

Tammiann Searle, a Sociology major, will be beginning her senior year at the University of New Hampshire this fall 2007.

The Psychosocial Stresses of Living with HIV and AIDS

Acknowledgements

This research would not have been possible without the help of so many people with whom I have grown very close to over the past year. I owe a huge debt of gratitude to the Knysna Aids Council, Knysna, South Africa for allowing me the opportunity to get to know the people who frequent their organization. Thank you to Millicent Seela (Director), Femke Hamming (Volunteer Coordinator), Nomalalu Fanti (House Mother), (Patricia Hartnic (Administrator), Susan Molo (HIV Counselor), Chapita Cima (HIV Counselor) and all the members who have taught me so much about HIV and living with the virus. I have learned invaluable lessons from all of you about the services needed to combat HIV and AIDS. And most importantly, to my best friend Aaron Wrightington (1971 -1998), who inspired my life's passion to assist people affected by this virus.

The Psychosocial Stresses of Living with HIV

Our awareness, as a human race, to the Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) began in the spring of 1981 (Montagnier, 1994). These names were not given to the disease at that time, for the understanding of the two was far less than it is today. Over the past 25 years since the discovery of the retrovirus HIV which causes AIDS, we have learned much about their physiological and biological characteristics. As people with HIV and AIDS are living longer we are also learning more about the psychosocial stressors related to the disease and the means for providing medical and psychological treatment to people who are infected and affected by the disease.

In the spring of 1981 the Centers for Disease Control (CDC) received reports from a clinician by the name of Michael Gottlieb, who believed he was coming across a potential epidemic. In a hospital in Los Angeles a number of young homosexual men were dying from pneumocystosis, a severe form of pneumonia. The disease was caused by an infection from a protozoan called *Pneumocystis carinii* that is usually very easily managed by the body's immune system. The parasitic disease was so rare that the only manufacturer of one of the medicines to cure it never went through the process that would make it readily available for sale. This meant that the CDC controlled its distribution, and started to recognize and increase in its demand. Around midsummer of 1981 a CDC task force was directed to give a profile to the disease that was waging war on the immune systems of many young gay men (Montagnier, 1994). "In late 1982, the CDC decided to give a name to this unidentified illness, which for a while had been called GRID (Gay-Related Immunodeficiency). It now became AIDS" (Montagnier, 1994: 45). By this time the disease had infected 850 people in the United States and Western Europe (Montagnier, 1994). Seventy-five percent of the infected at that time were homosexuals or

bisexuals with multiple partners and twenty-five percent of them were heterosexual men, women, children, intravenous drug users, hemophiliacs, and recent Haitian immigrants to the United States (Montagnier, 1994). This was only the beginning for researchers, but they had evidence that could give them some direction. Through further AIDS research over the course of many years, we have come to gain extensive knowledge about the retrovirus HIV, which weakens the immune system through viral replication and causes AIDS.

There are distinct differences between being HIV positive and living with Acquired Immune Deficiency Syndrome (AIDS). An individual who has contracted HIV has viral particles in their body but is not necessarily living with AIDS. HIV particles usually attach themselves to T₄ lymphocytes, presently called CD₄ which are a subgroup of white blood cells. HIV makes a protein bond with the CD₄ T-cells allowing RNA to replicate the virus, and then killing the CD₄ T-cells (Montagnier, 1994). An individual who is infected with the HIV virus will have a viral load, indicating the amount of HIV RNA present in their body. This measurement is the number of HIV RNA per milliliter of blood. CD₄ T-cell levels are also regularly checked by a physician in people living with HIV. A person who is HIV negative will have a CD₄ T-cell level between 500 and 2000. The CD₄ T-cell level is one of the defining factors between being HIV positive and Living with AIDS.

When an individual who is HIV positive has a T-cell count of less than 200 they are considered to be living with Acquired Immune Deficiency Syndrome, meaning the provirus, AIDS, has taken course. Their T-cell count may again rise to a number greater than 200, thanks to advances in medication, but they will still be diagnosed with “full blown AIDS”. The other defining factor of living with AIDS is being HIV positive and contracting an opportunistic infection. Opportunistic infections can come in many forms: bacterial, fungal, malignancies, protozoal, viral, and neurological. In short, diagnosis for AIDS is being HIV positive and having

a T-cell count lower than 200 at one point or another, or having an opportunistic infection, such as; Hepatitis, Herpes, Human Papilloma Virus, Syphilis, Salmonella, Kaposi's Sarcoma, Lymphoma or AIDS Dementia Complex. HIV and AIDS can affect all aspects of the body, depending on the individual and the HIV virus, as it too is unique to each individual (Montagnier, 1994).

