off steadily for 10 years is starting to rise, according to the Center for Disease Control. Low birth weight, a major cause of infant mortality and birth defects, is more than twice as common among Blacks as whites; at last count, 13% of Black infants were born under 5.5 pounds, and is rising faster in the Black population.
>
> What's killing the Black population in such numbers? The hazards of drugs and violence take an awful toll on the young. In New York and New Jersey, AIDS is now the leading cause of death for Black women aged 15 to 44 while the chief killer of young Black men nationwide is gunfire... "But, these killers are more than matched by the fact that cancer, cardiovascular disease, diabetes and just about

> every other disease you can think of hits Blacks much harder that whites."

In an article which appeared in the Philadelphia Inquirer, October 31, 1990; C. Everett Koop, former U.S. Surgeon General stated:

> "...bring back the whipping post for doctors who advocate the idea of compassion towards patients but then treat the poor with disrespect... Medical professionals reprimand colleagues who treat any patient, wealthy or poor, without respect. Until we begin to police ourselves we are never going to do it."

But, during the ethnography, I sensed the existence of a closed society as exemplified, maintained and perpetuated by the doctors. The closed ranks at time to support one another. That places real limitations on Dr. Koop's idea that medical professionals should police one another in the less than dignified treatment of poor or ethnic minority patients. Further, the fact that physicians speak a unique, highly technical jargon if not language, serves to further insulate them from the general public. Their is an image cultivated by the years of schooling, controlled access (certification) to the profession and their specialized knowledge which serves again to segregate them from and elevate them above the general public. Of course then, they are furthest above and beyond the underclass.

Many of the patients in the study group lived in poverty. They lacked regular, gainful employment, permanent housing, proper nutrition, finances, family and community support. They experienced violence, crime and other forms of physical or psychological abuse. Drug abuse was a part of the fabric of their lives. Not all were direct participants in the drug "scene" but many were users. There was also significant alcoholism. Mental illness to one extent or another was not uncommon.

As a group, this population lacked control of their lives. They responded to changes in the economic or social environment. There was little knowledge as to how to plan for the future and no discipline as to how to make personal goals and objectives a reality. They were not empowered to survive, much less achieve or succeed in this life. There is no awareness of the community resources or their personal rights as American citizens.

In the same article; C. Everett Koop, former U.S. Surgeon General stated:

> "....Under [the American capitalist] system insurance companies insure those who need it least while

> denying it to the neediest. That system has left about 37 Million Americans with no health insurance. Insurance for public health in this country often operates like a shell game. It is a system in which a well intentioned Medicare program has become a disappointment that doesn't work anymore. Medicaid is a 'fraud' that excludes too many poor people with unrealistic poverty gaps... Americans should change their traditional perceptions of health care as a 'patch up' system; one that is activated only when the person becomes sick. Instead, the nation must begin to realize the importance of practicing health prevention and promotion... If you could find a way to make preventive medicine more glamorous, we could win this battle."

This point highlighted by the fact that too many members of the study group had not seen a doctor for a check up in years, since childhood. Many arrived in the hospital via ER.

At the start of this research the use of prophylaxis and neoplasms in the treatment of HIV infection and opportunistic AIDS infections was limited or nonexistent. Two and a half years later, the use of prophylaxis, specifically, antiretroviral drugs such as AZT (Zidouvdine), Pentamidine (Nebupent and Pentam) and Alpha Interferon are made available to this patient group. During the first year (1988) of this observation, intravenous drug users were given Bacterium or other antibiotics, while few received AZT. None of the patients were included in on going clinical trials.

Currently, patients who test HIV positive are referred for clinical follow up. This refers to patient scheduling with doctors for further examination and the possible initiation of treatment protocols. If their T-cell count drops below 200 they are prescribed AZT and other prophylaxis type treatments. The less connected to family or community are not likely to remain in compliance with the treatment process, because there is less reinforcement and support during this trying and stressful process.

An internal publication dated Autumn 1990, noted that the facility spends $5 Million annually for AIDS related care to patients. This amount includes the cost of doctors, nurses, infection control specialists, social workers, nutritionists, administrators and other support staff. This figure does not include the cost of supplies and medicine. "...At any given point in time [Oremus Hospital] serves 2,500 HIV infected patients. Each month 150- 200 persons are tested for HIV exposure... there are on average 65 HIV-infected patients in [this] hospital's beds at any time, and 10- 15 new patients begin treatment each week..."

The hospital claims the development of a "primary [AIDS] care model" which offers an interdisciplinary approach to treatment. Despite this coordinated orientation, it is my observation that serious gaps remain in the provision of service and treatment.

The health care workers do not always cooperate with one another. There are stringent stratification barriers limiting communication among the various care givers. In general the staff has a stigmatized perception of these patients. They consciously or subconsciously deal with the issues of counter transference. Such issues were described by Joan Dunkel and Shellie Hatfield in their articles which developed in their work among AIDS patients, specifically, fear of the unknown, of homosexuality, of contagion, of death and dying; the denial of helplessness, anger and the need for professional omnipotence. I observed a certain amount of professional lethargy among staff workers who had held their jobs for so long, had seen so much and were so close to retirement that they went about their duties like automatons; doing only what was required to stay employed or as little as possible. It was not uncommon to see these workers avoid the less appealing duties until their shift ended and other co-worker became responsible for changing bed linens, cleaning patients, etc.

> "Estimates of the number of persons who already have been exposed range from 1 to 2 Million. About 10 to 40% will develop full blown AIDS. Approximately three quarters of the diagnosed cases die within two years of the initial diagnosis (Curran, Morgan and Hardy, 1985). While there is extensive research in developing a vaccine the rate of genetic change in the virus makes development of a vaccine difficult (Wong, Stall, Shaw & Hann, 1985).

DEATH

The primary causes of death among the urban poor include: accidents, cancer, heart disease, cirrhosis and other liver disease, stroke, Diabetes, kidney failure and homicide. Drugs, alcohol abuse and random violence are important contributing factors. "In New York and New Jersey, AIDS is now a leading cause of death for Black women aged 15 to 44 years, and males aged 19 to 42 years; while the chief killer of young Black men is homicide." [AMERICAN HEALTH, 1990]. In conducting this research I noted that 87 (53%) of the total (N=164) population died in the hospital. The mean age distribution at the time of death for males was X= 34.4 years. The mean age of the population which expired during the research was X= 35.8 years.

The impact of such an AIDS death on the underclass community is varied. Most died in a more or less anonymous state. They were unattended by family or friends. It appeared that no one would mourn them or miss them. So what could the impact be on the community? The vast majority of the unattended were not claimed after death. Their bodies were held in the hospital morgue until they were given a "funeral" at the city's expense and a burial in "potters field."

For those whose family knew of their illness but left them unattended and for those who received some measure of attention by family or friends, there was a strange silence surrounding their AIDS related illness and death. The time between diagnosis and death was so short, that the family had little time to cope with the disappointment, sorrow or anger let alone the economic, social, psychological problems attending the illness and demise. The family and friends expressed a sense of helplessness. In many instances this feeling was not new, they felt it in failing to help the deceased cope with drug or alcohol dependency, joblessness, or a perceived sexual deviancy. A few chose to stay away toward the "end" to avoid facing their emotions and the reality of death.

When the family was close to the patient during illness, hospitalization and at the time of death, there were difficult expressions of grief, often a strong sense of guilt and the burden of losing a loved one to a less than respected illness. Many family members and or friends expressed a concern that this would happen to them or other family members because of possible exposure to the illness. It was not uncommon to hear that other family members or friends had died from AIDS related illnesses. Now, their grief and worry is compounded.

It was not uncommon for the dead patients family or friends to express anger now. They were mad that the deceased "brought this on the family or exposed me to this." "...its been hard dealing with the fact that he's a homosexual... or drug addict; but now we have to deal with this AIDS thing!" As family or friends they felt embarrassed and humiliated; expressing a wish that "the whole thing be over" or "... he's better off dead, there's no future for him anyway." In waiting for "it to be over" there was silence and isolation.

> "Often people in these groups hide their activity and behavior from family, loved ones, employers and other associates. This can no longer be done after an AIDS diagnosis. Family members and loved ones often share fears similar to those of the health care providers. Loved ones... often express "survivors guilt." (Faltz & Madover, p. 152):

Surviving children were probably least equipped to cope with the death. If possible, they were now to live with other relatives, usually grand parents. There is no way to forecast the long term implications of the patients death on relatives or friends.

Death does not discriminate as to age, gender, race, religion or economic status. But, upperclass Americans, even those dying of AIDS related illnesses, go through the process with varying degrees of assistance and support from health care professionals, medical and psychological support resources, family, friends and the broader community. Even with the knowledge that death is near they continue to deal with life and living, even if in a restricted manner. They have the opportunity to resolve old conflicts, "tie up loose ends" and make the necessary preparations for those who will survive after they are dead. After death the community comes together in a public way to bid farewell, to eulogize, and to remember their contributions.

The underclass patient with AIDS must deal with death and dying in near isolation and ignorance. They are totally dependent on the care and goodwill of the dominant society's institutions- hospitals, public assistance organizations and the like. But, there can be no human bonding here. I witnessed these patients dying in silence and alone. The last human beings on earth to be with them, the hospital workers, were rather detached. There was little touching, comforting even grooming. Few staff members have the inclination or time to help the patient cope with the eventuality, and the inevitability of death. With no one to talk to, their fears went unchecked, the "loose ends" were left untied. There was no concern about Last Wills and Testaments. What did they have to leave anyone? Their was no one to give them hope, no one to make them feel brave or worthy. The only affirmance available, strength on which they could draw, some might say the only real power, was God. Even the agnostics, put their lives "in His hands... turn to the Lord, it's up to Him." After death, they are unceremoniously discarded, as they were in life.

Appendix 1

Interviewing Tool

I. <u>Identification</u>: S.S.#______________ Adm. Date:________

Service:________ Address:______________________________

<u>Marital Status</u>: ( )M ( )Sep. ( )W ( ) Single ( ) Divorced

<u>Sex</u>: ( )M ( )F Citizen: ( ) Yes ( )No ( ) Undocumented

Telephone # ______________ <u>Education</u>: ( )Elem. ( ) H.S.

( ) College Age:______ D.O.B.________ <u>Birth Place</u>:______

Ethnicity:() W ( ) B ( ) Hisp ( ) P.R. ( ) Oriental

( ) Haitian ( ) Other

II. <u>Current Living Situation</u> (Check One)

( ) Undomiciled ( ) Alone ( ) Family ( ) Friend
( ) Facility (Specify:)________________
Can Return After Discharge ( ) Yes ( ) No

III. <u>Financial Status</u> ( ) N.A.

Employed ( ) Yes ( ) No
Employer: ______________
Occupation:____________

Telephone #:___________
D.S.S. ( ) # __________
S.S.() #______________
S.S.I.()#____________
OASDI ( ) #____________
N.Y.S. Disability ( ) ___
Unemployment ( ) ________
Compensation ( )_________

<u>Insurance Coverage</u> ( ) N.A.

Medicaid ( ) #______________
Pending ( )
Medicaid () Pt. A ( )
B ( ) #_______________
Pending ( )
No Fault # _______________
Workmen's Compensation #___
Private Insurer#___________
COMMENT: _________________
____
____
____

IV. <u>Social Support System</u>: (Primary Person)
Name:_________________ Age: _____ Relationship:
Address:______________ Tel. #________________

Can Assist Patient, If Need be, After Discharge ()Yes ( )No ( ) N.A

V. Psychiatric History ( ) N.A.
In-pt. ( ) Out-pt. ( ) Day Treatment
Diagnosis (if Known) ________________
Medication (If Known) _______________
Comments: ____

VI. Drug/Alcohol History ( ) NA
Age at onset _____ Drug Used ______ How Administered ______
Quantity ____________ How Often ______________________
Comments: ____

VII. Drug/Alcohol History ( ) N.A.
Age at onset _____ Drug Used ____ How Administered ______
Quantity _____________ How Often _____________________
Comments: ____

VIII. Drug/Alcohol Rehabilitation History ( ) N.A.
Facility Name: ______________ Duration of Treatment:
Address: ________________ ______________________
Comments: ____

IX. Presenting Problems Needs:

____

X. Psycho-Social Assessment (Include patient's response to present illness)

____

XI. Counseling Goals: (Complete if applicable) ( ) N.A.

____

____

Appendix 2

During unstructured interviews the following questions are among those covered:

1. What was known about AIDS prior to patient's diagnosis?
2. Where and how is such information obtained?
3. What prompted their medical treatment.
4. What was their understanding of the physical difficulties which resulted in hospitalization?
5. Is health assessment and/or medical treatment obtained in their neighborhood?
6. What are the present thoughts concerning diagnosis and/or subsequent illnesses.
7. What role in the treatment process, if any, is played by family members, friends or significant others?
8. What is their present knowledge about HIV infection, ARC, or AIDS?

Appendix 3

Case Histories

Canute: ...is a 29 year old Hispanic male diagnosed with AIDS, Toxoplosmosis, Herpes, TB, Anemia, Seizure Disorder and Oral Candidiasis. He has spent the last year in the hospital.

On the afternoon we met, "Canute" lay in bed, an intravenous dextrose solution pumps into his right arm. His matted, long, black hair is parted in the middle. It seems he had not bathed recently, as his arms and legs are blackened. The tattoo on his upper left arm reads "Perdon Madre." Is this a plea for forgiveness from his natural mother, the Blessed Virgin Mother or simply art?

He has not seen his four children, ages 5, 7, 8 and 9 in five years- a result estrangement from his wife prompted when he was caught in bed with her best friend. This is the only family Canute has known. At age 17 he was abandoned by his parents and no extended family members would care for him. He has since learned that his parents died in the early 1970s and a brother died in 1979.

