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ABSTRACT

In this paper, human immunodeficiency virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) are analyzed in terms of stigma and illness trajectory. The primary purpose is to conceptualize how individuals with HIV/AIDS experience stigma and to demonstrate how these experiences are affected by the social and biophysical dimensions of the HIV/AIDS disease course. This paper is informed by existing conceptualizations and ongoing research into the experience of HIV/AIDS caregivers. Three stages are used to analytically describe the HIV/AIDS illness trajectory: the At Risk stage, the Latent stage, and the Manifest stage. The Latent stage is subdivided into the Latent Acute and Latent Asymptomatic phases while the Manifest stage is subdivided into the Early Manifest and the Full Blown AIDS phases. It is noted that the nature of stigma and its management change as the individual progresses from one stage in the trajectory to the next. It is proposed that, in going from being at risk for HIV infection to full blown AIDS, the individual and the caregiver must address several problems: (1) the experience and impact of stigma; (2) information control and management; (3) identity changes; and (4) physical decline and impending death associated with HIV/AIDS. How the individual and caregivers address these and other problems of HIV/AIDS stigma are analyzed and discussed. (Contains 75 references.) (Author/NB)

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**STIGMA, HIV AND AIDS:**  
An Exploration and Elaboration of the Illness Trajectory  
Surrounding HIV Infection and AIDS

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## ABSTRACT

In this paper the human immunodeficiency virus [HIV] and the acquired immune deficiency syndrome [AIDS] are analyzed in terms of stigma and illness trajectory. The primary purpose is to conceptualize how individuals with HIV/AIDS experience stigma and to demonstrate how these experiences are effected by the social and biophysical dimensions of the HIV/AIDS disease course. This paper is informed by existing conceptualizations and ongoing research into the experience of HIV/AIDS caregivers.

The three stages and four phases used to analytically describe the HIV/AIDS illness trajectory are: a) the At Risk stage; b) the Latent stage with 1] the Latent Acute and 2] the Latent Asymptomatic phases; and c) the Manifest Stage with 1] the Early Manifest and 2] the Full Blown AIDS phases. The nature of stigma and its management change as the individual progresses from one stage in the trajectory to the next. In going from being at risk to HIV infection then to full blown AIDS, the individual, as well as their caregivers, must address the following problems: a) the experience and impact of stigma; b) information control and management; c) identity changes; and d) physical decline and impending death associated with HIV/AIDS. How the individual and caregivers address these and other problems of HIV/AIDS stigma are analyzed and discussed.

Since 1981 and the isolation of the human immunodeficiency virus [HIV], acquired immunodeficiency syndrome [AIDS] has become a personal, health, and societal problem. In the United States, AIDS has claimed over 133,232 lives [CDC, 1992], billions of dollars in societal and research resources, and the stigma associated with HIV disease has radically effected efforts of the gay community to be recognized as an alternative lifestyle. The illness will become an even greater problem since there are now an estimated 1 million HIV-infected persons in the United States [CDC, 1992] and persons with HIV disease are living longer [Moore, Hidalgo, Sugland and Chaisson, 1991; Gorman, 1993]. As a consequence there is a need to understand what these individuals are experiencing in terms of the disease process, social identity, stigma and an illness career. This understanding will enable provision of more appropriate health care and social services, development of more appropriate education strategies and an expanded understanding of the nature of stigma.

In this paper HIV disease and AIDS are analyzed in terms of stigma, deviance and illness perspectives, and trajectory or illness course. The goal is to conceptualize how individuals with HIV disease experience HIV/AIDS related stigma and also to examine the interaction between the social and biophysical dimensions of the disease process and trajectory [Strauss, 1984]. In addition, this analysis considers the various dimensions of stigma which have to be reconceptualized or specified to take into account the unique processional nature of the HIV and AIDS trajectory. No one to our knowledge has elaborated the relationship between HIV disease and stigma in terms of specifying the nature of the HIV/AIDS trajectory and the social processes of experiencing stigma or the

social trajectory of stigma. Many analysts have spoken to the fact that certain illnesses produce stigma but none have attempted to specify the critical points over the disease course where stigma is differentially experienced and managed. While it is acknowledged that there is no single trajectory for HIV/AIDS and that at the individual level each trajectory appears unique, it is also evident that by moving to a higher level of abstraction common themes become apparent as individuals simultaneously address the intersection and interaction of both the stigma and HIV/AIDS trajectories. In addition, it is important for both theoretical and applied reasons to provide an analytic understanding in terms of trajectories for both the patient and his caregivers, and for persons whose task it is to develop social policy, to manage social services, and to provide care and support for those stricken with HIV/AIDS.

This paper is informed by existing conceptualizations and ongoing research into the experiences of HIV caregivers [Reynolds, 1991]. We will begin with a brief background on the nature of stigma, followed by a discussion of illness and stigma, an examination of stigma and HIV/AIDS, and finally we elaborate on three stages of the HIV/AIDS illness course in relation to stigma. While the focus of attention will be gay males, and to some extent bisexual males, we will also, where appropriate, extend our analysis to other at risk groups, namely, injection drug users [IUD] and others placed at risk or having HIV disease.

#### STIGMA: DEFINITIONS AND CONCEPTUALIZATIONS

Stigma is a broad and multidimensional concept whose essence centers on the issue of deviance. As a starting point for this discussion Birenbaum and Sagarin [1976] offer a very useful definition of stigma. When we speak of stigma, they suggest, "we are discussing the entire field of people who are regarded negatively, some for having violated...rules, others just for being the sort of people they are or having traits that are not highly valued." [p 33].