In 1996 the Centers for Disease Control reported 580,000 cases of Acquired Immune Deficiency Syndrome and more than one million others who were living with the Human Immunodeficiency Virus in the United States alone. In 1997 the CDC reported a decline in the incidence of AIDS and a 23 % drop in the number of AIDS deaths (Gorp & Buckingham, 1998). "These figures reflect increased success with the medical care of HIV/AIDS including the development and increased utilization of antiretroviral combination therapies" (Gorp & Buckingham, 1998: 10). As of 2004 there were 42,514 documented cases of AIDS and an estimated 1,185,000 cases of HIV, approximately 25% of who are undiagnosed or unaware of their status. Since 1981 there have been a reported 529,113 deaths from AIDS (Centers for Disease Control).

Making the decision to be tested for HIV is a difficult one in itself, and if a person tests positive for HIV, decisions regarding the course of treatment can be even more difficult. There are a number of factors to consider throughout the course of treatment. One of the most stressful aspects of treatment is that there is no one perfect treatments for HIV; no two HIV viruses are alike (Montagnier, 1994) making the course of treatment very tedious. Sometimes many different treatment combinations need to be tried before the best match is found for each person infected with HIV. Some strains of HIV are resistant to certain drug therapies, again making the process very overwhelming. Compounding this process is the factor of cost and thus availability (Dilley, Pies, & Helquist, 1993) as well as the fact that some people test positive so late in the

course of the disease that they cannot work, and thus losing their income until a treatment option is found. People who are weighing their treatment options must also consider whether they can maintain such strict regimens as antiretroviral cocktails can be very intensive and specific in relation to the number of pills and times a day they are taken. Many drugs also have side effects, which also vary from person to person, so individuals very often have to see which side effects affect them the most (Dilley, Pies, & Helquist, 1993).

However, there are some effects of HIV that cannot be combated by antiretroviral therapy alone. These are the neuropsychiatric effects of HIV. HIV can affect all aspects of the body, joints, muscles, immune system, nervous system and the brain. Many of the effects on the brain are caused by opportunistic infections. “In the United States, the most frequent [central nervous system] opportunistic infections leading to neuropsychological deterioration are cerebral toxoplasmosis [10-15% of all HIV infected Patients], cryptococcal meningitis, and progressive multifocal leukoencephalopathy” (McArthur, Selnes, Glass, Hoover, & Bacellar, 1994: 251-272). Cerebral toxoplasmosis usually causes abscesses on the basal ganglia and frontal lobes, however, it is treatable with pyrimethamine and sulfadiazine in 80% of cases (McArthur et al., 1994). According to Rainiko, Elovaara, Vira, Valanne, Haltia, & Valle, structural abnormalities, such as cerebral atrophy are found in 70% of people in the late stages of HIV infection. HIV also affects the functioning of ganglia as seen through PET scans (McArthur et al., 1994).

“In 1987 the Centers for Disease control published diagnostic criteria for HIV-related encephalopathy” (McArthur et al., 1994: 3) also described as AIDS dementia complex and now defined by the DSM IV as Dementia Due to HIV. The DSM IV gives a case study of a man who owned a multinational corporation, but 8 months prior became ill. He had since lost 85 pounds, suffered from diarrhea, fatigue and did not enjoy eating the way he used to. The man continued to worsen, becoming delirious, frequently hallucinating, and was often incoherent, even in his

first language, Spanish. The man had been sexually active with prostitutes in the Far East, but left his doctor in disbelief that he could have AIDS. His wife brought him back six months later for an evaluation of his mental status. His physical health was good, but he remained disoriented, confused, had short-term memory loss and could not perform simple calculations.

Delirium caused by HIV is another neuropsychiatric disorder that affects an individual's awareness to their environment. This is accompanied by memory problems and illusions and develops over hours or days and fluctuates throughout the day. The difference between Delirium and Dementia due to HIV is that Dementia due to HIV will also involve abnormalities in cognitive and motor functioning. Minor Motor-Cognitive Disorder is a diagnosis for less severe, subtler difficulties in motor and cognitive functioning, but does not necessarily progress to Dementia Due to HIV. Treatment for neuropsychiatric disorders caused by HIV may include antiretroviral therapy and psychotropic agents (Gorp and Buckingham, 1998).