He traces exposure to the virus to intravenous drug use and talks openly about sharing needles in a 'shooting gallery'. The drug use began with his abandonment. He has lived on the streets since his teens. When first hospitalized for what now seems to be an HIV related illnesses, the Human Resources Administration (HRA) placed him in a SRO (single room occupancy) hotel. He feels lonely there and dislikes the hotel. "I'm by myself and the home attendants won't come to the hotel..." When possible he leaves the hotel, returning if absolutely necessary. Now, he's concerned that a lengthy hospitalization may have led the HRA, Division of AIDS Services caseworker to halt the rent payments which would mean eviction.

Canute has a dubious understanding of the medical diagnosis. Most of the time he is in a state of denial. By his definition, he suffers from TB, AIDS virus and dimentia. The treatment process is confusing to him. "... I don't understand why I'm taking so much medication... They started telling all us drug people [that] we got it [AIDS]... I don't believe it!" "If I take it seriously, I worry... I worry about dying." [What do you think of dying?...] "Nothing, I'm just not here anymore."

The ward in which Canute is hospitalized, serves many terminally ill patients. Routinely each week, four to five of the 36 die. The death process is plainly visible to patients like Canute.

Despite his discomfort and boredom, Canute is reluctant to leave the hospital because that would mean living on the streets and the return to drug dealing and usage. "... I don't want to leave the hospital... When I'm alone, I know I will go back to doing drugs... I want to be in a place where people understand me... Nobody listens to me on the streets... I'm by myself... I ain't got nobody to turn to, my [extended] family don't care, they got their problems... What makes me go back to drugs is, if they don't care, why should I? ...I'm going to die sooner or later, what's my choice?"

There is no family support for Canute. At times the hospital personnel is accommodating and supportive, even generous. Some bring him candy, loose change or simply visit during their shifts. When Canute becomes 'difficult' and refuses to take medication or instigates arguments, they leave him alone in his room. Much of the hospital staff really does not pay much attention to Canute. They feel he's uncooperative; refusing to take his medication and disturbing the other patients.

Over the past nine months, Canute has been hospitalized three times. Canute endured several hospitalizations. He had few visitors. To help him deal with the loneliness, we attempt to arrange for his Aunt and 9 year old daughter to visit the hospital. He has not seen either of them for nearly a year. On the visitation dates, he showers and neatens the room. But, time after time, they fail to arrive. He is always left waiting.

During telephone conversations with his Aunt, I learn that she knows little about his condition. She expresses sympathy but remains unsupportive because of his past unpredictable behavior. Besides, she has not been well enough to visit "...and the hospital is too depressing for a little girl." Eventually, I am able to arrange telephone contact with his daughter. Canute is happy to speak with her and tells her how much she is loved, promising to buy her many things after the discharge. She's asked not to believe the things her Aunt may have told her about him and promises that they will live together when he is feeling better. He can not understand why they do not visit.

While he may now truly miss his daughter, somehow he did not visit her during previous discharges. He would go directly to the old neighborhood; meet old friends and renew old street socialization behaviors.

"You know I've been calling my Aunt's house. Sometimes they let me speak with my daughter. They're still surprised I'm alive... It's not fair. I'm the only nephew that would help her. Damn, I know I fucked up, but damn I'm still a person. Sometimes I wish I were dead. You know Ayala, while I've been in here, I used to rap to the girls. But, I've been in here so long that now I can't communicate with them. It's fucked up." [I ask do you want to have sex?] "Yes, sometimes. [I just want to]... murir jarto de crica [die after I get enough pussy]."

Coincidentally, his wife entered the hospital in labor. She heard that he was here and came to visit. They have a long discussion and he tells her that he has AIDS. She responds, not to worry, a cure will be found. Her visit made him wish to see his children again, eventhough two are in foster care. "...I think she's attractive and I would like to be with her and the children again... I wonder if we can make it again, maybe I'll give it [drugs] up..."

Somehow, he gets word out to his friends that he's in the hospital. One of them visits from time to time. At least they'll provide some emotional support during the hospitalization.

A few close friends have died from HIV related illnesses three of them in this hospital. "That hurt me... I used to [come here to] feed him... tell him that he was not going to die... I think its bad... I don't want to get to that moment... You know, die... I think that the hospital can't do nothing." Canute does not think that the doctors told his friend the truth about the illness. "...I feel sad and say it this way, we are all going to die, but let a man prove himself. Some of the people ignore us. The nurses, doctors; don't care. Let us die like human beings. Listen to [us], once in awhile. You see [we] feel lonely, bored, depressed. I think its important that people listen to us... I sometimes think of cutting up [suicide]... When I was 18 I jumped out of a second story window... because I was depressed." Since he's been in the hospital he's had those feelings again. "...What am I going to do?"

My friend Rable is my street friend. I worry about him. He's real bad... You know he's the only one left. My last friend from the community was hospitalized in this same place, he died... That hurt, I use to feed him... tell him he was not going to die, well he died three days ago." He had three other friends on this floor, one of whom was a dealer.

Being in the hospital, especially when restrained [to the bed] reminds him of prison. Canute spent two years in jail for burglary. "It wasn't so bad... fun at times. I had someone to talk to... [He didn't have sex in jail] but, there's more drugs in there than on the street... [sometimes brought in by relatives or guards]... They charge $20. for a dime [$10.] bag... you just can't walk out of here... Its like prison."

He sometimes seemed unconcerned about death. "Everybody has to go sometimes. At least nobody killed me, nobody hurt me." But, he admits being afraid. "You never know when its going to strike, you know sickness and death." [How do you cope with the fear?] "...I take drugs, sometimes I spend time with the other patients."

I ask him to tell me what he thinks about. "When we talk about all this death, I think its bad. I don't want to get to that moment, you know die. I think if the hospital can't do nothing, they shouldn't supe me up [make him believe he will recover].

He does not discuss his feeling about death with the doctors. "They don't care, they just act like they're treating me. They give me all these pills, then come into my room and say 'Canute, how you doing? Sometimes, they don't wait for an answer. They treat me like a bum."

They need to tell the truth... I don't hardly leave my room anymore, Most of my friends left or died. That's why you see me laying down. I feel sad. Some of the people [staff] in here ignore us. The doctors, nurses don't really care. At least they should let us die like human beings. They should listen to us once in awhile, that's all. That's all my friends wanted. You feel lonely in here, it's damn boring and depressing in here. I think it's important that people listen to us. ...Sometimes I'm depressed, when you come in you take me out of a spot.. You know that helps me out a lot. You're okay, you listen to me."

"Sometime, I think of 'cutting up,' you know like cutting myself or some stupid shit. He remembers attempting suicide when he was eighteen. During previous discharges he has attempted suicide by way of overdose and was readmitted when opportunistic infections left him unable to care for himself.

During the following month, another friend of Canute's enters the hospital. George A. did not remain long. He died within four days. This left Canute more depressed than ever. "I used to hang out with George... drugs, rob, you name it, I considered him [to be my] brother... He did more for me than what my family did... That's my fifth [friend] to die in here. "...They're not dying the right way,... the family only comes when they're dead. If you really sick like we are, you need somebody there to talk to you, to hear you!

George used to take care of me when I was sick, you know we sometimes went to the shelter together. I just hate seeing a guy waste like that up here. I hate to see that shit, why do they have to die in here? That hurts me.

George used to tell me that his family never came to see him. He would say... I'm suffering in here alone... What he did was past, the family should at least have come to see him." I feel like this is a dream, [he cries]... wherever he [George A.] is, God bless him."

"When is my day going to come? ...I don't know when I'm going to die... It's funny you know when you're gonna be born, but you don't know when you're gonna die."

"They're all going to leave me, I can't blame nobody, when its your time, its your time! ... [but], I hope it's later, I don't want to die here. This [hospital] is a motherfucker, these people leave you in your room and shit, they don't pay attention to you. Yeah, they bring the medication and food, but that's it..." "After I die, I don't care what happens."

Don't get me wrong, I have had ideas. But, I don't care no more. I don't want to live. I've lived my life. I'm exhausted. I'm bored, disgusted. I feel like giving up." This train of dialogue prompts me to refer the case to an in-house psychiatrist. Upon consultation with the attending physician, the psychiatrist prescribes Cojenton and Haldol (to control halucination and depression).

Canute has his 30th birthday in the hospital. He's been here for about one year now. He's become withdrawn, noticeably more depressed and uncooperative. He is left alone in the room, seeing people only when medication is dispensed.

"I just want to know when I'm going to die; just let me know, so at least I can tell my son and daughter, at least speak with them. I don't want to suffer... I ask God to take me, take me, let me know when. I don't want to suffer. I'm not scared. I'm tired of suffering... just get it over with. If I could find a way I would do it myself. I'm tired of this, wasting my time, wasting the doctor's time. I'm tired of all this shit."

Canute wants to have his own place to live "...like everybody else. So, lately, I work with HRA to obtain appropriate residence for Canute. There is concern about his self sufficiency. Even Canute in his desperation to leave the hospital, knows the limitations. "I don't know if I can take care of myself but, I'm willing to try. I just want out of this place." He qualifies for placement in a long term medical care facility but the admission process may take up to six months. This angers Canute. He becomes very agitated. The anger is transferred to the nurses.

Sometimes he feels that the doctors are rushing him out of the hospital. "...They say that I have to leave because they need the bed; I'm told to go on Welfare, they'll help me to find a place." Canute's application for assistance rests with HRA, DAS which is unusually slow in this instance. It is proposed that Canute be moved to another hospital, but the alternative is an inpatient facility for the bedridden.

Canute is eligible for SSI (Supplemental Security Insurance) but his dimentia requires discharge to a permanent residence providing 24 hour supervision. A long term medical care facility is the only viable alternative for a patient with Central Nervous System Toxoplosmosis, TB, anemia, seizure disorder, Oral Candidnitis and Herpes 3.

Placement in such a facility requires processing numerous forms which may take at minimum one month to arrange. Interviews are arrange for the requisite case examiners and workers.

Coincidentally, a staff reassignment resulted in new doctors and nurses for Canute. He was angered by this because it meant repeating 'his story' all over again to yet another group of hospital workers.

During a later meeting, a HRA caseworker informs Canute that he has been accepted for admission to a long term care facility. Discharge will be delayed because there are 25 people already on the waiting list. This news is not received well. Canute is visibly upset since this news is received shortly after he learned that another patient and friend died on a respirator this morning. "Everybody is dying! They're all leaving me. All my friends, that's the sixth one. I wish I were dead; instead of taking them. I was worse than them. He's [God] is killing all of them. Only if it were legal, you know the death injection, I would sign for it. I already had my fun. I'm tired of living. I told the psychiatrist, I know I'm going to die sooner or later. You see when I act crazy, they [staff] pay attention to me. You know, I call for the Psychiatrist and they get her right away. I feel that they're testing something on me. The way I look at it, using me as a guinea pig.

Canute is certain that he's going to die soon. "I look good on the outside, but I'm all messed up on the inside. I think the doctors are practicing on me."

Canute believes his state is the result of "...a maldicion [evil spell]. I can't do nothing...work, sex, no se me para [my penis doesn't get hard anymore], I don't have no feelings... I can't do what I used to do."

"The staff don't even weigh me, they just feed me and give me my medication... I just want to know when I'm going to die. Just let me know Ayala, so I can call or see my daughter and son... I'm not scared of dying, I don't give a fuck whether I'm dying or not. I'm angry cause I'm living. You see I'm alive and nobody cares about me since I'm on the way down. I'm tired of being in here. This is like a prison. You can't go outside or do nothing.

We met today so that I could try to arrange a family visit. "Oh today is Sunday." No. I respond it's Saturday. "I think I'm going crazy. I'm forgetting the days I'm living in." The family will not visit. Only a phone conversation can be arranged.

Canute is back on Methadone. "I was talking with the Psychiatrist. I told her about the Methadone. She voted for that. I was worried about taking so many pills, you know the AZT, TB pills, the stuff to calm me down. You know since I'm getting Methadone, they just cut me off the other medication."

It [Methadone] feels good. It's not to get high, just to calm down. I can eat better, move around better. I don't get so depressed. For me, the Meth holds me.

The recent blood sampling worries him. "Am I dying or what? You know I think about some crazy shit. But, the Meth blocks that. I think about doing some crazy shit. If I could grab one of the doctors and hold a knife to them, hold them against their will, I could get out of here. Yeah, grab somebody and take them hostage.... How much of this can I take? How far can I go? I'm getting tired of this. I want to leave before I do something stupid.... I hear voices telling me to do it." Sitting upright on the bed, his hands are shaking and he is rocking his leg. "...there's another person inside of me. They [staff] stop me from doing what I want to do. I believe I'm going crazy. I was going to ask the doctors to tie me up... you don't know what I will do... Do you blame me? I used to go to the sixth floor to see the children, now they don't let me go anywhere... this ain't no prison."

He is not planning to hurt himself yet. But, by his own admission if he were to do so he would "...jump out the window and other crazy shit man. When I get crazy thoughts like this, I go to sleep and relax my mind."

During a walk in the corridor, Canute is administered a 20 milligram Methadone injection. Afterwards, he walked over to a window and starred outside. I thought it prudent to warn the nursing staff of his thought to jump from a window. To paraphrase '...we don't need anything like that today. Good thing he's had his shot... We'll keep an eye on him. If we have to we'll restrain him."

In a few days Canute responds to treatment. As his condition stabilizes, the doctors pressure the HRA caseworker to relocate him. In the meantime, he is transferred from the medical ward to an alternate care unit. Seventy days later he is discharged to a SRO hotel, enrolled in a special outpatient program offering supportive counseling and public financial assistance.