In general there is consensus in the stigma literature that stigma represents a deviation from some ideal or expectation, whether the ideal is for correct sexual orientation or to be free of a disfiguring or fatal infectious disease. At its most basic level, stigma, from Goffman's [1963] perspective, is a powerful discrediting and tainting social label that radically changes the way an individual is viewed as a person. While Goffman [1963] circumscribes his comments on stigma as only applying to face to face encounters or "mixed contacts" between the normal and the stigmatized, we are hard pressed to find any author who would limit Goffman's stigma concepts to such a narrow set of situations. His stigma observations can be applied to face to face settings, as well as to societal concerns for discrimination and prejudice.

Katz [1979], interpreting Goffman broadly, argues that stigma encompasses a perception of a negative characteristic and a global devaluation of the possessor of the characteristic. Issues of isolation and rejection, and subsequent prejudice and discrimination, stem from the fact that we often try to avoid interaction with individuals whose bodily and psychological characteristics deviate from our own group norms [Katz, 1979]. Stigmas also have a temporal dimension in that they are ineradicable and irreversible as the terms ex-mental patient or ex-convict imply [Albon, 1981; Freidson, 1971]. In fact, stigmas may follow us through the life cycle [Ainlay, Gaylene and Coleman, 1987].

As Goffman [1963] notes, stigma is not merely an attribute, but represents a language of relationships. The possessor of a stigma, confirms the usualness of another. Stigma creates outsiders and social boundaries between normals and the stigmatized. In so doing, the life chances of the stigmatized are reduced [Goffman, 1963]. Thus, the meaning which guides this analysis is that the stigmatized are a pejorative category of people who are devalued, shunned or otherwise lessened in their life chances and in access to the humanizing benefit of free and unfettered social intercourse.

It is ironic, as Goffman [1963] suggests, that the stigmatized accept the norms that actually disqualify them from comfortable and equal participation in social interaction. Drawing from Goffman, Albon [1981] argues that deviants are doomed to "eternal stigmatization in their own eyes as well as those of society" [p. 8]. Freund and McGuire [1991] go even further by suggesting that self hatred, and we might add shame, develop from internalizing negative values and repressed anger from discrimination. The individual "stands a discredited person facing an unaccepting world" [Goffman, 1963, p. 19] all the while internalizing the perspective of the rejecters. This is not to say that stigmatized groups do not develop "sad tales" [Goffman, 1961] or ideological defenses to account for their plight. As Gassow and Tracy [1968] describe in the case of Hansen's disease, individuals develop theories that "attempt to disavow their imputed inferiority and danger and expose the real and alleged fallacies involved in the dominant perspective" [p. 317].

Stigma theories are developed to attenuate the process of self-stigmatization and correct misinformation and its consequences in terms of fear, prejudice and discrimination. Goffman [1963] further suggests that no matter how small or bad off a particular stigmatized group is they are given some kind of public presentation and an "intellectually worked-up version of their point of view is thus available to most stigmatized persons" [p. 25]. Television and films, aside from newspapers and magazines, are voracious consumers of human interests stories which allow us to vicariously enter the world of the deviant, the distressed, and the stigmatized. These sources of information have the capacity to enlighten, to liberate and to focus attention and generate sympathy and compassion. But for the stigmatized, these presentations also establish the boundaries between them and "normals." While the thrust of these presentations can engender sympathy, understanding and compassion, by expressing the point of view of the stigmatized group, they also stress the undesirability of membership

in the group by reinforcing norms of the normal community. The essential reason for developing strategies to disavow their imputed inferiority is because "normals" construct stigma theories to explain inferiority and account for the dangers they represent [Katz, 1979].

Stigmatized individuals, who are devalued, shunned or who otherwise have their life chances lessened, do however have one refuge to attain or regain their otherwise devalued and soiled identities. Stigmatized groups have generally attempted to have their deviation assessed, treated or otherwise managed within a medical framework. Placing oneself in the hands of medical practitioners and having one's deviation medicalized and turned into a disease, allows one to disavow inferiority by appealing to the randomness of disease and the potential medicine offers for absolution from responsibility.

#### STIGMA AND ILLNESS

Disease is a social construction which emerges from the value of life itself and health as an instrumental value in pursuing life. From an epidemiological perspective, disease is a natural consequence of environmental transactions with disease producing agents and genetic endowment. Disease is problematic to the extent that it interferes with pursuit of life in its biophysical, social and psychological, or generally human manifestations. Diseases are essentially deviations from what we expect or what we have been told to expect by our medical authorities. However, some diseases are imputed and laden with additional meaning and significance or become as Sontag [1978] notes, metaphors for sinfulness and evil. With stigmatizing illnesses "disreputability and even evil" may adhere to the person so afflicted [Freund and McGuire, 1991, p. 137] and, as Goffman [1963] notes, to his family and friends in the form of a courtesy stigma. Conrad [1988] further suggests that stigmatizing illnesses are connected to deviant behavior either by producing it,



as in the case of epilepsy or mental illness, or being a product of it, as in the case of a sexually transmitted diseases such as genital herpes or gonorrhoea. Illnesses which are stigmatizing frequently go through the process of first being considered sinful, next willfully deviant, followed by an illness and, finally, if lobbying efforts have been successful, a normal, accepted variation. Stigmatizing illnesses, however, do not attain full acceptance, at best only tolerance.

As Parsons [1951] and Freidson [1970] both point out, illness is generally not viewed as the responsibility of the afflicted, whereas within religious and judicial contexts responsibility adheres to the sinful and the lawbreaker and both must either atone or be punished for their failing. Ablon [1981] notes, however, that some diseases, more than others, are more biophysically discrete and identifiable and absolve the bearer from fault. These diseases, drawing from Freidson [1971], are classified as conditionally or unconditionally legitimate and depending on their imputed degree of seriousness, require the suspension of role obligations and the allotment of privileges by others. Freidson [1970] then suggests, following Goffman's [1963] views on stigma, that certain diseases are viewed as illegitimate and stigmatizing. From a social constructionist perspective, if one can socially and politically lobby for or against an illness in terms of whether it is sinful, deviant or an illness, then the degree of extrinsic meaning attached to it must have little intrinsic value, aside from the disease interfering with the value of life.