Also common to people with HIV is depression, "Like most people who are told they are HIV positive, Marvin has become increasingly anxious and preoccupied with thoughts of his illness and death" (Spitzer, Gibbon, Skodol, Williams, & First, 1994: 402). Marvin is depressed, however, not diagnosable with Major Depressive Disorder or Anxiety Disorder because he is not experiencing mood symptoms that fit the diagnostic criteria and his mood may be brought on by his medical condition. He is diagnosed with Adjustment Disorder With Mixed Emotional Features and Depressed Mood because of his knowledge of his HIV infection. There are certainly cases of HIV positive individuals how are suffering from Major Depressive Disorder or Anxiety disorder and Marvin could progress into either of these if he does not receive professional help (Spitzer et al., 1994).

In assessing depression in people with HIV and AIDS several issues arise that warrant specialized consideration. The primary difficulty in assessing depression in people who are

infected, is distinguishing between symptoms of depression and those of physical illness. Symptoms that are usually used as diagnostic criteria for Major Depressive Disorder are also common effects of the HIV virus. These symptoms are fatigue, diminished sleep and appetite, weight loss, and somatic complaints that are likely in part from the physical illness. Measurements used for screening, such as the Beck Depression Inventory, Hamilton Rating Scale for Depression and the MMPI-2 have been known to show false positives in people with HIV. The Geriatric Depression Scale minimizes the influence that physical symptoms have on assessing depression. It is very important to assess the potential for depression in people with HIV because of the risk that it may lead to the “dementia syndrome of depression” (Gorp & Buckingham, 1998: 28) causing complications with cognitive functioning.

Related to depression, regarding HIV status is anxiety brought about by a number of concerns. Symptoms of AIDS anxiety include, but are not limited; to panic attacks, phobic symptoms, generalized anxiety, morbid obsessions, anger, depression, persistent hypochondria, self-absorption and despair. Due to the social nature of the illness, virtually all individuals have experienced serious disruptions in their life that go beyond those attributable to any other physical illness. Such anxiety about living with HIV can cause severe life changes including poor concentration and performance, withdrawal from co-workers, friends, family and even doctors. The most severe of these symptoms usually occur upon testing positive for HIV-antibodies or being diagnosed with HIV-related disease (Dilley et al., 1993).

Along with the risks of these psychosocial troubles is the risk of self-medication by means of alcohol and drugs. Such behavior puts the individual at risk for greater health problems, other high-risk behavior related to HIV transmission, co-infection and re-infection. Substance abusing behaviors need to be addressed in conjunction with medical and psychosocial treatments because people with HIV who exhibit signs of substance abuse tend to report poorer

adherence to antiretroviral therapy than do people who do not exhibit signs of substance abuse (Tucker, Orlando, Burnam, Sherbourne, Kung, & Gifford, 2004).

“The following are common symptoms of a substance abuse problem to evaluate:

1. Emotional, social, relationship, employment, legal or other difficulties that can be linked to the use of alcohol or drugs;
2. Loss of control of frequency or amount of use;
3. Preoccupation with drug(s) or alcohol;
4. Self medication for anxiety or sadness with drugs or alcohol;
5. Drinking or using drugs while alone;
6. Rapid initial intake of drugs or alcohol;
7. Protection of drug or alcohol supply—stocking up or hiding supply;
8. Tolerance to large quantities of alcohol or drugs
9. Withdrawal symptoms; or
10. Blackouts (with alcohol abuse)” (Dilley et al., 1993: 128).

Further diagnostic criteria can be found in the Diagnostic Statistical Manual, Fourth Edition.

Individuals who are considered to be substance abusers present additional psychosocial concerns because of issues of denial that are usually a characteristic of such abuse. Substance abusers commonly deny the potential threat or reality of having HIV or AIDS. Concerns are equally elevated for people who are IV drug users and HIV positive because of the stigma related to both the behavior and the virus. Additional support is required for substance abusers who are in recovery and dealing with the stresses of living with a life threatening illness.