One month later, Canute is readmitted to the hospital. He tells me that he has been doing Cocaine intravenously. He tried to commit suicide. He tried to see his daughter but the family would not trust him to visit. He is despondent and asks to see the Psychiatrist. "... I need medication, but it ain't worth it."

For the next few months, Canute remains in the hospital. His medical and psychological conditions deteriorate. He rests silently in his room, forlorn and withdrawn.

The nurses, in a round about way, try to lift his spirits. He is told that he was doing well but that the present state is a result of his "...messing up." They impose a regimen and strict rules on his behavior. His weakened physical and emotional state eliminate most of his options to resist the new discipline. He fights back with passive aggressive behavior. He and a few patients begin using drugs. Canute does not attempt to deny it, "...what the fuck, why not, just leave me alone. Yeah, I'm using. What's the difference... They ain't doing nothing for me in here. I'll take care of my own pain."

In a short time, Canute's body weakens even further and now he is unable to ambulate. This exacerbated his sense of isolation. He became more withdrawn. By wheelchair I took him to my office in order to telephone his family; if not just to get him out of his room. At first he denied wanting to speak with them. But, he cried when he heard the voice of his ten year old daughter, ".. I love you, daddy." The contact seemed to lift his spirits.

A few days later, he began what would later be called the 'final stages.' He floats in and out of consciousness. There is no one to cut his hair and the beard has grown long and unmanageable. His face is distorted by pain; one eye is nearly closed. He cries incessantly and often yells for help. He had to be restrained.

Over the next few days, he grows weaker. In a barely audible voice, he complains about the pain. It was difficult to watch Canute's slow dissent into death. We sit quietly together for awhile, then he'd ask, "... what do you think is happening?" As I responded, he would close his eyes as if he did not really want to know. The obvious physical decline and pain was not enough to initiate a confrontation of his dying. The fear of death prevented him from talking with me about his feelings. There were few questions or comments about his perceptions.

The routine of the hospital went on all around him seemingly oblivious to his dying. During the last few days I stopped by his darkened, silent room to find him laying in the unlaundered sheets, starring blankly at the ceiling. His face unshaven, hair uncombed and meal trays untouched.

Canute resisted the hospital chaplain's visit because he felt that it was not "... time yet." There is no one to hear his struggle. He is left alone, except at meal and medication time. On March 24, Canute died wearing rosary beads.

Santos: Canute invites me to visit his friend in the next ward- Santos a 28 year old Hispanic who was admitted recently "...through the emergency room; half dead with a high fever." Santos is homeless and an intravenous drug user, hospitalized with TB and PCP-Pneumonia. "The shelter supervisor called an ambulance for me. [But now, I've] lost my bed... If you ain't got no money you ain't got nothing... I don't have no friends..."

Santos has lived on the streets most of his life "... running around like a nut... At first I thought 'fuck it,' people look at you as a germ... I've had people spit on me... I found this place [to live] in Grand Central Station... I panhandle.. get my clothes from the Salvation Army... At Grand Central Station they have showers for $.25; after I finished I was a new man... but, like for how long am I going to do this- for the rest of my life? I can't work.. I've always been sickly."

"I left home when I was young... there were a lot of misunderstandings in our home... I was a good student in high school and then I met this girl.. that's when all the shit started; ...started playing hookey, found a job; stopped going to school. I started using dope-shooting Cocaine for three or four years... I just fell into a crowd... I shared needles... I'm healthy... not weak, my hair ain't falling out. You can look at a person and tell [if they have AIDS]. Thank God I ain't caught no AIDS. The Lord ain't going to let me kick like that... I got luck, it stays with me."

Santos would like to stay in the hospital in order to get stronger. "...stand up on my own to feet... get [back] the little respect I have for myself... Its hard to be a man. Having a dick and balls don't make you a man. A man has to have priorities, be responsible, care for himself and others... that's why I don't deal drugs. I don't want to hurt nobody; when you do that [deal drugs] you don't care about yourself... or your people."

"I use a scum bag the majority of the time; depending on how sexual the woman is... If the bitch is a baldie [hair loss], losing weight, I don't have sex with her... I love myself enough. Some men say, let me get you a needle and fuck the bitch, even if she is dirty. That piece of pussy can wind up taking your life. I'd rather be a virgin."

Miguel: Today Miguel is stable and calm but appears somewhat confused and unaware of his whereabouts. He is a 32 year old Puerto Rican male widower with three children who reside with his mother-in-law. Miguel's wife, an intravenous drug user died of HIV-related illnesses two years ago. He entered Oremus Hospital in June 1988 with a diagnosis of rule-out seizure disorder, drug overdose. Further examination revealed PCP.

He has been staying in a men's shelter on and off during the past four years. When he was not in the shelter he slept on the subway and in the park. During the winter Miguel would sometimes stay in the shelters. There is no means of financial support or medical insurance. Asked when he last was examined by a doctor, he responded "You must be kidding, it was back when I was 17."

He has not seen his six brothers or three sisters for about ten years. Miguel dropped out of school at age 13 and boasts about shooting Heroin for the first time with his brothers at age 12. It was at 17 that he started using Heroin regularly just after his brother committed suicide. "He shot himself in the head in our bedroom." Miguel had to clean it up and still gets emotional when speaking about the blood and brains all over the room. At 16 he started working as a custodian. At 17 he left home because of family violence and his father's alcoholism. He met his future common-law wife Nena around this time. Between the ages of 19 and 22 his three children were born.

Miguel describes their home life as happy. His drug usage declined but was replaced by heavy alcohol consumption. Heroin and speed (amphetamines) were for special occasions. His wife began to use drugs heavily and since she could not care for the children adequately, they sometimes stayed with other family members. Soon thereafter his father was killed by a hit and run driver. Miguel was sent to the hospital in order to identify the body. His mother and another brother died in the same year. The next four years were equally difficult as his wife became more drug dependent and a financial setback resulted in eviction. His children were placed in foster care. Homeless, he became a drug user. In 1986 his wife died of HIV-related illnesses.

Regarding drug use and sex, Miguel comments, "I use cocaine... mainly for sex [and I have primarily] unprotected...My wife used 'crack' cocaine and alcohol. She usually had sex with other men in order to get 'crack'. She was 30 when she died. But, I have sex with crack bitches... I can't use fucking bags... I hate them things... I had sex with men... I've been the aggressor, the dicker. I've always had the shotgun. I've always done the shooting. I'm no homo[sexual], I usually did this sex... so I could get money for my stuff [drugs]. Well, now when I have the feeling...I sometimes jerk-off."

I used to share needles a lot, I would go to my friend's house, about six guys; we would all share needles. I was always the last one to get it... I just wanted to get hit. "...Well, I only have a chipee [minor drug problem], I'm not a junkie...

There are times when I've worked odd jobs... to get a bag of dope... They [U.S. government] should make a law, anyone who has AIDS should be allowed to get high... It doesn't matter anyway."

During my next visit, I found the feeding tube disconnected. Miguel said that it came out yesterday afternoon. This observation prompts a discussion about the care he receives in general. "I'm a junkie, nobody cares... I know how they are, they say, Oh! he's a junkie, let him suffer."

Miguel asked a family member to bring him Nyquil, which he thinks will help since "...the doctor's ain't giving me nothing [for the pain]. I won't let them put the intravenous in my neck. I won't let the nurse take my blood... she's trying to collapse my veins." "The nurses are a bunch of scum bags... especially the 4PM to midnight shift. They say, "Oh he has the chills again."

Miguel spends two months on alternate levels are care- he is in no acute medical distress and is finally medically cleared. His medication is maintained however and the doctor visits although less frequently. Miguel has a lot of time on his hands and little to keep him occupied. Unfortunately, He doesn't have the five dollars necessary for television service. So he spends much of the day walking up and down the corridors with other patients.

After three months of hospitalization, Miguel's sister, his niece and in-laws come to visit. At first Miguel acts as if nothing is wrong- telling the family that he will son be released. He has difficulty telling them about the true diagnosis. He asks a social worker for help and finally tells his sister that he has AIDS.

In tears she expresses sympathy and frustration that she can do nothing to help him. "I can't believe it. How did he get this? I feel so upset for him... But, tell me, can I get it?" She has three small children at home and doesn't feel that Miguel should visit her home now, especially in light of his reckless past.It isn't easy for Miguel to ask for their help. "They ain't got no room... they got problems. It's a waste of time. I know my family... I know how they are. Nobody really wants to trust [me]... They know [that] I'm a drug addict... They're afraid." The last time he stayed with his sister, she would not give him a key. "They would only allow me in the house only when they were at home. Usually, I would have to leave [the house] when everyone left for work... return around 7PM. My people are afraid. The last time, I stole some things from them... I sold them for drug money. Usually, I would not have a key. While I waited for them to return, I spent the whole day getting high. Its hard living with the family, they just don't trust me... why should they? I've got six brothers and one sister- only one lets me visit."

This would be the only time his family came to visit Miguel. The sister telephones his social worker to keep abreast of new developments. The conflict between her love for Miguel and the fear of AIDS exposure leaves her distant immobilized). The hospital was able to discharge Miguel in October 1988 one DAS provided Supplemental Security Insurance and supportive services. He was placed in a YMCA and later moved to SROs and finally six months later to a private apartment. Within four months he returned to Oremus with a PCP diagnosis. In the interim, he started using Heroin, 'Crack,' and alcohol again.

Esperanza: Today, 24 August 1988, I meet "Esperanza," a petite 28 year old Puerto Rican female. The lights in her room are turned off, she lays in bed with the sheets pulled over her face. When she realizes that I am in the room she pulls the covers down revealing large wire frame glasses and a handkerchief wrapped about her forehead. The pink room is accentuated with cards, flowers and a child's drawings posted on the bulletin board. Clutching her rosary beads, she complains of a severe headache. She misses her three children, ages 8, 9 and 10. "I just want to go home. I've never left my children for any time. I want to go home." Her husband died last month [July] and she feels badly that the children must stay with relatives.

Finally, Esperanza meets with her doctor who in a distracted manner informs her that she has CM, (Cryptococcal Meningitis) and AIDS. The condition is serious and prognosis guarded. She will receive Bactrium, AZT and multivitamins until a special medication (Amphiterphrin) arrives. Esperanza cries and asks that I spend some time with her. She's angry at her husband and spoke about the circumstances surrounding his death. "You see, 'Papo'and my brother worked odd construction jobs. They hung out at the bodega [grocery store]. I knew that my brother was on drugs although he denied it... my father threw him out of the house and forced him into detox [clinic] for two years. While he was away he got sick and lost sixty pounds. He landed in this hospital... passed away about two years ago- in fact he was in that room right across the hall. Some of the doctors said that he died of AIDS, others said ulcers. You know, I never forgave my parents for throwing him out on the street and then forcing him into that program, but I guess that we had to face the fact that he was an addict. He shared drugs with my husband. I found out after my second child. Papo was real good with the kids, but when I found out about the drug use things really changed. I made him check into a drug program, but he signed himself out. He said that he didn't do the hard stuff, but was drinking heavily. Finally, he stayed with his mother and visited the children on the weekends. He got sick and was hospitalized on and off over eighteen months. He hated the hospital and I would take him in... I didn't want him on the streets. I thought he had liver disease- you know from all that drinking. Damn, Papo why didn't you tell me?"

"I found him at 4:15AM, the kids were sleeping. He had fallen off the couch and was on the floor. I touched him, he was so cold. I got upset and started crying. But, I didn't want to make noise and wake the kids. I called my neighbor and then the police. He stayed on the floor from then until about 2:00PM the next day. I had to keep the kids in their room... Well, he's up there... I can't complain."

"I found out that Papo was HIV+ in March, 1988. The doctors wouldn't tell me what he had. On his death certificate it read 'Cirrhosis of the liver'." Recently, Esperanza heard that her pregnant sister in-law was very ill and lost her baby. "It looks like AIDS... Oh, my God, we've been living with this thing for years and never really knew it."

A priest visits, bringing Holy Communion. Esperanza receives the Body of Christ but does not ask the priest to stay for spiritual direction or prayer. "I want life around for a while, until my children are big enough to take care of themselves, Oh God please."

The doctor visits to tell Esperanza that the new medication has arrived, but that a second spinal tap is necessary. She remembers how painful the first one was and refuses to consent until after a long talk with the hospital psychiatrist. During the discussion her mother, Mrs. Rivera enters the room and upon hearing about the second spinal tap cries, "Oh my God, my children, my children.... I've been through hell, first my son, now my daughter... Oh my God give me strength."

Esperanza is visited by her children and other family members. She is in good spirits, stating "... you don't know how much I've prayed to God so that I can walk again... I want desperately to take care of my children again." Mrs. Rivera prepares to do her daughter's nails and talks of frosting Esperanza's hair.

Esperanza's mother arrives with a home cooked meal, (arroz con pollo) and pretty balloons. She's unable to go home for Thanksgiving, the hospital provides her with a food basket- turkey and the trimmings. She hopes to be discharged before Christmas. Although she wants to leave the hospital, she's concerned about being unable to move about freely or care for the children.

Recently she lost the feeling in her legs... "I can't walk, I'm bed bound. Sometimes my legs shake uncontrollably... I can't believe [that] this is happening to me!" The nurse enters the room dressed in uniform, mark and rubber gloves. Despite this she passes the thermometer to Esperanza so that she can take her own temperature.

Mrs. R. holds her daughter, gently stroking her hair. She has brought home cooked food to the hospital and gives Esperanza pear juice to drink. Because of the painful spinal taps and her generally weakened state, Esperanza is unable to feed herself. When visitors are not around she simply goes without food. This prompts Ms. River to bring food. Esperanza inquires about her children. Arrangements have been made for a special pass so that the children can visit on Saturday. But, she's afraid that the catheter in her right shoulder will scare the children.