What is problematic in the case of stigmatizing diseases is the social imputation and construction of negative meanings that adhere to all those who have contracted it, who are destined to have it, or who are suspected of having it. The potential for discrimination on the basis of a stigmatic disease is so great that Nelkin and Tancredi [1989] speak of a "biologic underclass" who could be found to be unemployable, untrainable and uninsurable because of the potential

abuse of genetic screening to search out those whose biologic destiny may be tainted. Individuals stigmatized by disease are devalued, shunned or otherwise have their life chances lessened because the disease they have, or are suspected of having, discredits their claim to be "moral characters" [Goffman, 1959].

### STIGMA, HIV AND HIV/AIDS TRAJECTORY

In the following section, the issue of HIV infection and AIDS stigma is introduced. First, brief consideration is given to how and why HIV and AIDS evoke such a universally negative stigmatic response. Next, the convergence of the biomedical and social stigmatic models of HIV is addressed to specify the variable and processional nature of stigma surrounding HIV and AIDS.

#### HIV and Stigma:

HIV and AIDS are manifestations of an extraordinary disease in terms of its potential for multidimensional stigmatization. In essence, the HIV/AIDS stigma is a socially constructed reaction to a lethal disease [Herek and Glunt, 1988]. Unlike other socially constructed stigmas where the constructive nature is evident by our ability to change its meaning by education or legislation, HIV/AIDS has a definitive biological basis that cannot be defined away. Thus, a social construction which addresses both the social and biophysical basis of the stigma must be considered.

To explore the nature of this social construction three sources are initially drawn from to develop the framework for the elaborated HIV/AIDS stigma trajectory. First, Goffman [1963] defines three basic types of stigma: 1) character blemishes; 2) abominations of the body, and; 3) tribal stigma. It can be seen that HIV-infected persons qualify for stigma in each of these categories. Questionable morality of homosexuality entitle AIDS patients to be stigmatized on the basis of a character blemish. Bodily deterioration in the later stages [e.g., the wasting syndrome] qualifies as an abomination of the body and tribal

stigma can be established on the basis of possible genetic traits. Second, Katz [1979] distinguishes four dimensions of stigma [threat, responsibility, visibility and sympathy] which are used to explain variations in the construction of stigma and the strength of the negative response. Third, and in contrast, Jones, Farina, Hastorf, Markus, Miller and Scott [1984] distinguish six dimensions of stigma: concealability, course, disruptiveness, aesthetic qualities, origin and peril. Merging these last two lists of stigma dimensions and taking them at face value, without a detailed discussion of their meaning, and recalling the previous discussions of stigma, it is rather patent why HIV/AIDS arouses such a negative stigmatic response. Individuals with HIV and AIDS are stigmatized because their illness is: 1] associated with deviant behavior, both as a product and as a producer of deviant behavior [Conrad, 1986]; 2] viewed as the responsibility of the individual; 3] tainted by a religious belief as to its immorality [Strommen, 1990; Kayal, 1992] and/or thought to be contracted via a morally sanctionable behavior and therefore thought to represent a character blemish; 4] perceived as contagious and threatening to the community; 5] associated with an undesirable and an unaesthetic form of death; and 6] not well understood by the lay community and viewed negatively by the health care community [Kelly, St. Lawrence, Smith, Hood and Cook, 1987]. In fact, while other diseases or character blemishes can be said to differentially stigmatize, HIV infection and AIDS are somewhat universal in their preponderant negative evaluation. In fact, persons with HIV/AIDS are becoming the untouchables of our age [Nardi, 1990].

To elaborate briefly on the significant stigmatizing dimensions of HIV/AIDS, the two groups who have experienced the highest incidence of HIV/AIDS are homosexual men and injection drug users. In the case of homosexual men and the responsibility/origin dimension of stigma, Weiner, Perry and Magnusson [1988] point to the significance of their "promiscuous or aberrant sexual behavior" as

being significant. Conrad [1986] goes further pointing to a religious theme when he addresses the "multiple sex encounters and once-forbidden 'sodomy'" that have touched our Puritanical concerns about promiscuity, permissiveness and, have connected HIV/AIDS with sexual irresponsibility. Intravenous drug use, the second most frequent means of transmission of HIV, also has a history of being perceived negatively. In essence, the cause in both cases is viewed as controllable or uncontrollable [Weiner, Perry, and Magnusson, 1988], with the controllable cause bringing anger and hostility toward HIV/AIDS and uncontrollable causes evoking sympathy and help-giving, especially if an illness is involved. Whether homosexuality is considered a volitional life style choice or a biological deviation will bear heavily on the issue of responsibility and blame. Those HIV individuals most likely to receive sympathy are hemophiliacs and other recipients of HIV infected blood products, heterosexual partners of HIV infected individuals, and infants of HIV infected mothers.

On a different level, Conrad [1986] suggests that our anxiety, fear and rejection of HIV/AIDS comes from its connection with intimacy and sexuality. In essence we perceive the gay community as having visited upon the collectivity a peril as a consequence of their irresponsible deviant sexual behavior. With the identification of AIDS and our ability to test for HIV the decades of progress in gay community acceptance were set aside [Conrad, 1986; Macklin, 1989; Ainlay, Coleman and Becker, 1986] and the gay community is once again seen as a generally and diffusely deviant group whose sexual orientation serves as their dominant identity. Conrad [1986] states that AIDS "...was a catalyst to the reemergence of a latent 'homophobia' that had never really disappeared" [p. 54]. The fear and threat of AIDS once again provided a master identity to gayness, an identity that even the gay community itself is attempting to disavow [Krieger, 1991].