HIV and AIDS are drastically different from other life-threatening illnesses because society has formed negative cultural outlooks active stigma that likely plays a significant role in

the ways in which individuals deal with the initial news that they are HIV positive and how they manage it in relation to society and those close to them. This distinct and uneven interaction between the individual and society brings about the topic of psychosocial concerns. Psychosocial concerns draw from a wide variety of topics; a need for information, distressing feelings, periods of crisis, substance abuse, a search for hope and social support (Dilley et al., 1993). These concerns are all interconnected and one event can draw on all of these categories. Take, for instance, the example of a twenty-seven year old homosexual male who has just found out that he is HIV positive. Like many people, his knowledge regarding HIV is limited and he is uncertain about his future health, sexual activity, income, and family stability based upon such a diagnosis. This causes him great distress and he does not know whom to turn to. So he shares his status with his family in hopes that he can find support in them, but his father, who has never truly accepted his homosexuality is disgusted and will no longer talk to him. It is too hard for his mother to see him because of the arguments it causes between her and her husband. He reaches his period of crisis, where he has lost all family support. He turns to excessive drinking and abuse of sleeping pills just to get through his days and nights, wondering what HIV will do to him next. At his next appointment with his physician he smells of alcohol and looks exhausted. His doctor talks to him about structured support instead of alcohol and refers him to an AIDS Service Organization (ASO). At this ASO he is given a case manager who encourages him to see one of the organizations' psychotherapists and to sit in on a support group session. The young man finds strength and safety in this community of people, many of who have been through such trying times as he. This is certainly a best-case scenario, but it appears to be the reality of living with HIV. This young man fared well as a hypothetical creation based upon information regarding loss, uncertainty, second coming out, identity, sexuality and meaning in life. (Weiss, 1997). Not everyone is so fortunate; the nature of the virus' life-threatening

characteristics can cause additional stressors for individuals who are infected and for those around them.

The emotions caused by death are not easy for anyone to cope with. However morbid, the topic of death is it is closely related to HIV and AIDS, necessitating further analysis. According to a study done by Martin & Dean (1993), the loss of a close friend or lover due to HIV or AIDS results in symptoms of depression, traumatic stress, sedative use, and suicidal ideation. They also found that having HIV and losing a close friend of lover to HIV or AIDS intensified feelings of distress and bereavement. “Losing a significant other to death is considered one of the most stressful events in a person’s life” (Dilley et al, 1993: 267), and more so for the AIDS bereaved who are living with HIV. Being HIV positive and losing someone close from HIV or AIDS makes the process of bereavement that much more complex because of the personal fears of death that the experience brings about for the bereaved (Dilley et al., 1993). This accentuates the need for a structured forum for the personal expression of feelings regarding loss, uncertainty and death.

Developing supportive ties with family, friends, community members and others who are living with HIV and AIDS is important to coping with psychosocial stressors and a medical illness such as HIV/AIDS. Such support networks allow individuals to maintain a sense of hopefulness and interconnectedness by discussing issues and problems related to the illness, while among people who are experiencing similar difficulties. These groups are useful with cognitive behavioral therapy (which work to change the thinking and behavior of individuals), therapy groups (expressing troubling feelings and experiences), and self-help groups for clients and their family members (Dilley et al., 1993). A study of cognitive-behavioral group therapy (CBGT) with medication for depressed gay men (Lee, Cohen, Hadley, & Goodwin, 1999) found that individuals’ core belief in regard to fighting the virus was, “Why bother? I’m going to get

sicker and die; it's no use" (Lee et al., 1999). Over the course of 11 months their results showed substantial reductions in the symptoms of depression, but feelings of self-blame continued to persist in these support groups. Support does not only come in the formation of social networks, but can also come from individual supportive relationships. A study comparing supportive individual relationships and medication adherence (Simoni, Frick, & Bu, 2006) in people living with AIDS or who were HIV positive found that supportive individual relationships correlated to improved medication adherence. These individual relationships with family members, friends, doctors and other clinical staff were regarded by the participants as being affirming, information enhancing, empathetic, or spiritual. The professional sector is also a productive means for support with regard to managing depression, anxiety, substance abuse and medication adherence.

Many people who are HIV positive or living with AIDS, who can afford it, chose individual therapy as their intervention of choice because of its structure in leading individuals to recognize and resolve grief. Various forms of individual therapies are useful for people with HIV and AIDS including supportive therapy, cognitive-behavioral, insight-oriented approaches. These approaches are particularly useful in addressing issues of managing distress, coping with loss, enhancing support, maintaining hopefulness, and maximizing decision-making skills. For the people with mental illness, individual therapy may be the primary means for education and support (Dilley et al., 1993).