Esperanza adamantly refused to submit to a fourth spinal tap. She believes the taps are the reason that she can not walk. "If I'm going to die, let me die..." Its difficult to wait, ...waiting to see children, waiting to go home, waiting for the food... waiting for medical treatment... waiting to die. She talked about her brother's death. It happened in 1986. He would have been 33 years old. She reminisces that her eldest son resembles him.

Esperanza talked about the Halloween costumes her children would be wearing. She thinks she'll be discharged soon. Doctor's tell her that she is ready to go home. They're waiting for DAS to obtain a home attendant, home care and nursing services. But, these services do not materialize, apparently her application was misplaced and another must be submitted.

Two months later, in the beginning of November 1988 the new application remains unapproved. This one was submitted with the prerequisite medicaid number. Someone entered her room last night stealing two dollars and a can of nutrient supplement.

One month later, her case was 'picked-up' by DAS. She was assigned a caseworker who indicated that it would take another four weeks to coordinate the needed services. The new medication (Amphiterphrin and AZT) required weekly blood tests effect. "I'm sick and tired of dealing with this...I want out of this place... [its] getting me disgusted. They take out blood every two days, but the doctor doesn't explain. I'm just so disgusted... I want to be with my children."

But, she doesn't want the children to visit the hospital anymore. They seem to cry a lot more after the visits. The children are not receiving therapy or supportive counseling. She's worried about what the children will do during the Christmas holiday. That is not possible since the new medications produced severe anemia to be corrected by a blood transfusion. The doctor's have said that a new protocol is required because the Amphiterphrin has had no affect on the Menegitis. "...We all got to die sometime, I'm fed up with this place... I just want time with my children... Thanks to you I'm trying to take one day at a time." She whiles away the time with her favorite novella [soap opera].

Three weeks later an associate of the case worker assigned to her application visits in order to obtain copies of Esperanza's birth certificate, medicaid card, social security number and benefits award letter. Perhaps now the awards process will begin in earnest.

The prognosis is six to seven more years of life. Esperanza and I discuss her feelings about death and dying. She hopes 'the end' will come quickly. She is anxious about the arrangements to be made for her children- its important that they not be taken by the Agency of Special Services for Children (ASSC). "I want my daughter to go with my sister and the two boys to go with my mother... My sister will care for all three if something happens to Mom."

Despite confinement to a wheelchair, hospitalization is not strictly necessary. Esperanza could be discharged in 24 hours if home care services were available. At this point only 12 hour services are available. For now a three day Christmas leave can be arranged. The emergency room holding pattern is well known to many patients and Esperanza is concerned that she may have to wait downstairs for a few days in order to get a hospital bed.

The holiday discharge was delayed but she is scheduled to be released in two weeks. The hospital and Social Services Department coordinate the provision of home attendant and outpatient medical care.

Six months later I ran into Esperanza in the hospital clinic. She has gained weight and conveys a sense of hope about the illness. She spoke of the fear, shame and minimal services available to the 'innocent victims' of AIDS. She is appreciative of her supportive family but finds the "...business as usual" attitude of the hospital workers to be disgusting. She has not told her children much about the illness, "I prefer them to live in the here and now."

Esperanza expired February 1991.

Orry: Today, I am assigned a new case, Orry- a 25 year old Black male. He expected to be discharged today and was anxious to leave the hospital in order to get back on public assistance and pay the overdue rent at his SRO hotel. But, earlier his doctor told him that he "... had the virus." Without any further explanation Orry was left feeling confused and angry. "What's the difference between the virus and AIDS?" I explain what I know about the HIV virus, transmission, symptoms and HIV-related illnesses.

"I don't think I got it from sharing needles... I don't share needles, I'm diabetic... so I get new ones [needles] all the time... Maybe I got it through sex with 'those' women... I really don't understand." For now he's medically clear and will probably be discharged tomorrow.

Magda: I left to visit Magda, a 30 year old Hispanic woman who was hospitalized with high fever and shortness of breath. I enter the room to find a doctor taking a blood sample and wait until he has finished to initiate a conversation. Magda confesses that she has had sex with drug addicts in order to get money to buy "... a taste of crack." She's well informed about AIDS and its transmission. She is worried about infection.

Marisa: I meet Marisa, a 30 year old Hispanic woman who has an eleven year history of drug use- alcohol, marijuana and lately crack. She consumes $100. of crack per day. She has used her mother's home as a meeting place for drug dealers and users who pay her in quantities of the drug. "Sometimes I have sex for crack... I don't remember if they used condoms... I can't really keep track." Her concern about infection prompted her to agree to be tested for HIV exposure.

Cory: ...is a 28 year old Black bisexual male and an active crack/ Cocaine user. A high school graduate, he served in the U.S. Navy for two years. Unemployed and homeless without medical insurance, he was hospitalized with PCP. He is separated from his wife of nine years and his family lives in California.

He is afraid that he may have infected his wife. Even though they have been separated for some time, they had unprotected sex four weeks ago. He would like to reconcile their differences but, his crack use alienated her. As the "man" in the relationship, he has always done exactly what he wanted to do; his wife had no control over him. He talked about leaving home to 'hang out' with friends and other women. They have two children. His fear makes him think to have his wife and children tested. In tears, he said "... I don't want to face this... I don't even know what it all means..." I am asked to leave so that he can be alone.

Cory is angry at the staff and resents the infectious warning sign on the door to his room. He has ripped it down twice before, "...they have no right to advertise..." He's offended that the nurses and doctors wear gowns, masks and gloves when in his room, "They're not taking blood... just my temperature or the IV... why the fuck do they have to wear those masks and gloves?"

He grew angry when learning that the doctor telephoned his wife with the news that he had AIDS. The doctor felt that it was the wife's 'right to know' but this reasoning did not placate Cory. She complains that the physical therapist only came in on Monday for twenty minutes when "...she supposed to come twenty minutes on Monday, Wednesday and Friday."

Cory: ...is a 28 yr. old Black male diagnosed rule out PCP pneumonia. A broncosophy confirmed PCP pneumonia and other exams detected genital herpes simplex.

Cory has a high school education; is unemployed and has been homeless for two years. Sexual experience with men began at age 15. Despite this, he met the "girl of his dreams and "...got married". Presently separated from his common law wife, he has two children; boys age 3 and 1 yrs. It was not long before he reinitiated homosexual affairs. Cory admits to recent sexual relations with men, although he claims never to 'take in' semen.

"I was living in the fast lane... I started using cocaine, then 'crack', ...I lost my job three years ago. My wife asked me to leave our home. After that I spent the winters sleeping on the trains, mainly because I couldn't stand the shelters." He visited the soup kitchens and stayed with anyone who offered him a place to stay or 'crack.'

He was sexually active with his wife last week, "...we did not use condoms." The contact was part of a reconciliation attempt. He has also had sex with "drug girls" while using 'Crack.'

He planned to inform his wife of the AIDS diagnosis shortly after receiving it. He hesitated because of uncertainty about her reaction. Before he could tell her, a doctor placed the telephone call advising her to be tested. This uncommon (?) action left Cory irate. Later, I heard that the wife had inquired as to the cause of Cory's condition and the doctor felt it unfair not to tell her the truth. Since then Cory has very little contact with his wife. She has great difficulty facing him.

He threatened to sue the physician for violating his confidentiality and requested another doctor. "As long as I am in this hospital I'll be depressed. I can't wait for the housing placement. I got to get out and start living again."

Likewise, the 'precaution' sign on his room door is upsetting. (All persons attempting to enter the room must report to the nurses station). He has taken the sign down. (The hospital has since removed all such signs in an effort to protect the confidentiality of the patient). Similarly, the protective garb worn by doctors and nurses entering his room angers him. "...These people are full of shit, they don't need those masks, I'm insulted.

During the twenty five days Cory remains in the hospital, he spoke often of the desire to get out. He felt as if in limbo. He says he wants to get out and play with his sons.

He does not want to return to what he was doing before he was hospitalized... doing cocaine and 'Crack' occassionally, sleeping on the streets and living in the shelters or staying with other men for shelter. During his hospital stay, his wife and the baby submitted to the HIV-antibodies test. The tests were returned 'positive.' The feeling was overwhelming for Cory. "Its a guilt trip, I could have prevented this, why was I out on the street? ...That cocaine and crack really did a number on me. I really went for it. Now look at me."

He complains that the doctors do not visit him anymore, "They make me feel dirty." He feels irritable and frustrated in the hospital... the treatment is over, I feel guilty being in this bed. He is afraid to die. "I feel so ashamed... I probably won't be able to see my son grow up.

When the PCP pneumonia was brought under control, he returned to the YMCA and visited the local outpatient clinic for follow up treatment. Cory hoped that he would soon return to his family, but right now he "wants to get himself together."

When we met at the clinic, Cory noted that accepting the diagnosis was "...the hardest thing..." He is still "... dibbing and dabbing with 'crack'." This helps him to "get it" under control or simply avoid thinking about the illness and death.

He never felt that "...it would happen to me... Before I really didn't care [about AIDS], but now that I'm one of them, I think about it."

He has spoken to his mother, with whom he has not been close. She inquired about his life insurance. But, he's aware that he will "...go through this illness alone,..." even though there are places to go, he hesitates because he feels so ashamed and guilty. He's still trying to "... get back with his little women, I'm still going to try, maybe things will be different, maybe there will be a cure!"

Anibal: ...is in guarded condition. The AIDS dimentia leaves him incommunicative. At this point he is yelling at his mother who has been with him since early morning. He was scheduled for release a few days ago and arrangements were made today for an ambulance to take him to his mother's house. But, the driver refused to take him in this state. His mother already angered by what she considers the poor treatment her son received in the hospital, became agitated by the driver's reaction. "... he's been lying in his own urine for two days... and the doctors have not been in to see him today."

Two weeks later Anibal died in the hospital. His sister died from HIV-related causes last year in the same hospital.

Delores: ...is a 43 year old Black female who was diagnosed HIV seropositive, rule out PCP pneumonia and rule out TB. There are high fevers, too. She has been homeless for four years and has lived in women's shelters or on the streets, occasionally with friends. There is a twenty year history of substance abuse including alcohol, Heroin and 'crack.'

After one month of avoiding me Delores finally speaks about her family. She has four children ages 10, 12, 15 and 18. Two of them live with her sister. The eldest is in Rikers Island prison for attempted murder. By her standards, she has been a neglectful mother. The past eighteen years are marked by drug abuse, prostitution, petty robbery and homelessness.

Her mother died in 1987 of a heart attack. A sister died at the age of 32 of a massive stroke; complicated by intravenous drug use. An intravenous drug addicted brother who frequently shared needles with her sister, died during the same month from AIDS-related illnesses. Delores used to share needles with her sister too. She learned that her husband, absent for five years, recently died from AIDS-related illnesses.

Her education is minimal. After dropping out of high school she had a series of maintenance jobs. It became clear that pushing drugs and prostitution would pay more money.

For now, the real issue is Heroin withdrawal. She would like a prescription for Methadone, "If they don't give it to me, I'll be real sick. ...[it] would help the aches and pains... and the phlebitis (in her legs) so that I can walk."

Delores is evaluated by a physician, who speaks as he writes on a chart. TB is the next ailment among the possible afflictions affecting her for which she is to be tested. She is left with a plastic jar into which she must deposit spetum. Coughing and shaking she misses the jar for the most part. I tell her its important for her not to spit on the floor. Angry she tells me to mind my own business. She believes that TB was contracted in the shelter.

The insertion of an intravenous tube into her neck was frightening and uncomfortable. A few of the nurses are kind to her (supplying cigarettes from time to time) but, "... Some of the others give me a hard time... They won't let me smoke in bed... and others yell at me for going to the bathroom in the bed... Sometimes I don't have the strength to make it to the bathroom. Boy, did they make me wait before changing the bed... that's not fair."

Quite the social butterfly when she's feeling well, Delores walked the hallways of the Medicine Ward. She visited neighbors; 'borrowing' cigarettes or leftover food. An old neighborhood friend is in a nearby room. This 30 year old Black male was in the last stages of AIDS. Restrained to his bed, he appears nearly emaciated. The movement of his lungs within the small rib cage and the constant drip of the of the IV are the only clues that he's alive. The AIDS dimentia causes him to talk to imaginary people and sometimes to himself. When strong enough to sit up- he rocks from side to side listlessly.

When alert he and Delores smoke cigarettes together and talk. Sometimes Delores has to hold the cigarette while he draws on it. Allen told Delores that "... my own doctor walked away from me..." He feels abandoned and persecuted. Someone recently stole a pack of cigarettes and his lighter. "I don't want to be here. They insist on strapping me up. I'm not going for this shit." He's upset by the regular interruptions by the nurses- to take blood pressure, temperature and administer medications. On the other hand he mourns the lack of human contact. "Nobody came to my room last night... I might [have] be[en] dead... I haven't seen a doctor in two days."

The fever and headaches are annoying. She wants the doctors to find out what is causing the high temperatures. "... Do the doctors feel they can cure a patient from AIDS or just prolong their life? ...They're prolonging my life."

She is responding to the medication prescribed for TB. Within a few weeks Delores is medically cleared; there are no acute medical problems. Now the doctors are eager to move her out of the hospital in order to make room for another patient. As her case worker, I must confirm her undomiciled status, contact the family in order to inquires as to their willingness participate in discharge planning. Since Delores has no supportive family network and has been intermittently homeless during the past four years, I referred the case to DAS. A case worker will be assigned to coordinate the necessary services.

But, before the application was processed and the discharge planned, her fevers rematerialized. Another spinal tap was performed which revealed CM. The presence of another opportunistic infection terrified Delores and she grew sullen. She was transferred to a semi-private room and a few days to later a private room.

A spinal tap reveals cryptoccis meningitis. During the next month she is treated for this opportunistic infection and finally died on March 25 1989.