Finally, turning to Goffman's [1963] third type of stigma, tribal, it is possible to suggest that the gay community has a "neo-tribal" stigma, if not an

actual tribal stigma as he delineates. While, we recognize the difficulties inherent in drawing racial boundaries on the basis of biological characteristics and that one thus neglects the social and cultural components of racial groupings, a part of the ideological defense of homosexuality has been inherent differences discernable by the individual since early childhood and adolescence [Hammersmith, 1987; Strommen, 1990]. Recent research by LeVay [1991] has suggested that homosexual men exhibit a smaller hypothalamus, a part of the brain believed to control sexual activity, than heterosexual males. Admittedly this finding is preliminary and the causal direction has not been established, but it is one bit of support, in addition to others [see Hammersmith, 1987], suggesting that male homosexuality is biological or the disposition toward homosexuality may be biological. If one adds to this the potentially stigmatizing dimension of race and ethnicity to the already HIV infected individual, there is the potential for a triple or even quadruple stigma. Whether, in order to soften social labels and thus prejudice and discrimination, it is better to be seen as a lifestyle choice or as a biological variation which should be recognized as a distinct neo-tribal community, will depend on how harshly public opinion evaluates the consequences of HIV infection. If lifestyle choice is seen as the root of the spread of HIV then the gay community will be seen as responsible, but if biological destiny is the source of behavioral deviation, perhaps there will be more sympathy and compassion expressed. The political action by the gay community has sought to have imposed on their sexual practices the "least restrictive alternative" [Bayer, 1989] in terms of efforts to control the spread of HIV/AIDS. This effort will possibly be seen as selfish and misguided as HIV spreads further into the heterosexual community in the United States.

Thus, given the types of stigma and the dimensions of stigma, it is not difficult to understand why individuals infected with HIV feel stigmatized and thus devalued, shunned and otherwise limited in their access to unfettered social

intercourse. Becker [1963, p. 34] explains for us why HIV/AIDS is such an encompassing master statuses when he asked and answered the following question, "What kind of person would break such an important rule?,'...'One who is different from the rest of us...'" We will now turn to what these individuals are experiencing in terms of biophysical signs and symptoms of HIV/AIDS.

#### HIV, Stigma, and HIV/AIDS Trajectory:

Current understanding of HIV/AIDS suggests that it can be expressed as a continuum, or as a career [Becker, 1963], at one end of which is an intact immune system while at the other a severely damaged system. In contrast to other stigmatic illnesses that primarily have a strong constructive quality (e.g., epilepsy or leprosy), HIV/AIDS also has an objective component which undermines the biophysical basis upon which our social reality is premised. Infection with HIV is characterized by advancing destruction of key elements of the immune system, primarily a subset of human T lymphocytes which express the virus receptor, the CD4 antigen (Merz, 1991). As destruction of CD4<sup>+</sup> T lymphocytes by HIV continues, HIV-infected persons typically progress along a continuum that begins with acute infection and ends with AIDS. Although disease progression varies widely among individuals, over a period of 12 or more years HIV-infected persons will usually experience several biophysical stages of HIV disease, including: (1) a transient flulike syndrome associated with seroconversion, developing within weeks or months of infection; (2) an asymptomatic period of more than four years average duration; (3) symptomatic HIV infection of more than five years average duration, and; (4) AIDS characterized by opportunistic illnesses, HIV wasting syndrome, HIV dementia, lymphomas, and other neoplasms, averaging 9 to 13 months for treated and untreated individuals combined and 21.3 months for those receiving antiviral medical treatments [Siegel & Krauss, 1991].

Considering the four stages of HIV infection discussed above, and the multidimensional nature of stigma discussed previously, the relationship between

the biophysical stages of HIV and stigma will now be further developed. Since so much of the nature of the HIV trajectory is tied to the status of the individual's immune system, the dimensions of stigma are discussed in terms of the biophysical course of HIV (See Figure).

Figure about here

### STAGE I: AT RISK, WORRIED WELL AND SERONEGATIVE STATUS

The "at risk" stage is not an actual phase in the HIV disease course. However, it is a period of time during which the individual may be engaged in risk enhancing behaviors and wonder if past indiscretions may have placed him/her at risk. As HIV enters the heterosexual community, sexual behaviors once thought to be "normal" or, in some instances, deviant, have now become unsafe, risky behaviors for heterosexuals and gays alike. Of course, there are also individuals who do not know they are involved with high risk partners, for instance, bisexual partners or partners who are HIV positive, but do not know it themselves. Some individuals are aware of the risks they incur, but for a variety of reasons chose not to or cannot acknowledge them in terms of protecting themselves.

The at risk group of individuals represent the "worried well" and some fatalistic persons who feel destined, because of their history, to contract the HIV disease. Individuals who are at risk or who fear their behaviors or contacts have placed them at risk for HIV disease are:

- 1] Persons with a history of sexual involvement with partners in high-risk categories [e.g., gay and bi-sexual males, or IV drug users].
- 2] Injection drug users.
- 3] Children of HIV+ mothers.
- 4] Blood transfusion recipients, hemophiliacs or persons with other

coagulation disorders.

5] Health care workers, especially those experiencing inadvertent needle sticks.

6] Family, friends and/or caregivers.

The worried well should well worry as to their HIV status if they are in groups 1 and 2 above for they have the highest incidence and prevalence of HIV infection [Heyward and Curran, 1988]. Among individuals who are cognizant of their risk, the meaning and consequences of HIV/AIDS is present in terms of a felt stigma of being either at risk and suspect in the eyes of others or known to associate with an at risk individual. As a consequence, the fear of contracting HIV/AIDS "permeates the lives of many gay and bisexual men" [Weitz, 1989, p. 272] and each change in health status may well confirm the fears of the worried well [Tiblier, Walker and Rolland, 1990]. In contrast, the remaining groups, children who are HIV+, transfusion recipients, hemophiliacs and others, while having a lower more ambiguous HIV risk, are generally viewed as unknowing, innocent recipients of HIV/AIDS and carry less of a stigmatic burden, though one nonetheless.