In any form of therapy the role of the caregiver is vital to successful treatment or intervention. A therapist who is working with people who are infected and affected by HIV and AIDS must be especially sensitive and accepting to other stigmatized topics related to HIV and AIDS; substance abuse, IV drug use, homosexuality and mental illness (Gorp & Buckingham, 1998) (Dilley et al., 1993). Therapists and caregivers have a primary responsibility to protect the confidentiality of their clients and members who are affected by HIV and AIDS (Dilley et al.,

1993). However there is controversy over this topic regarding one particular area; the protection of third parties. Tarasoff policies outline conditions supporting breach of confidentiality in the duty to protect others who may be at risk for contracting HIV from people who are living with HIV or AIDS. The study "Do Tarasoff Principles Apply in AIDS-related Psychotherapy?" (McGuire, Nieri, Abbott, Sheridan, & Fisher, 1995) attempt to answer this question. The duty of a therapist is to encourage the client or member to reveal their status to those who may be at risk of contracting the disease by sharing needles or taking part in sexual intercourse. However, this issue is still affected by stigma and prejudice related to IV drug use and homosexuality. Evidence from the study (McGuire, Nieri, Abbott, Sheridan, & Fisher, 1995) predicts that therapists who are homophobic are more likely to breach confidentiality to protect a third party. The sample of therapists was likely to breach confidentiality if the client's behavior was perceived as imminently dangerous to others. Some therapists indicated that they might detain a client in an attempt to convince them to warn at-risk sexual partners.

Overall, the stressors that accompany HIV and Aids are as devastating as the disease itself. Its manifestations are as vast and unpredictable as the virology. The scope and magnitude of the psychosocial effects are overwhelming to those infected and affected by this disease.

REFERENCES

- Centers for Disease Control, (2005). *Statistics and Surveillance*. Basic Statistics:
Retrieved August 19, 2006
<http://www.cdc.gov/hiv/topics/surveillance/basic.htm>
- Dilley, J., Pies, C., & Helquist M., (1993). *Face to face: A guide to AIDS counseling*. San Francisco, CA: AIDS Health Project.
- Gorp, W., & Buckingham, S., (1998). *Practitioner's guide to the neuropsychiatry of HIV/AIDS*. Updated Version. New York: The Guildford Press.
- Lee, M., Cohen, L., Hadley, S., & Goodwin, F., (1999). "Cognitive-behavioral group therapy with medication for depressed gay men with AIDS or symptomatic HIV infection" *Psychiatric Services*, 50(7), 948-952.
- Martin, J. & Dean, L., (1993). "Effects of AIDS-Related Bereavement and HIV-Related Illness on Psychological Distress Among Gay Men: A 7-Year Longitudinal Study, 1985-1991" *American Psychological Association*, 61(1), 94-103
- McArthur, J. C., Selnes, O. A., Glass, J. D., Hoover, D. R., & Bacellar, H. (1994). HIV dementia: Incidence and risk factors. In R.W. Price & S. Perry III (Eds.), *Research publications of the Association for Research in Nervous and Mental Disease: Vol. 72. HIV, AIDS and the brain* 251-272. New York: Raven Press.
- McGuire, J., Nieri, D., Abbott, D., Sheridan, K., and Fisher, R., (1995). "Do tarasoff principles apply to AIDS-related psychotherapy? Ethical decision making and the role of therapist homophobia and perceived client dangerousness" *American Psychological Association*, 26(6), 608-611.
- Montagnier, L., (1994). *Virus*. Editions Odile Jacob. New York: W. W. Norton and Company.
- Simoni, J., Frick, P., & Bu, H., (2006). "A longitudinal study of a social support model of medication adherence among HIV-positive men and women on antiretroviral therapy" *American Psychological Association*, 25(1), 74-81.
- Spitzer, S., Gibbon, M., Skodol, A., Williams, J., & First, M., (1994). *Diagnostic and statistical manual of mental disorders*. Fourth Edition. Washington, DC: American Psychiatric Press, Inc.
- Tucker, J., Orlando, M., Burnam, A., Sherbourne, C., Kung, F.Y., & Gifford, A., (2004). "Psychosocial mediators of antiretroviral nondherence in HIV-positive adults with substance use and mental health problems" *American Psychological Association*, 23(4), 363-370.
- Weiss, J. (1997). "Psychotherapy with HIV-positive gay men: A psychodynamic perspective" *American Journal of Psychiatry*, 51(1), 31-44.