Delores' confrontation of death and dying is especially revealing. From the beginning she denies the veracity of the diagnosis. Each time we talk about her condition she concentrates on a particular illness such as TB. She directs her anger at her experience with drugs. She is now in the negotiation stage, talking about her family and her wish that she could be different with them. She negotiates the ability to care for herself.

She reverts to denial of the dying process, wishing to leave the hospital so that she could resume her 'life.' She refuses to see that her 'days are numbered.' The hospital staff relate to her as if it were business as usual. The doctors treated each symptom separately as the occasion arises; "treat the acute medical condition." Their aim is her eventual discharge. The issue of her death was never really discussed with her. Towards the end- the last two weeks of her life, Delores resumed drug usage. While the staff supposed this, the issue was not pursued because they could not prove it and they did not want

to actually confront her.

Although Delores is surrounded by other AIDS patients in various stages of demise, she believes there is time to live before she goes through the same things.

As the 'end' approaches, people avoided her room. There is less and less staff-patient interaction. The doors remained closed, lights turned off, less and less routine care was provided.

Larry: Although Larry does not meet the entire criteria of this study, I have included him as an interesting vignette.

Larry, a 39 yr. old Black gay male entered the ER in medical crisis. He is suffering from a very high fever, uncontrollable shaking, occasional memory loss and 'black outs.' He is evaluated and then transferred to a medical ward. Tests reveal CM- Cryptococcal Meningitis. During the initial dialogue with doctors, nurses and social workers he denied practice of the 'at risk' behaviors associated with HIV infection. It was during subsequent conversations that he admitted to sex with multiple male partners. He regularly "spent the nights cruising in my mother's car," looking for trade.

Larry is the sole provider for his elderly mother. Presently employed as a medical insurance claims processor for a city hospital. They live on his salary and her social security payments. Since he is a fellow health care worker, an administrator of the hospital telephoned the manager of the company employing Larry. His colleagues asked that Larry be given the best of care.

He has not told her that he has AIDS or about his sexual preference and activity. He does not feel that she or any other family member will understand his attraction to other men or the way in which he satisfies the sexual urges. Even in the hospital Larry becomes uncomfortable if we discuss this part of his life too loudly. He is ashamed, scared and feels isolated.

He is most concerned about his medical condition and its future implications. He is fearful that his mother will find out the details of his illness and that one day he will leave her all alone.

During Larry's hospital stay most of the nursing staff are attentive and supportive. They learned that Larry was the sole provider for his elderly mother. So, they made a point to speak with her often, telling her only that her son had Meningitis. Mrs. H. is engaging. She brings homemade cookies or pies for the staff as tokens of appreciation.

His mother visits daily. Her visits do not stop even if he unconscious. When he is intibated (attached to a respirator) in the ICU she prays in the hospital for his health and the efforts of the staff treating him.

In time he responds to the intensive care and as the doctor's put it, "bounced back." He is returned to the general ward. He condition stabilizes and he regains strength. His progress continues and he is scheduled for discharge. Once discharged, it is some time before Larry can act on the hospital's recommendation that he engage community support groups which can provide much needed counseling and support services re: the AIDS diagnosis.

One day I meet Larry at the outpatient clinic. He appears to be in good health and is happy to see me. I am thanked for being his only support during the hospitalization. He still has not told his mother about his medical condition or prognosis. He will carry on until something else happens.

Since his hospitalization "...my 'girlfriends' don't want any part of me, ...they just disappeared, no one comes around anymore... we just stopped camping and dancing, why me?" On 12 November 1988 Larry expired. He never told his mother, other relatives or friends about the diagnosis.

Milton: Milton is a 32 yr. old Black, gay, homeless male. His diagnosis includes Meningitis, Brain Abscess, Oral Thrush, Chronic Wasting Syndrome and severe diarrhoea.

When we first met, he has the covers pulled over his face but it time responded. He has difficulty answering my questions. He obtained an Associates degree in 1978. and since then, has worked at several odd jobs over time, most recently as a purchasing asistant for a local college.

Nearly fifteen years ago Milton met and lived with a woman who later gave birth to a daughter, Kate who is now twelve years old. Milton and the woman have since separated. He has not seen the child or her mother for about five years. During a three year period he maintained a domesticated relationship with a Gay lover who died one and one half years ago. The death and reduction in household income forced him to vacate their apartment.

Miltons sister and mother are aware of his sexual orientation but, he has not informed his father. The mother and sister do not accept this lifestyle. Their occasional visits to him in the hospital surprise Milton since they will not permit him to move back home. "...it hurts, but at least they pay for the TV."

At present, he is staying with his grandmother, but despite the numerous hospitalizations she asked that he make other arrangements. But, the illness has drained the meager resources. He has been technically homeless for the past year. He has an application in process for SSI disability payments.

Despite the cheery Christmas decorations in the room, Milton is despondent about the family's rejection of him. He thinks often about how to ask them again, but is hesitant because of past reactions. Instead he asks another sister and an aunt to stay in their apartment, but they declined noting spatial limitations. I'm asked to help Milton prepare yet another request of the mother, but his overall depression works against us. "I'm very depressed, I just want to forget all this AIDS stuff. I've been praying everyday. I wish a miracle would happen... I'd like to start a new life, I don't want to worry about where I'm going after the hospital... If only I could go home."

The last time Milton was hospitalized he attempted suicide. Someone stopped him before he could jump out of the window. He attributes the act to despondency concerning his mother's rejection. "...I'm tired of being rejected by her especially since I haven't seen my father since he left her."

During a visitation, his mother brings him toiletries and slippers. Later I was told, "... I talked with her... she says that she tries to understand this

AIDS thing...doesn't want to change her lifestyle; she's not going to play nurse or disrupt my fifteen year old brother's privacy, since we'd have to share his bedroom.... she said that the hospital will just have to find a place for me... she says I'll make it, like I did before. He crys, " I can't believe how cold and insensitive that bitch is!... I was expecting something negative... thanks for preparing me for it."

He complains about not being given the chance to talk with the doctors "...They come in, I want to talk but, they ask how am I doing and then run out." For many days now he attempted to talk with the doctors about the numbness in his legs... "But, the doctors just kept going, telling me just one thing at a time.

To treat his illnesses Milton is prescribed AZT, Mediane (for seizure disorder), Lotrium (for a rash); he is also dealing with Oral Thrush, a fissure and hemorrhoids. Sometimes his vision is blurred. "But, every morning the doctors come in... How you doing   Chief and then leave... I can't believe it, but at least their treating me...I don't want to cause trouble."

A surprise, his father and new wife come to visit today. His father asked "...do you think you got this AIDS thing?" Oh, my God, the wife responds...They should take all AIDS patients and put them in the furnace... they got no business doing what they're doing." Milton asks them to leave because he's tired. I spend the next hour holding him as he cries, asking him to accept his feeling but, to focus on the good things in his relationship with his mother and sisters. I documented some of his emotional feeling in the medical record in light of his attempted suicide.

The next time we spoke, Milton said he was "...still going through my negative period...I'm feeling like why? I'm thinking too much, driving myself crazy... thinking about where I am going to go... It's been two months. I'm going through that closure, facing the reality and disappointment of my family not wanting me back."

"At least the nurses are nice to me,. You know they thought that I was a bum, I guess that's what I looked like when I came here. They changed. They treat me much better now." "...some have given me reading material, candy or just plain conversation. Others look at me as if

I'm just a gay germ. They say... are you, um... homosexual? What you been doing boy putting yourself in danger." A nurse came into the room to give him a shot. "But, I'm afraid of needles." "Great," she replied, "just turn over." He thanks me for the pajamas and robe that I bought him.

The conversation is switched to his feelings of anger and frustration. He has gone through much during his life. His father's brother raped him when he was eight years old and at twelve he was forced to have sex with another adult male. And now he's angry at the staff who can sometimes be "so stupid." The rotation of staff is sometimes disconcerting, "I can't believe I got another doctor... I can't communicate with him, Yesterday I told him that I didn't get my AZT, he said... Oh, don't worry you'll get it..."

Milton's hospital stay is extended past the medical crisis and recovery period because he is undomiciled. HRA will locate a SRO or apartment when the case is picked up in about three months time. "I'm worried about housing, I don't know what I'm gonna go into when I get out of here.

During the hospital stay he develops friendships with two other patients, who all have AIDS. The visit one another's rooms often and have become an informal support group.

In time, HRA located an apartment. When I met Milton again he said that he was happy with it, eventhough he was alone. Unfortunately, the place is located in a known "crack" dealing zone, "Honey, you got to be damn careful!" His family does not visit often, for the most part they are keeping the 'Grand Silence' about his "AIDS thing." "They act like it doesn't exist. They tell me to be strong and try to help myself...

They don't understand my lifestyle, they think I'm doing this to myself!" Later I was informed by another patient who lives in Miltons the same group home that he started to use 'Crack' again.

Ruben: ...is a 24 yr. old Hispanic gay male. Diagnosed with CNS (Central Nervous System) lesions, toxoplasmosis and KS recently, he told me that he tested HIV + one year ago. Ruben has a very good understanding of the diagnosis and prognosis.

As I enter the room, I extend my hand to Ruben and touch his shoulder, offering my services as a supportive counselor. Family members are present but his mother dominates the conversation, insisting that I identify myself. She is protective of her son and repeatedly interrupts the interview. "Why must you [staff] keep asking him the same questions about his history ("at risk" behavior or comprehension of the diagnosis)? I explain my role as hospital case worker and the tension subsides. She confides much about her fears and concerns regarding Ruben's hospitalization. "...Look, I got here at 4PM [to find he's] been sitting in urine since this morning." There is concern about his impaired vision (a side effect of the brain lesions). "He can't feed himself!..." I am the target of her anger. I listen, trying to direct her to the appropriate personnel for redress.

More encouraged now, Ruben speaks frankly and with anger about his medical condition. The presence of family provides the unusual opportunity for holistic counseling since the entire group is present to discuss the feelings about a condition that affects each member's life.

This is his second experience with brain lesions. They cause dizziness and blurred vision. This hospitalization is most difficult for him because the illnesses are getting more severe. He will not allow other patients into his room. His only visitors were family members.

"I accepted it [having AIDS].. I know I'm going to die, that's it. I just want to have a good time now. I still like to go out and party with my friends, like go dancing- and be with my ex-boyfriend. We were lovers for four years."

"I get angry, I'm young, I worked.. I think this shouldn't happen to me. This is fucked up! I hate this hospital. Everybody who comes in here thinks that I am a drug addict. [On a earlier visit a nurse remarked "Oh, you're not what I expected, your arms are clean. How did you get AIDS?"]. Its just horrible, I don't want to be here. Knowing that I'm dying by myself really bother me. People just don't understand, so what if I'm Gay." His lover left him when he found out about his AIDS diagnosis. This was the first man with whom he shared an apartment..."It's the first time I fell in love...I just want him back. I want to be with him for the time I have left... I want him... I'll never have the chance to start over with anyone else ...If I met someone and they told me that they had AIDS, I would drop them... I just can't start over."

"I don't want to die.... I just don't want to... I'm afraid of dieing alone ...I just don't want to...die alone." There is a fear of the unknown. He asks "What will it [death] be like, how will it happen?" He does not want to expire in the hospital. I'm afraid that I'm not going to have a chance to be with my parents and ex-lover again."

Later, I met Ruben's mother. She's aware of her son's sexuality and the illness. She's very supportive and wants to take him home. She is however, angry at the staff for not being attentive enough; making him feel dirty, just because he's gay. "Look, my husband and three other children understand Ruben's lifestyle. We love him no matter what... All we want... is to take him home." When first hearing of his diagnosis, she didn't know what to expect, she just didn't understand AIDS. "I know it will be hard, but we want him with us ...whatever time he has left, we want to be there for him."

The family signs him out of the hospital in order to take him home for a few days. When I telephone, Ruben will not speak to me, according to Mrs. G. he is depressed, angry and does not want to speak with anyone. She however needs someone to talk to and asks that I call again. There is a feeling that the family is totally isolated. Despite the medical assistance of the hospital and staff, they feel alone in caring for him at home. A gay men's support group assigned a 'Buddy' to Ruben, but he doesn't seem to appreciate the cultural values of the family and his case load does not permit regular visitations. "People [neighbors] just don't understand... sometimes I feel so ashamed."

Three months later Ruben is readmitted to the hospital in acute medical distress. He remains for three days when his family signed him out again. The next day he returned.

I am asked to review the 'do not recusitate policy.' They disfavor artificial life support. Ruben wants to die at home. He is discharged again but, within hours developed breathing complications and is returned to the hospital. The family is confused as to what to do next. Since they are not in the room during the exam, he is placed on a respirator. Despite best efforts, Ruben expired within a couple of hours.

Arturo: ...is a 31 yr. old Hispanic male, is hospitalized with medical diagnosis of rule out PCP, a high fever and wasting syndrome. He had lost 30 pounds in one month.

He never really knew his parents and spent much of his childhood alone, especially when his mother went on drinking binges. He remembers home as filled with different men when he was growing up. Growing more and more dissatisfied he eventually dropped out of high school and finally left home.

There is a history of bisexual relationships. The intravenous drug use and preference for Heroin is attributed to attempting to cope with his mother's activity. He has shared needles with his sister who tested HIV+ three years ago. He did not know of her AIDS-related illnesses until just after the recent funeral.

He was sentenced to three years in Almira State Prison and, later one year in Rikers Island Prison. Inside, he was sexually active. Upon release in 1977, he met C. They were married and now have two children, an eight year old son and six year old daughter. There has never been any discussion of his sexual past with C. He explains, "...I'm not a fuckin' homosexual! I was doing the fucking. Can't you understand I fucked those men, sometimes I stayed over their apartments, for money and sometimes for a place to stay. I stole from them... to survive after my wife kicked me out. Now, occasionally he lives with his wife, sometimes other men but, recently he has been homelesss.