Actions to evaluate HIV status and the issues raised in testing are similar to those raised by the Health Belief Model [Kirscht, 1988] in terms of a sense of vulnerability and whether the test for HIV is accurate. While the test itself is quite accurate and reliable, the knowledge it provides may be too stigmatizing and threatening in terms of a potential for rejection by family, partners, friends and co-workers. In addition, at risk individuals believe that testing will jeopardize civil liberties [Tiblier, Walker and Rolland, 1989] and encourage all types of discrimination [Bayer, 1989]. Quam [1990] certainly expresses this reality when he states: "[T]here is a widespread and recurrent demand that infected persons be relieved of obligations, or perhaps deprived of opportunities, for normal social interactions and role performance" [p. 31-32].

The term the "socially worried well" applies to those individuals whose



initial concern of being in an at-risk group is not entirely with the disease itself but the social risks of being perceived as being in an at-risk group. For the stigma associated with HIV/AIDS represents a social death [Coleman, 1986]. The irony is that HIV/AIDS represents both a potential for social death and the certainty of biophysical death. As a consequence, denial is one of the primary coping mechanisms discussed in describing the behavior of at risk and recently diagnosed HIV+ individuals. Denial leads these individuals to discount educational information and the enacted stigma associated with their homosexuality, injection drug use, or unsafe sexual practices. However, there may also be at-risk individuals who freely acknowledge their risk and flirt with its potential consequences.

A more subtle form of denial may be a "suspension of the possibility" of risk of infection or a sense of invulnerability to infection among gay men, bisexual men or injection drug users. Weitz [1989] in attempting to explain or present theories as to why individuals did not believe they were at risk, suggests that at-risk individuals needed to explain why they were really are not at risk despite their behaviors. They essentially disavow infection potential by stating that: "...AIDS attacks only physically weak, 'promiscuous' persons, who chose their partners unwisely" [Weitz, 1989, p. 273]. Thus they are suspending the possibility of HIV because they are not one of the above types of people. In essence "AIDS occurs only elsewhere" [Weitz, 1989, p. 273]. More importantly, as Moynihan, Christ and Silver [1988] point out, treating individuals at risk for HIV in categorical terms, for example, homosexuals and injection drug abuser, rather than in terms of risk behaviors, reduces perception of risk and encourages, what we call, a suspension of possibility.

Because of the social consequences of HIV/AIDS the individual fears moving into the stigmatized category. However, in doing so he begins to take the perspective of the condemners and to recount the meanings attached to the

stigmatized category, noting all of the things that he does not want to be, or is not. In essence the individual experiences himself from the perspective of the condemners and may well be in a position to understand himself from other's perspective and therefore to apply a negative evaluation to himself and his behavior.

One way to cope is to assume a "double life" [Siegel and Krauss, 1991] and to conceal a deviant identity if one is gay, bisexual or an injection drug user. Thus, one discusses one's risk status as carefully as one's HIV status when in the at-risk stage. No one wants the double stigma [Nardi, 1990] of being gay and HIV+ or the more negative stigma of being gay if one has hemophilia. By virtue of their exposure via blood products and transfusions, hemophiliacs are thus at risk for the double stigma of hemophilia and HIV/AIDS. The potential of a double stigma encourages hemophiliacs to deny both their hemophilia and later their positive HIV status for fear of being associated with homosexuality and injection drug abuse [Scheerhorn, 1990]. This coping tactic significantly places their spouses and significant others at risk of HIV and keeps the hemophiliac from receiving appropriate medical care for fear of discovery.

To varying degrees and in specific locals support for being at risk is available to gay, bisexual and non-gay segments of the population. However, bisexuals may have the fewest ties to the gay subculture and therefore are neither encouraged to get tested nor supported in a decision not to get tested. Bayer [1989] has noted the absence of support for testing in the gay community for fear of civil liberty infringements and potential for labelling or stigmatization. While testing may relieve anxiety concerning one's HIV status, acknowledgement of being at risk represents an admission of deviance and, as noted above, an assumption of the perspective of the condemners and a certain degree of self-loathing.

The at risk stage ends with the result of testing for HIV. The at risk

stage, as indicated, is a period of anxiety, ambivalence, denial and fear. For the unknowing partner of a bisexual, or recipient of a transfusion, there may be no at risk stage, only the unexpected realization of HIV positivity. The anxiety and fear of being at risk is only the initial burden HIV/AIDS individuals experience on the downward slope of the illness trajectory.

## STAGE II: LATENT ACUTE AND LATENT ASYMPTOMATIC PHASES

The second stage of HIV disease begins when HIV enters the bloodstream and stimulates the immune system to develop antibodies. Antibodies to HIV usually develop within 3 months of infection, and by 6 months approximately 95% of infected persons can be expected to seroconvert (test positive for the HIV antibodies) (Horsburgh et al., 1989). HIV antibodies are usually detectable by the enzyme-linked immunosorbent assay (ELISA) or the Western blot test. The initial acute infection with HIV is generally characterized by a mononucleosis-like syndrome, usually appearing 2 to 6 weeks after seroconversion (Moss, 1989). This syndrome, that presents with symptoms such as maculopapular rash, fever, myalgia, arthralgia, headache, diarrhea, and sore throat, may accompany seroconversion in as many as 50% to 90% of adults [Tindall et al., 1988]; others undergo asymptomatic seroconversion or misdiagnosed conversion, especially individuals in low risk categories. These signs and symptoms disappear in a few weeks. Although the number of CD4 T lymphocytes will continue to decrease, following initial infection and seroconversion, most HIV-infected persons will remain asymptomatic for a period of up to several years. As a consequence, during these two latent phases we can expect the greatest independence between the HIV trajectory and the HIV/AIDS social trajectory.

### LATENT ACUTE PHASE: HIV Infection and Information Management

In the latent acute phase, attention of the individual is drawn to matters pertaining to changes in identity and self-esteem, concealment, discovery and

disclosure of their HIV positivity. The individual must struggle with the meaning and consequences of their HIV status in terms of managing its potential discovery and orchestrating its disclosure to companions, family, friends and relevant others. Moreover, there is also the pressing need to cope explicitly with the felt and enacted stigma associated with their newly emerging and disreputable status as being HIV positive.

As Moynihan, Christ and Silver [1988] note, it is a profoundly disturbing realization, especially for a young adult and his family, to have to address having HIV with the possibility of a significantly shortened life span. Quam [1990, p. 37] points out that "[d]eath at an early age is itself stigmatized," for family as well as the individual. For the young mother, a positive diagnosis is even more disturbing with the possibility of an HIV infant or eventually needing to place young children in the hands of aging parents and/or family members.

As with any secret, and especially a potentially discrediting one, the individual must engage in "information management" [Goffman, 1963]. For Goffman the primary questions become: "To display or not to display; to tell or not to tell; to let on or not to let on; to lie or not to lie; and in each case, to whom, how, when, and where" [1963, 42]. Siegel and Krauss [1991] suggest that the salient concerns of the HIV+ person are fear of rejection, avoidance of pity, the wish to spare loved ones emotional pain and concerns about discrimination. However, because of the quiescent quality of this stage, the individual does not have to struggle socially with these questions yet, only personally. However, there is the profound knowledge that they "... have crossed some line, some boundary of 'nature' that makes them less than human and essentially dangerous" [Quam, 1990, p. 38]. And, as Triplet and Sugarman [1987] suggest, there is good reason to attempt to conceal HIV status as AIDS patients have the lowest interactional desirability among several chronic diseases. Thus, concealability

becomes a defense against enacted stigma. But concealing may not be an entirely adequate strategy; research and clinical accounts describe HIV positive persons as feeling isolated, estranged and alienated [see: Forstein, 1984; Fullilove, 1989; Holland and Tross, 1985].

On the other hand, in this stage, the individual has the advantage of choosing the time to disclose, which, in some cases, gives the individual an opportunity to first demonstrate "worth" and "humanity" [Jones et al., 1984]. However, in a study of caregivers, Powell-Cope and Brown (1992) noted that disclosure in relationships ranging from the most intimate to the most public often involved intense emotions such as embarrassment, pain, confusion, and anger. Caregivers typically employed the strategy of staging information, that is, carefully selecting certain amounts and types of information in order to slowly paint a more complete picture of their patient's situation. Thus, while immediate disclosure would seem reasonable, fear, anger and anxiety associated with disclosure are often inhibiting.

These feelings arise, as Seigel and Krauss [1991] and Weitz [1989] both note, because HIV positive men have assimilated the perspective of the larger society toward HIV/AIDS and so doing feel devalued and blameworthy in their own eyes as well in the eyes of the gay community. Being gay in and of itself is negative, but being gay and HIV positive is more devaluing and may necessitate even more of a "sham" [Goffman, 1963]. Further, individuals are denied use of attributional strategy as discussed by Crocker and Major (1989) to overcome the impact stigma may have on ones identity.

In concealing his HIV status the individual may be able to protect his self-esteem [Jones et al., 1984] by avoiding episodes of enacted stigma [Scambler, 1984], but there are also several negative consequences in doing so. First, it is emotionally exhausting-- "Trying to remember who has been told and who has not, what was told to whom, having to hide AIDS materials and pamphlets--

in other words, the vigilance required to maintain a lie--can be an emotionally draining experience..." (Stulberg & Buckingham, 1988, p. 357). The stress of living a double life is a heavily felt burden [Weitz, 1989; Siegel and Krauss, 1991], especially if interacting in both straight and gay settings.

Second, suspicion may adhere to any individual of known risk who deviates in terms of health status. Thus, the potential for others to discover the individual's HIV status is increased if one is a member of an at-risk group. The individual may be highly motivated to sustain participation in social and occupational activities so as not to let others know or be suspicious of his or her HIV status.

Third, the individual is deprived of social support that presumably would normally be available to him/her (Stulberg & Buckingham, 1988). By failing to disclose there is also the risk of engendering the hostility of others when they realize that the individual is HIV+ and they were not informed. Stulberg and Buckingham [1988] note that devastation of revelation is even more profound for the heterosexual spouse of a person who is HIV+.

Fourth, the individual may refrain from activities that signal diagnosis, such as delay in seeking appropriate health care. As Lang [1990], points out, those individuals who remain secret or in the closet, are the least prepared to deal with HIV positivity either as a disease or as a cultural issue. These individuals are also the least likely to seek or join support activities. Thus, some may jeopardize their health status to remain to appear normal or to be "moral characters" [Goffman, 1963] when early health status evaluations and support would be beneficial.

Fifth, the individual may engage in activities that dismiss and deny the diagnosis, such as unprotected sex with unknowing partners. In so doing the individual attempts to disavow his HIV positivity but at the cost of placing others at risk.

While the consequences of concealment may seem detrimental, the consequences of revelation are also quite costly. Individuals view the diagnosis of HIV positivity as exposing them to the "...harsh and injurious realities of lay ignorance, intolerance, and discrimination" [Scambler, 1984, p. 214]. There may be an oppressive fear of enacted stigma [Scambler, 1984] in terms of being rejected by family, friends and companion. Quam [1990] argues that this fear may be well founded as HIV+ individuals report being shunned by friends and family and removed from housing and employment. When and if rejection comes it is more often from fathers, men, blue-collar workers, fundamentalists, and the less educated, than by the opposites of these.