His mother, wife and sister visit regularly. But, often arguments break out, cutting the visits short. Arturo tells them he has TB or pneumonia. They attribute his deteriorated physical state to "the hard life he has lived." They know of AR's "bicio [habit]"

There is harsh criticism of the staff and care received. He has recurring fevers and claims that the doctors have given him nothing for it. He threatens to leave the hospital, "I might as well, sometimes there's only two nurses here working...They don't do nothing about my fever... my whole body aches... How the fuck can I be nice to the staff, when they don't do nothing for me." Someone on the staff told him that he's "...going to die anyway!" "My doctor is never here... The psychiatrist ordered medication for him, but it hasn't arrived. "Me encabrono [I get furious]... you got to get loud with the motherfuckin' staff... You ain't gonna play with me like a guinea pig- I yell at them. I'll get these motherfuckers."

He believes that the nurses think that he is a homosexual. "I'm tired of worrying about that.... I got my wife; I think that she will put me up; she better."

A broncosophy is scheduled today which makes him very anxious. The results are negative. There is no pneumonia present. This knowledge bolsters his spirits somewhat.

He has not paid much attention to the "AIDS issue," even after learning the cause of his sister's death. He has yet to tell his wife the truth about his illnesses. Perhaps she has an idea. "...I'll tell her when I'm ready." He's concerned that a hospital employee who lives in her neighborhood will spread the word about his condition. Perhaps she will tell his wife. I encourage him to break the news to her. "I don't think I have enough time, I can't take the way life is treating me, maybe it's my fault. I'm just concerned that if my wife finds out, she just won't want me back."

A second broncoscopy confirms the presence of PCP. After much support and counseling he decides to tell his wife about the diagnosis. She responds with disbelief. "What does it all mean?" When we meet, I try to explain the meaning of a PCP confirmation. We talk about AIDS. She is in shock and has great difficulty absorbing the information. She's despondent and angry at her husband. "...I wish he would die!" She has had suspicions about his health for some time but, but felt that she could not question or confront the "man of the house." Later, she expresses a wish to help him, but confesses not knowing what to do. She's confused, ashamed and overwhelmed at this point. We speak of the possibility of her exposure and I recommend testing. I encourage her to think about her health and that of the children.

On the next visit, she reassures Arturo that she will take him home if he is discharged. She will try to do the best that she can. "I must do this." She will take the test and seek medical guidance on an outpatient basis. For now the rest of the family will not be told about the matter. They are afraid of the possible reactions. Perhaps people will stop visiting their home. Perhaps the city will take the children away.

"I think about dying a lot. I think about the kids. I think about the things people say if you're a junkie... they think you don't care about your kids or your family [if you're a junkie]. I'm scared of dying. I won't be able to take it. I'm scared of being alone." The thought that his wife may also be infected in troubling "... If my wife gets the disease, I will fuckin' kill myself...what will I do, who will take care of my kids."

Marlon: ...is a 32 yr. old Black males diagnosed with PCP- pneumonia and Anemia. He lives with his girlfriend who is several years older. He has a high school education and has worker as a butcher, welder and seamen.

At present he is unemployed and has been so for one year. His lover supports him and he earns money through odd jobs. To "get by" he will need public assistance and medicaid.

This is Milton's first hospitalization. As he states ".. I have never been sick and ...have no need to see any doctors."

The AIDS diagnosis came as a shock to Milton, he has no idea as to how he might have been exposed to the HIV virus. He spends a lot of time trying to "make sense" of the diagnosis and to share his feelings with his family.

It is difficult to tell his mother, brothers and sister about the diagnosis. It make him even sadder to imagine the sorrow that will be in their faces. His own pride makes the telling difficult. He often cries.

The family receives the news with shock and denial, they cannot imagine how this could happen to Milton. Several visits and discussions with staff later, they begin to face the diagnosis. They ban together to decide how to help him. For now, they provide food and company.

He and his lover, have known one another for twelve years and have lived together for five years. "We plan to get married, right now she is very sad."

His drug use started five years ago- a secret kept from his girlfriend. He used(s) cocaine once or twice a week. He denies sharing needles. He denies having sex with men but, he had sex with female prostitutes when he was in the Navy.

As he understands AIDS, there is no cure. "Knowing that there is no cure, ain't much that I can think about... there's a block. During the first few days [after the diagnosis] he kept the door closed and the lights turned off. He was very withdrawn.

Anxieties increase while Milton tries to decide how to tell the extended family. They are curious and concerned, trying to get information from anyone in the ward. I'm told "...You are playing with people's lives, who wants to die, you must tell us, people have to know about these things." Contagion is a primary concern as there are young children at home.

Milton does not feel that anyone besides the immediate family should know, "...we can't tell everybody, they won't understand... they don't even know I use drugs." "I've done a lot of wrong things, I'm being punished ...something disastrous is going to happen... I will be destroyed, my body will be destroyed... Dying is all right... but going to Hell is something else.

During a twenty three day hospital stay, Milton processes the meaning of the diagnosis. He begins to feel more comfortable with his girlfriend and the family's knowledge of his condition. They make preparations for his return home and pledge more honest communication. He promises not to do 'crack' anymore or "other private things." His main concern is that which others may say if the find out he has AIDS. He forbids anyone to tell his friends or the rest of the extended family.

His case is referred to HRA for SSI and supportive services. A few days after discharge I called him at home. His girlfriend says she's having difficulty with him. He's very depressed and extremely concerned that people in the neigbhorhood will find out about his diagnosis. She found the HIV testing process very stressful. Even though she tested negative, she feels that she is not out of danger and waits to be tested again in six months. She is afraid to return to the clinic and worries about being HIV infected.

"I can't tell my family about the medical diagnosis, I can't even tell anyone that he might die. I have no support and feel very alone, ...how much must I endure.... MT and I fight about using those bags [condoms], he tries to blame me for being promiscuous. "Why should we use these? ...you been foolin' around?

They don't have enough money to buy food or some of the other little things. "...The whole damm thing is up side down I'm just the house maid. He doesn't want to marry me now, I'm not going to leave him, I'm 46 years old do you think it will be easy to find some one else and now that I may be infected."

After the phone conversation I contact a community group to get food and supportive counseling services for MT and the family.

A week later I spoke with Milton "... I haven't been keeping my appointments with the outpatient clinic and slipped back to doing a little crack." His relationship with M is strained and he not so sure what's going to happen. He agrees to visit with me at the hospital, but never shows up.

Allen: ...is a 39 year old homeless Black male who has had a substance abuse problem for fifteen years. He was diagnosed HIV+ with PCP Pneumonia one year ago. When I first saw Allen he was extremely withdrawn, the proverbial "skin and bones." I could see the outline of his skull beneath his face. He has to be forced fed and the NG (Nostrol Gastrointestinal) tube has been inserted into his nose.

Most of the time he is incoherent. His movements are as if in slow motion but his eyes rotate constantly and rapidly. He breathes with great difficulty. Suddenly he grasps the bed railing in an attempt to raise himself off his back and blood is expelled from his mouth. I ran to the nurse's station with the news. Calmly a nurse responded in Spanish, "...just leave him alone... I would rather shoot myself three times than to have contact with his blood. The doctor on duty is reluctant to sound the Code Blue, the emergency 'last effort', for it would require attaching AR to a respirator. The other nurses walked slowly away from the station and I returned to Allen's room.

Four days later Allen was restrained to the bed in his room. He is conscious now and able to converse. In response to questions about the things happening to his body he responds, "... I am being persecuted... They're going to keep me strapped in here... I'm not going for that shit... Why are you strapping me down?" In fact the staff is afraid that in a disoriented state he might fall out of bed.

He has exhibited somewhat violent tendencies in the past; pulling out his catheter on more than one occasion. He says that was "...defiance. What is this shit. If I'm going to die, let me die free. I don't want to be strapped down like some animal. The nurse said, Don't worry, we won't strap you down, but don't you know when you've had it? What's with this lady?"

His condition improved two days later. During our discussion he tells me that the other social worker is trying to find his brother. Even though he wrote a letter asking him to visit the hospital, he doubts that they will locate the brother. "He's a dope fiend.

He's very sad that no one comes to visit him. He has two other brothers nearby. At least one knows that he's in the hospital. " I don't know anybody, I'm tired of it...Nobody seems to give a shit. It's really starting to get to me.

Allen asks, no, commands that I stay awhile "...shit, please stay, I don't know what to do here. He shouts, "Nobody came in to see me last night, I guess they gave me a break... I might be dead tomorrow evening, I need someone here to bear witness... I haven't seen my doctor in two days."

Two days later, Allen looks stronger and is more focused. The doctor told him not to look a gift horse in the mouth. "They said I was really out of it a couple of days ago... I don't even remember being here. Thank God for bringing me back. I guess He's giving me a little more time. "I know [that] I have only two months to live, I'm not afraid of death...I done faced it many times. He was shot once and beaten on the streets in conflicts with other drug addicts. "...you know, man, people tryin' to take my turf.

During healthier times he was "...very active with the ladies. Just then a young woman passes the door and Allen comments, "... look, she sure is a stacked mama."

He asks that I not forget to bring him Christmas and wonders if I noticed that his room is clean. "They stripped the wax, cleaned the air vents and waxed the floors. It makes me feel good, I think its for me.

Allen is not in the mood for conversation during my next visit. He thinks that he's getting better, but wants to sleep right now. "Besides, there's not much to talk about... I'm just waiting... bring me some cigarettes.

He is uncomfortable with the nursing staff. "... some of them are sick! They're crazy and mean... I'm dealing with double trouble, my family doesn't visit and sometimes the nurse give me a hard time. "The nurses run from me, I need help with them... I'm gonna die, but let me die in peace."

Four days later, I return. He complains, "I feel lousy... They [doctors] got me strung out on Demerol for the pain, now I'm gettin' codine... My stomach is in knots... one codine tab is not going to do it." The medical chart confirms his 60 milligram dose of Demerol per day and notes that he was complaining so the prescription was changed to 30 milligrams of codine.

Two days later I visit Allen. The smell of urine makes me gag. He is in good spirits. His brother came to visit yesterday. They used to 'shoot' Heroin together. Right now he's concerned that his brother will cash his SSI check to buy drugs. There arrangement is that "...he gets the check, brings it up here. I sign and he takes it to the bank... then brings the money back here to me... I'm paying him to do some labor. He's supposed to buy me a TV for this room. I'm bored here. I'm testing him to see if he'll come through. I want to see if he's worthy of holding my money. I ask what he expects to happen. "My mind is clear, whatever happens, is going to happen. I'm still in control; Danny's got to come to me. Danny hustles the street." I returned five days later. He appears confused. His brother never came back with the money.

His complaints continue about the nurses and their aides. "...the fuckin' nurses. They have very nasty mouths. They curse worse than sailors." As I leave, he asks that I not say 'Goodbye', just 'See you tomorrow.'

Two days later I visit Allen. He's very lonely and unhappy that he does not have cigarettes or a TV. He describes a female patient who visits his room is"... a vulture, all she wants is my leftover food and fuckin' keeps asking for cigarettes. She needs to get out of my face."

A day later, he's scheduled for transfer to another floor. He's awaiting placement in a long term care facility. But, he expires at 10 o'clock that morning; there was no 'Code Blue'. He was handled efficaciously, wrapped and transferred to the morgue. A co-worker expressed surprise that a 'Code Blue' was not sounded.

Weeks later, no one has come to claim the body. Attempts to reach the family are in vain. The body lies in the morgue for some time. He is eventually buried, probably in Potters Field.

Deborah is a 28 yr. old white female who enters the hospital with a medical diagnosis of bilateral pneumonia, rule out Bacterial Endocarditis. She was found lying unconscious on a parked car. She has a history of alcohol addiction as well as IV drug use; specifically heroin, cocaine and speed.

Although homeless for three years, she will not stay in the women's shelter, "... You can get hurt in there...

I don't like being with all those women." She spent the last five years on the streets, sleeping in subways or sometimes with a "friend," who sells drugs, tries to make her "walk the streets" and beats her. "But [I didn't stay] that scene got too rough." She speaks of the violence, the prostitution and the drug use, "...I was trapped. I was sometimes locked up in that house, he kept me drugged."

Her father and brother are contacted. At first the father doesn't want anything to do with her, "...until she cleans herself up!" He wanted her to enter a drug rehabilitation clinic. "All she ever was, was trouble.

After her mother died, all she wanted was to hang out with the wrong crowd. Don't ever call this house again! Tell her to clean her act up... after that she knows where I am if she wants to come home. Let her get welfare and into a program, first."

She cries when I tell her the things her father said. "He's a sick bastard... He's always given me a hard time... Doesn't he know that this time, I have nowhere to go...and I'm really sick!" Angrily, "...that sick bastard tried to rape me, that's why I left the fuckin' house. I stabbed him in the stomach. It took twenty stitches to close that gut. I guess he can't forget that. Well, why would I want to go back there... All he's interested in is what I can give him." In the past he charged her rent, since she was on public assistance. To make money, he would sell her his needles (he is a diabetic).

Later, I contact her brother who resides with the father. After much convincing he agrees to see her.

Deborah was surprised to see him. She cried and asks his forgiveness. She asks that he to speak with their father. "All I need is a place to stay!" His only response, "You know how he [father] is."

The nursing staff is greatly agitated by Deborah. Her cursing, criticisms and generally uncooperative manner are disturbing to them. She pulls out the IV on several occasions and forbids them to enter her room. She refuses medication, often throwing it in the garbage.

Deborah avoids all talk of HIV-infection. She will not take the HIV-antibodies test or any other exam for that matter. She refuses to speak of "at risk" behavior.