The primary process in this stage in the disease trajectory is dealing with identity consequences and discovery or disclosure of HIV positivity. Individuals at in this stage have seen and felt the consequences of the HIV/AIDS stigma and must manage information carefully and prudently, usually under much stress and tension. In Stage II the individual is most uncertain as to his own HIV trajectory and is terribly uncertain when death will occur. At the same time they must begin to come to terms with their shortened life span, highly probable death and what they now symbolize to society. However, because of the fear and consequences of enacted stigma, HIV+ individuals potentially pose the most threat to society during Stage II because of their ability to conceal their HIV status. As noted above, in an effort to pass as normal individuals may engage in unsafe sexual behaviors. Thus, a latent consequence of stigmatizing the HIV+ person, society places itself at risk. While this stage is not highly symptomatic, the next stage is even less so and makes denial and normalization even more inviting, feasible and risky for society.

#### LATENT ASYMPTOMATIC PHASE: "Worried Well" and Beginning Treatment

The uncanny retrovirus nature of HIV has created, according to Goldstein [1990], "...a new class of 'patients,' forced to live between sickness and

health, giving a tangible twist to the old medical term, 'worried well'" [p. 316]. The source of worry in this phase is again information management, but because of having crossed a boundary [Quam, 1990] or feeling different from the rest of us [Becker, 1963], the individual begins to experience isolation, denial and the building of an identity as a stigmatized person despite opportunities for normalization.

With the exception of a brief period when the individual seroconverts and may have mono-like symptoms, this is the time in the trajectory when the disease is most concealable and also the least disruptive in general; but it continues to be disruptive in terms of internal feelings of stress, anxiety and matters relating to information management, as noted above. Because of the quiescent nature of HIV the individual typically tries to normalize his life and it is quite easy to do so. Further, if acceptance has not been achieved denial is frequently used. Jones et al. [1984] asserts that people who can, will conceal their stigma. As in the acute phase, individuals in the asymptomatic phase still harbor feelings of shame, self blame and fear of rejection or abandonment by friends, neighbors, co-workers, and employers (Brown and Powell-Cope, 1991; Stulberg and Buckingham, 1988) and the dread of enacted stigma (Bennett, 1990).

In this phase, prolonged isolation begins, individuals may terminate work and other customary social activities independent of biophysical impairment. Schneider and Conrad (1986) point out in their study of epileptics, that "passing" can be isolating because the concealer is aware that he or she is secretly different from others. In essence, and consistent with our definition of stigma, the individual's access to the humanizing benefits of free and unfettered social intercourse is further impaired.

There is, however, after recovering from the knowledge of HIV infection and managing information and isolation, the realization that during the latent stage



the individual is at the top of the disease trajectory. Gibbons [1986] argues, within the context of stigma, that one coping strategy is to make a downward comparison, wherein the individual needing to boost a threatened self-esteem makes comparisons between himself and others more stigmatized or, in the case of HIV/AIDS, further down in terms of the disease course. In addition, as Gibbons [1986] makes clear, individuals with less severe and, we might add, less detectable or asymptomatic stigmas wish to avoid the more obviously stigmatized because their efforts to pass as normal may be jeopardized by association. However, just in the desire to pass as not having HIV/AIDS and in comparatively derogating those who do, the individual is embracing the perspective of the stigmatizers [Coleman, 1986] and in the process derogating himself. It is possible that the individual looks down the illness course, knowing his feelings of self rejection on the basis of downward comparison, and shudders at the prospect for his future.

Among individuals who are at risk and find their way into the health care system and test positive, the at risk and asymptomatic phases have the quality of being quiescent or latent in terms of the disease process as well as the potential for enacted stigma, but there is a high potential for felt stigma expressed in feelings of self-loathing, fear of rejection, isolation, downward comparison and the stress associated with information control. The duration of the asymptomatic phase, estimated to be four years on average, makes it quite easy and almost necessary for the estimated 1 million HIV+ individuals to normalize and, to some extent, deny their HIV positivity. However, this extended period of coping, dealing with matters relating to concealment, discovery and disclosure, further builds and fixes a stigmatized identity. Some of these individuals, unfortunately, are unable to manage the realities of HIV/AIDS and do commit suicide rather than experience the unpleasant demise associated with AIDS and the social death [Coleman, 1986] its stigma brings. In the next stage

consideration is given to what individuals must cope with in terms of managing the manifest disease, or full blown AIDS.

### STAGE III: EARLY MANIFEST AND FULL BLOWN AIDS PHASES

Months to years after HIV infection, generally following a latent period of asymptomatic disease, individuals begin to develop manifest clinical expressions linked to HIV, such as oral candidiasis (thrush), oral hairy leukoplakia, and constitutional symptoms such as sustained weight loss, fever, fatigue, night sweats, and persistent diarrhea (Moss, 1989). These early manifestations do not meet the original or revised CDC definition of AIDS, but indicate significant immunologic impairment and can precede acquisition of an AIDS-defining condition (Merz, 1991; Moss, 1989). Once the CD4<sup>+</sup> T lymphocyte count falls to less than 500 CD4<sup>+</sup> cells per cubic mm, antiretroviral therapy is usually initiated with zidovudine azidothymidine [AZT, Retrovir]. Studies have demonstrated that AZT delays progression to AIDS and may prolong survival (Fischl et al., 1990; Volberding et al., 1990; Moore et al., 1991; Aboulker and Swart, 1993).

Despite the success of AZT therapy, the immune system continues to deteriorate, and HIV-infected persons begin to experience more severe, and eventually life-threatening conditions. As a syndrome, AIDS is characterized by a number of opportunistic infections, neoplasms, and HIV wasting syndrome. The specific opportunistic infections, a function of the patient's degree of immunosuppression and history of exposures, are often severe and difficult to treat and require extended treatment regimes.