One day, against medical advice she walks off the floor. Four months later, she returns with accelerated Bilateral Pneumonia complicated by alcohol-live disease, severe diarrhea, fever, night sweats and rule out TB.

This is her fourth hospitalization in one year. She left because she didn't think anyone wanted to do anything for her. She is afraid to find out what is really wrong with her. She prefers to return to her "own ways." Now she's back with her old boyfriend, "... at least its a place to stay and I can get what I need."

She stays in the hospital long enough to get the situation under control. When the antibiotic treatment produces some improvement, she leaves again.

Brunilda: Brunilda is a 46 yr. old Hispanic female who enters the hospital with a high fever and a severe case of Herpes Zostor. Her medical diagnosis was AIDS.

Before I go into her room, the doctors cautions me against touching her. I enter and am aghast by the sight of her face, arms and legs covered with a psoriasis like rash of puss filled sores. She has lost a lot of hair and much of her scalp was raw.

She is very sensitive about the condition, "Why are you here, am I some sort of freak show, get the fuck out. I heard you talking to the nurses and social workers." It took some time and many apologies to convince her that I was there to help her. She broke down a cried after giving me permission to stay awhile.

Brunilda is a very special lady. She is an engaging personality, a unique ability "to draw you in." She would say "Gee, you're cute, if only I were younger." She has quite an inventory of dirty jokes too. "Lighten up, it ain't the end of the world, ... don't worry I won't bite you, but I can teach you a few things."

In time she begins to trust me and we speak of her life. She's been living with her sister for many years. "That bitch knows I get $80. cash and $100. in food stamps every month, that's why she lets me stay with her."

She has three children, but couldn't care for them because of her drug habit. "I let my sister take them. I think I did the right thing, I just can't provide for them. ...My sister and her husband, they made it you know, they have a home, both work... so I just turned over the kids. Sometimes I see them, they still love me.... what I can't give them, let someone else do it."

There's an irony in her life, "...when you are alive and have so many family, but you're all alone... the family is not really there (Una amista te hare mas que familiar- A friend does more than family). I'm a loner. I've had a bad life- this drug scene is hard."

She's had a habit for twenty years but, "...I made my bed, now [I] sleep in it. "You know you hear about this AIDS thing, but I just turned around and did it [shared needles]; having sex without condoms. That drug is powerful... I'm going to die using drugs." She admits to bringing drugs into the hospital. About three months ago, a friend staying on this floor in the hospital said "Yo te voy a currar- I will cure you;" she cooked up some manteca [heroin] and 'hit' her. "Maybe it wasn't the right thing to do in the hospital, but when you're strung out or enferma [sick] only a true user knows the feeling."

She speaks of her family again saying, "Look they know I was sick, it was real bad in that house. I passed out. Look, its been four days, nobody's come... family dumps you in here, they never come. I think this is my fifth time in here. They come when they can or need something.

Does the family know of her diagnosis? "I'm sure they know by now. I've been hospitalized so many times, they must know." Have you ever told them, directly? "Well, I tell them I'm very sick and maybe its the virus going around." Do you think that they understand? "Well, I think they do. We don't talk about it. It's like my drug use, people know and they just try not to see it."

Do your children know of the AIDS diagnosis? "Boy, you really know how to get to the heart... All of my life I've had to deal with people telling my kids there was this and that wrong with me." Maybe for the first time she would like to tell the children about her self? Angrily, "Let it alone! I'm not ready,I don't think I can handle telling them I might not be around much longer." I ask her to think about it, it may make a difference to the children in the future. "Stop it, butt out!"

Another AIDS patient comes into her room. She asks for leftover food. "Some things never change! Its like this on the streets, give me, give me, give me.... La pobre [the poor thing]... some people are like vultures." BM was recently ripped off, "... some motherfucker came into my room, could you believe it, where I was sleeping and took some change that I had in the drawer. Thank God, they didn't get the other stuff." I ask about the other stuff, "Come on nene- you so green- just let's talk about something else.

She has a pretty good idea as to what is happening to her body. "I'll just have to take care of myself more... I haven't kept my appointment with the clinic.... some days I feel good and I just say, Today I'm not going anywhere, so I just hang out."

She is discharged and returns to her sister's apartment. But returns five months later because of severe shortness of breath, wasting syndrome and a confirmed case of PCP pneumonia. She hides in her room with the lights turned off. There is no sign of the candid, kidding woman I spoke with months ago. Upon entering her her room, I am greeted with "Oh, here we go again!... I hope this won't be it." Her family does not visit. She remains in the hospital for two weeks, all the while in a darkened room. She resists talking and is withdrawn, depressed.

The hospital staff is not terribly sympathetic. They nicknamed her "the Pain." They say, "...here she goes again, she does it to herself; she'll never learn!"

A week later she expires. A few days later to my surprise, the family comes to the hospital. They complain about not being notified as to the seriousness of her case. "Where's the body, we want to see her." A nurse tells them that they will have to go down to the morgue. Near pandemonium breaks out. As the assigned caseworker, I try to offer supportive counseling. Some of them have no idea as to the cause of death. They are all grief stricken. Others are so angry, they fight with one another.

Norma: Norma is a 28 yr. old, Black, Hispanic woman who was hospitalized with an advanced case of PCP Pneumonia. She has been homeless for nearly one year. Mother to two children; a boy 11 yrs. and girl 10 yrs. Both are in foster care.

There has been no medical treatment since she was diagnosed with AIDS two years ago. She's been living with a 22 yr. old heroin addict. She found out that he was a IVDA about three months into their year and a half relationship. He died just under two years ago. "I never though he would give me AIDS."

They did not use condoms during sex. She denies sharing needles with him. "...I used to snort my manteca [heroin], in fact I could go for a bag right now. She last used two days before coming into the hospital.

Her understanding of the diagnosis: "I know I'm dying. The kids are the only thing that bothers me. I can't deal with this pain, my whole body hurts... I just want to see my kids, can you call my social worker and ask him to bring the children as soon as possible?" Visiting arrangements are made for the children.

"I just want to be with my kids before I go." She has no other family. She hasn't seen the father of her children since they were born. Her mother and sisters have not been in contact with her in three years. They visited her children in foster care for a while.

The children's visit goes as scheduled. A few days later Norma's condition worsens. "I think I'm unfortunate to have this. I don't know why I have this. My poor boyfriend is dead, It's nobody's fault. It's just something that happens. I'm already pure with God. I hope I make it to Heaven." Well why wouldn't you make it?, I ask. "I don't know, sometimes I was making trouble; I took drugs." I tell her to forget the past. She wants a cigarette and I oblige. This angers the nursing staff since the the presence of oxygen tanks clearly makes smoking a hazard.

One day I received a phone call from a co-worker informing me that Norma had expired.

Zita: During our first meeting "Zita" said that she did not like being alone in the hospital. She cried, "... why me?" There is a very limited understanding of her medical diagnosis.

She is afraid and dwells on the likelihood of growing weaker and more sick. But, she denies the possibility of HIV infection. "I'm sure I never got AIDS, ... I don't want to face it if I have it..."

The absence of her family makes dealing with the illness even more difficult. Her 9 year old daughter resides with "Zita's" mother. A 2 year old son lives with her boyfriend's mother. He recently tested HIV+. She shows me photographs of the kids and describes them to me. She is a proud parent.

The illness, uncertainty about the future and possibly avoidance prompt her to make plans for the children. "... this is something I never expected... [it has] really knocked me off my feet." She wants the respective caregivers to adopt the children. I am asked to contact a lawyer who can finalize her plans.

Nevertheless, she speaks of wanting to leave the hospital in order to start a new life.

She is disappointed about the care she receives in the hospital. She engages her family in intervening on her behalf with the nurses and doctors. They are in general very supportive and aggressively work to make sure that she is comfortable. They are particularly angry to find Zita from time to time resting in a bed soaked with urine. The inoperative call button is a major irritant. They are suspicious that the hospital will attempt a premature discharge; they cannot afford the cost of at home attendants.

Familial visits are irregular. Are they too disheartened by her situation or are there too many other urgent matters with which to deal? When they visit, there are flowers and home cooked meals. But, in my presence anyway they avoid direct discussion of the disease or the prognosis.

Nevertheless, she speaks of wanting to leave the hospital in order to start a new life.

Since our first meeting months ago she has lost weight and now weighs about 60 pounds. She can barely walk and complains of constant pains in her chest, abdomen and legs. She has difficulty eating.

No one is able to tell Zita what will happen as the disease progresses. Her immediate experiences are determined by the strangers who work around her and on her. This heightens her fear. "It's scary... Here I am kinda gettin' everything on a silver platter, you know people taking care of me. But, if I go out to the street I have to care for my self... It's not going to be the same.... I'm gonna have to take care of myself. It's weird all of a sudden, everything is taken from you." The stress, fear and boredom of being bedridden result in wide mood swings. "... sometimes up and sometimes down.... I'm getting tired of being here... It's depressing... I want to go out to the world, do the best I can." I wonder if Zita's hope to leave the hospital was just her way of dealing with the fact that she's dieing and would ultimately live her remaining days in this place.

Since Zita's case is less than critical, the hospital administrator's aggressively pursue Zita's discharge to a long term care facility or low income housing project. In their opinion she has been here "... too long." They focus on her strengths and down play her "guarded condition." The family is unable to provide the constant care she would need at home.

In time we are contacted by an HRA? social worker in order to discuss the possibility of securing an apartment for Zita. There is concern that she will not be able to care for herself even with the regular calls of a home attendant. Zita admits that she is weak and that the situation will not be easy to manage, but she's anxious to try. The hospital environment has become so depressing to her that it may be affecting her recovery.

A few days later I call on Zita to find that she is having difficulty breathing. She is in no mood to talk with me today. I leave, planning to visit with her again the day after tomorrow. But, I would be informed by a hospital administrator that she died that day. There is speculation that she died in the morning although she wasn't discovered until the early afternoon by the staff person working on her anticipated release.

Anne: ...is a 43 year old Black woman diagnosed with PCP pneumonia, anemia, oral candidias and AIDS. This is her second hospitalization in two weeks. At first she refused the Broncosophy which prevented a thorough diagnosis. But, on the second visit it revealed the extent of her condition.

She has a history of substance use. But, tells me that she stopped using Cocaine, 'crack', heroin and alcohol nearly 8 years ago. Anne has experience as a prostitute as well. She is homeless and until her hospitalization has been staying in "... a place filled with 'crack' and Heroin people."

Anne perceives a great difference in the way the nurses treat her since the diagnosis was pronounced. The frustration and anger combine with the loneliness ("... I'm down and out, nobody comes [to see me].") and fear of the disease to leave her moody and agitated. She doesn't have much of an appetite either. "When the doctor's told me, my whole shit changed. I was cursing to myself. I cried.... Look, I've just been exposed to HIV. Do YOU think I got a chance?...I'm hurt.... Why me? Why did this happen to me?"

For the most part, Anne appears resigned to her demise. "I know all about it [AIDS]. I'll leave it in God's hands. I know I don't have much time. I know what's happening. I know I'm going to get sicker... I'm a fighter, I'm a Cancer. I leave it in God's hands. If it ain't my time. I'm not going no where."

There is too, the seemingly conflicting drive to survive. "I'm going to kick down to the last of it [breath], with God's help maybe I'll be here for ten years.... When I get out of here I want my own room. I don't want to be with anyone. Shit, I refuse to go down. I want another chance."

In time as the disease progresses she begins to have more difficulty. On two occasions she passes out. This is frightening and increases her feelings of depression. Anne begins to withdraw. I find her laying in bed in the fetal position. She prefers to leave the lights turned off and the door closed. "I want to be alone..." When she speaks to me, she appears confused, unfocused and disoriented.

"What's gonna be is gonna be.... I'm gonna die [but] I just can't think about it." Beyond this, Anne will say nothing of her feeling about death and dying.

In time Anne's condition worsened. She began to experience high fevers and swelling (ademia). There was difficulty breathing and she was intibated. I'm asked to contact her family. I sent a telegram to an address listed in her case record. There was no response. No one came.

Days later she remains on the respirator. The ademia has worsened. The doctor's expect renal failure. We spend time together quietly. When I hold her hand her eyes open and she winks at me. She struggles to breath even on the respirator. The doctor thinks she made need to be suctioned"...but, perhaps this is it."

She struggles to get out of the bed which angers the doctor. I know she's terribly afraid and tell her it's okay to let go if she wishes. I wiped the tears from her eyes. She winks at me and grabbed my hand. Moments later, she died.

Jerome: ...is a 44 year old gay male, originally from Jamaica, West Indies. I was amazed by the sight of him at our first meeting. His face, arms and legs were covered with purple lesions, a manifestation of the cancer called Kaposi Sarcoma. He is in extreme physical discomfort and pain. He vocalized an excellent understanding of the medical diagnosis and prognosis But, he does not want to think of that now. "... I though about it the first time [I heard about it]. I just accepted it! What can I do? There's nothing I can do. I'm not denying this.... I just hope for the best... I don't want to lose hope, oh my dear God!"

The disfiguring lesions characteristic of Karposi Sarcoma which covered his body made Jerome reluctant to leave his room. To avoid the sight he nearly always left the lights turned off. He is particular about changing the bed linens. The staff is accommodating in this, although they gave him a hard time about it. They were not especially gentle when pulling him up from the bed and made him sit in a chair outside the room while changing the bed. This bothered him because he did not want people to see him.

During his hospitalization he focused on the business of living [Social programs such as SSI, Medicare crisis intervention referrals, SS Disability]. An important goal was discharge to his home setting. But, this was not to be as his condition worsened his needs escalated beyond the capacity of home care providers to meet them.

Jerome was fully conscious of his near demise. He spent a lot of time talking about his faith in God. He sometimes asked that I read to him passages from the Bible. He liked to listen to religious music so I secured tapes from his church and the hospital loaned a tapeplayer (which was later stolen from the room). But, the arrival of death was not so much a topic of conversation ([That's] in God's hands...") as the recollection of what life had been like for him. In his frame of reference life was finished.

In terms of the staff there were some nurses and other hospital personnel who would bring John coffee in the morning. During their shifts they stopped by to ask how he was doing, perhaps bring things such as clothes or newspapers. They were genuinely concerned for his welfare.

But, there were others who made his experience difficult. These were the tourists, who called on him only to view his facial disfigurement. They'd say "... that's what AIDS can do... you see, he's a homosexual. If he weren't doing those things he wouldn't be here. God don't like ugly.... God don't like that anti-man [the West Indian equivalent of faggot] stuff."

During our last visit, Jerome began to fade, slipping into death. He asked that I have a minister visit him. Jerome was Protestant but I was only able to get a Catholic priest to pray with him. He died some time later; alone and unattended.

David: ...is a 38 year old Puerto Rican male. Brought into the hospital ER in acute distress. He has difficulty breathing and high fevers. The medical diagnosis is 'rule out' Pneumocystis Carinii Pneumonia (PCP). He is transferred to the medical unit.

He has a long history of intravenous drug use. He was 'using' the morning he fell ill and was rushed to the hospital. He blames the hospitalization on a bad bag of heroin. He started using after his wife left him, taking the three children with her.

The diagnosis worries him. He is comforted by other family members, however they are not a calming influence. In fact his brother, sister and mother are nearly frantic. Intermittently, they rush back and forth to the nurse's station for pillows, blankets and information about David's condition. But, the test results are not yet available and the nurses begin to lose patience with them.

This morning, I find David laying in bed, shirtless and wearing rosary beads. He wears an oxygen mask and responds to me by writing on a pad.

Later that week his condition worsens and he his placed on a respirator because breathing has become very difficult with our assistance. The family reacts badly to the sight of him attached to the hardware. Every time it makes a noise, one of his sisters screams and runs for a nurse.

I think that specific information about David's condition and treatment might help to allay the family's fears. But, clinical facts are hard to communicate when people are in an intense state of anxiety.

Despite stabilization, David is very anxious. It took alot of comforting to calm him. He is conscious and alert however. The doctors believe that he has a good chance of recovering from the current crisis. Many issues are raised during this meeting. Inside the back cover of a Bible he writes " Am I going to make it?" He wants help finalizing his "...last wishes." His bank account and Social Security are to be left for the children.

Two days later I am informed that David died early that morning. He was highly agitated and the nurses on that shift had to restrain him. He was given a sleeping pill and later suffocated because there was too much mucous in his lungs.

The head nurse expressed disappointment that more adequate staffing might have provided for more attention to David's case. As things are the nurses have time to do only the bare minimum to serve the patient. If someone had the time to spend with him, they might have noticed the complications in time to save him. Then too, they would have had the time to calm him since he was so afraid of being attached to the respirator.

David's family was shocked to learn of his death. It may not have helped to receive the news by telephone. They angrily demanded to speak with the hospital administrator and physician assigned to his case. By the time they reached the hospital, the body had been transferred to the morgue.

Remingo: Remingo is 36 yrs. old, a Hispanic Male who entered ER in medical crisis. He had diarrhea and a high fever, was seriously underweight and diagnosed rule out PCP pneumonia. He told me of his long history as an intravenous drug user. He prefers manteca, heroin; but when its unavailable he uses 'crack' or cocaine.

Presently homeless, he has lived on and off in various men's shelters. He would prefer not to return to the shelters after discharge because he has been robbed, mugged and beaten by other shelter residents.

He calls himself a drifter. When he does not stay in the shelters, he sleeps on trains or abandoned buildings, sometimes with women who take him in when he has drugs to share. Eventually, they kick him out. To survive he steals, mostly car radios, food or when possible he combs the vacant buildings for scrap metal or empty cans. "...when you got cash you got drugs, women and friends."

His family lives in Puerto Rico. He left because he did not want them to know he used heroin. He hasn't seen them for five years. Upon arrival in New York, he met a woman with whom he lived for a while. He and a friend started to deal heroin. In time his girl friend ran off with his partner. He started to use more of the drug as a way to cope with the betrayal.

Now, there is no one in his life. "You know its been a while... I've gone from this one to that one... I just don't got no one to love me. I've never had that. I'm a loner, just surviving on those damn streets... It's hard in New York, people don't give you a chance."

Today, Remingo is scheduled for a broncosophy to verify the presence of PCP pneumonia. The results are negative.

He shows me a scar under his right arm. He had stitches there for five months. He did not return to the clinic to have them removed. "Do you think they'll take them out here?" I encourage him to ask the doctors. "Ah, no me voy a molestar- I'm not going to bother myself."

A fellow patient shares with him some of the food brought by family members. Remingo is happy about this; its been a long time since he has had a home cooked Spanish meal. This type of support is good for him. He likes talking to other patients, occasionally 'bumming' cigarettes from them.

The antibiotics cleared up Remingo's infection, the fevershave subsided. He grows stronger and is soon released. He's referred back to the shelter. But, three days later he is readmitted to the hospital. He felt a shortness of breath. A second broncosophy is suggested. He refuses, is given minimal treatment for a few days and discharged.

At first Remingo resists taking the routine tests. Still he is diagnosed 'rule out' PCP and Endocarditis. He has high fevers, oral candidiasis and anemia. A second admission to the hospital includes more extensive tests. He is found to be HIV+. Remingo is striking in his denial of the AIDS diagnosis. He admits only to having TB. He attributes his extreme fatigue to the drugs and homelessness he has experienced.

One month later, Remingo returns to the hospital in a more serious state. He has lost about 20 pounds, has high fevers and difficulty breathing. Now, he begins to fear having the AIDS virus. We talk for some time about the meaning of HIV seropositivity. Still reluctant, he focuses on TB and anemia.

This 'back and forth' leaves him confused. He doesn't know whether he has AIDS or TB. He does not want to face an AIDS diagnosis. But, a doctor confirms the HIV+ status. Remingo will not believe it. He becomes withdrawn and refuses to interact with the other patients. He stays in his room most of the time. But is observed talking to visitors, entering the rooms of other patients and is suspected by the staff of drug trafficking along with the friends of a patient in the next room. Remingo spent a lot of time in that room which was unusual considering that he was a loner and had recently become withdrawn.

During this time in the facility, Remingo spends most of the time alone, occasionally walking the hallways and borrowing cigarettes from patients and visitors. In a short time, his condition stabilizes and he is again discharged.

As his condition deteriorates he draws closer to the Pentecostal witnesses who visit the hospital on occasion. He seems to take comfort in the time spent with them. Remingo decides to join the church. For two months the Pentecostal witnesses were his only contact. In our discussions he expresses fear about what will happen next. When the fear is felt too strongly he changes the subject to Social Security and low income housing.

He complains about the hospital care. The doctors and nurses are the brunt of his complaints. He feels that they do not care about him or provide the care he deserves. He notes that more often than not the doctors peer into the the room and ask how he's doing that day, then quickly move on. " I don't understand that. What's going on here? What do I have? Why don't people level with me?"

During my visits, I attempt to focus on the diagnosis and prognosis. Remingo resists talking about the illness or the prospect of dying. But, over the next few weeks his condition declines. During our time together I held his hand and tried to make him comfortable with the process of letting go. In these last few days he "... started to take care of things." He asks that the Pentecostal witnesses spend more time with him. Even now however, there are rumors that he has also been keeping time with visitors suspected of supplying drugs to patients.

Suddenly, he expired. A few of the staff think it was a drug overdose.

Alberto: Alberto is a 43 yr. old homeless, Hispanic male with a sporadic history of intravenous drug use. By his recollection he hasn't had Heroin in three years. He has been married twice, but is now separated from the second wife. This is the fifth hospitalization in two years and his fourth bout with PCP pneumonia.

He was uncustomarily frank and open, "I know what I got.... La Sida [ ] ... I got my days... I'm going to try and take care of myself.... How long do I have to live?" He knows that he will not recover from this disease. And copes by remaining very still in his room, alone and in prayer. There is a calm, quiet strength about him. He is for the most part cooperative with the medical staff.

His body was shaking uncontrollably. He could not get out of the bed and begged me "...not to let my mother see me like this, can you please stall them." Alberto's mother is visiting from Puerto Rico. She plans to stay for one month. They agree to postpone their visit for a few days.

He has played the conga drums in bands on and off all of his life. "Drugs and music have been my life for a long time."

Alberto has been homeless for three years. His last apartment burned down and he has been unable to find one he can afford. He's lived on and off in men's shelters. Occasionally, he stay with a brother. The brother is difficult to live with because he has a drinking problem and becomes violent.

Alberto is estranged from his family. He has not seen a sister, who lives nearby for five years. He has not seen his mother more than three times in the last five years.

He has been a drug user for twenty five years. He started using Heroin and Cocaine when he was in Puerto Rico. He entered a Methadone treatment plan nearly three years ago. His last IV drug use was nine months ago. He reverted to drug use when he left a shelter to find his treatment clinic had closed. "Me tenia que currar, I had to cure myself, so I shot up."

He well understands the medical diagnosis. "Well I got some days left and I have to try to take care of myself... [aggressively,] Look, I can't and won't go back to the shelter. I just can't go there, I'm sick." An application was filed to obtain SSI as a supplement for the public assistance he receives.

Two days later I meet Alberto's brother Felix who arrives at the hospital quite drunk. They argue and Alberto asks Felix to leave. Before leaving, Felix tells me, "I don't know what I'm going to do. I feel for my brother, but I can't have him in my apartment, its just one room." He has a limited understanding of AIDS, "...how am I going to tell the family? I haven't seen them for some time... Both Alberto and I are the 'black sheep' of the family." I encourage Felix to go home, rest and return when he's feeling better. He became angry and cursed me, then decides to sit in his brother's room. They argue again and Alberto throws a pitcher of water and the food tray at Felix. The hospital police escort Felix out of the hospital.

Five days later, Felix returns a little calmer to surprise his mother and sister who are visiting Alberto. Each is cordial. The mother is comforting, but she has not be informed as to Alberto's diagnosis, rather that he has a bad case of pneumonia. She hopes that he will recover soon, so she can return to Puerto Rico next week with a clear mind.

During another visit she, still uniformed, prays with Alberto. She reminds him that she's going back home; all of the noise here disturbs her. She doesn't like "being locked up in the apartment." She asks that Alberto "...give himself to God" and she disparages his past life. He is asked to promise that "... he will let the Lord in..." Alberto responds, "I already walk with God, don't worry." He encourages her to return home.

My discussions with the family were attempts to recruit their assistance in Alberto's eventual discharge.

I remind them of his homelessness and serious medical condition. But, "...it's very difficult for us to do anything, we just can't." Alberto's mother begins to cry. "I could do more. If only Alberto would do something with his life, maybe he could come to Puerto Rico."

Despite their inability to help Alberto, they bring him home cooked food everyday. As planned his mother returns to Puerto Rico and his sister visits, but less frequently.

During the next few days, Alberto's condition worsens. He complains of severe headaches and throat pain. Complaints are not restricted to the physical. He is dissatisfied with the staff. A request he made for aspirin last night, still has not been fulfilled. He speaks in a very low voice, "Oh my God, what are these people doing to me? Almighty God, please help me!"

His condition grows steadily worse. His face becomes shallow and gaunt. His heavy breathing sounds like rattling. The next day he is intibated and transferred to ICU. All the while conscious. The family is notified and his sister, accompanied by her husband and Felix, visit the hospital. Emboldened by fear and nervousness, Felix tells his sister that Alberto has AIDS. She becomes furious that this information was withheld. I try to convince her that only Alberto had the right to tell her. He was trying to find the words. ? Their primary concern is about contagion since they have small children at home.

One week later Alberto is removed from the respirator and transferred out of ICU. For the next several days he rests quietly. He can not speak and communicates by note. He refuses to see with his brother or sister about the diagnosis. He feels ashamed; it is impossible to face the family.

During our sessions he focuses on how well he is caring for himself; eating all of his food, taking his medicine and sleeping as much as possible. It's almost as if he believes that if he's 'good' and listens to the directions given by his attendant that his life might be prolonged.

We spoke little of his imminent death. If I raised the subject, he would change it in short order. Acceptance of the reality could not be translated into a frank admission to other family members. His mother has been told that he has pneumonia. My repeated attempts to encourage him to tell his family about the diagnosed were rebuffed. He felt that they would not understand. Since the relationships were already estranged, he felt that they would abandon him altogether.

A few days later Alberto began to have respiratory complications. He was transferred to ICU and intibated. This was his first real experience with the many permutations I had described earlier. The experience left him frightened and withdrawn. Attached to the respiratory, there was little he could do. But, he spent much of the time holding and reading his Bible.

Over the next few days he continues to rest. A truce was struck with Felix and they discussed his diagnosis. Early two days later the 'Code Blue' was sounded and he was returned to the respirator. After a few days, his condition improved. He was given oxygen at regular intervals and eventually moved out of the ICU. He interpreted this as a reprieve; God had given him another chance. This comment is significant in light of the fact that he is so very ashamed of the disease and his experience as a drug user.

It would be some time before Alberto could speak again because of the intubation. We communicated by pad. He wrote of the plans that he and is brother were making after the discharge. Alberto hoped to find his own apartment, a place where he could live during the rest of his life.

But, five days later Alberto died quietly on a respirator. It took some time to reach the family. When they came for a visit they were informed of his death. The body had already been transferred to the morgue.

Confused, bewildered and more than a little angry they demand to speak with his physician. He tells them about the deteriorated state, intibation and three resuscitations. During the last 97 days the staff had done all that they could to save him.

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