AIDS represents the more severe end of the spectrum of HIV disease and AIDS-related conditions can impact virtually every organ/system of the body. The conditions that are most visible, have the greatest implications for individuals in terms of stigma. For example, Kaposi's sarcoma is most typically manifested

as nodules that are usually pigmented and violaceous (red to blue) and difficult to conceal (Heyer, Kahn and Volberding, 1990). Distinct patch-stage lesions appear quite early in some individuals and may be initially mistaken for bruises (Friedman-Kien and Saltzman, 1989), but the patches then form into plaques and eventually form into nodular tumors that may appear at any time, characteristically on the tip of the nose, eyelid, hard palate, posterior glans penis, thigh, and sole of the foot (Heyer, Kahn and Volberding, 1990). Ocular changes in the HIV-infected individual, most often associated with opportunistic infections (especially cytomegalovirus), may be accompanied by severe visual impairment and in some cases blindness (Ungvarski, 1992). Gastrointestinal [GI] manifestations are particularly common among HIV infected persons and can be severely debilitating. GI involvement may cause dysphagia, postprandial emesis, hematemesis, diarrhea, abdominal pain, malabsorption, malnutrition, and weight loss [Grady, 1992]

The individual may also manifest a number of extreme central nervous system changes including seizures, hemiparesis, aphasia, or changes in cognitive functioning, including personality changes, inability to concentrate, memory impairment, generalized confusion and obtundation that can progress to coma [Grady, 1992].

While there is no fixed HIV/AIDS trajectory, because the clinical course is very individualized and successful treatments are available for the above clinical manifestations and AIDS-defining conditions, it is still possible to analytically distinguish the intersection of a disease and social trajectory of AIDS as the disease course progresses downward. As the individual and his caregiver experience fewer quiescent and symptom free periods and as the opportunistic infections accumulate, the individual's attention drifts more and more into matters relating to disease and infection control and near the end stage works little on managing stigma, a concern that forcefully drives behavior at initial

HIV diagnosis and in the early manifest phase of the disease trajectory. In essence, over the following two manifest phases the behavior of the individual progressively becomes driven by the clinical manifestations of HIV/AIDS described above with matters of stigma diminishing in salience and matters surrounding social and physiological death becoming dominant.

#### EARLY MANIFEST PHASE: The End of Optimism

In Stage III, the interaction of social identity issues, stigma and the biophysical disease process become intensified. The end of the near normal, quiescent phase, or the false consciousness of the latent stage, becomes shaken by a decline in the CD4<sup>+</sup> cell count and punctuated by the onset of signs and symptoms of the AIDS defining conditions described above. The period of seeming reprieve and the optimistic sense of possibly having escaped the disease is lost. The issues of stigma, temporarily set aside after the acute stage, must now be fully addressed. The psychological isolation that may have been imposed is now reinforced by early, potentially stigmatizing signs and symptoms. As physiological parameters change and signs and symptoms begin to appear there is a realization, for some, of progression to the final phases in the disease trajectory.

Issues concerning information control, temporarily set aside in the latent phase, resurface and must again be addressed. Initially, the illness may not be manifest in terms of disease symptoms, but rather because the individual begins anti-viral therapy. Early acknowledgment of HIV infection and a willingness to accept the identity of HIV positivity will increase the likelihood of earlier anti-viral treatment. However, this therapy and other therapies are stigma producing since they are associated with HIV/AIDS or a fatal disease and thus some individuals may postpone anti-viral therapy, especially if they are asymptomatic. In addition, since these drugs are known to prolong life, the individual is caught in a quandary; taking a drug that acknowledges to oneself

and to others that he or she is HIV+, or not taking the drug and continuing a period of denial reinforced by the previous latent, asymptomatic phase and the possibility of being one of the long-term HIV positive survivors who could escape AIDS [Gorman, 1993].

While anti-viral therapy may biophysically enhance the individual's immune system, it may not entirely overcome other anxieties related to the body. Moynihan, Christ and Silver [1988] report that early in this phase individuals feel like a "walking time bomb," just waiting for the first medical crisis or 'explosion' to occur" [p. 384]. A great deal of uncertainty is experienced as to the meaning and purpose in their lives. The unpredictable nature of the HIV trajectory is addressed by the individual with close monitoring of the disease course, treatments, symptoms, infections, test results, side effects and other dimensions of the illness. As in the case of chronic diseases in general, such attention reduces the sense of uncertainty or existential crisis [Strauss, 1984].

Although early signs and symptoms are concealable, the "wise" may discern that the individual is ill. The wise, in this instance, could be family, partners and friends who are familiar with the individual's risk and, more importantly, with the signs and symptoms of HIV infection. While the individual may feel fine, others may insist on approaching the individual as if he or she is sick and unable to perform normal role obligations without placing others in jeopardy [Quam, 1990]. Thus, enacted stigma in the form of seemingly reasonable exclusion begins to reflect the individual being shunned and social interaction abridged. However, as the disease process becomes more manifest and others begin to fully understand the individual's condition, there is also the possibility that unexpected sources of support and sympathy will emerge to overcome abridged interaction [Reynolds, 1991]. As opportunistic infections become more numerous and manifest, it is the biophysical trajectory that begins to drive social behavior as the HIV continues to suppress the individual's immune system.

### FULL BLOWN AIDS PHASE: A Fixed Identity and End Stage Disease

The transition to an AIDS identity may be in the form of a "sharp rite of transition" to AIDS as a "master status" [Gerhardt, 1985]. The "normal" identity of the individual is essentially worn down and the AIDS identity becomes fixed by multiple opportunistic infections, repeated hospitalizations, physical changes, weakness, social isolation, dependence on others, increased contact with medical practitioners, and sometimes either increased contact with estranged family and friends or essential rejection. As the illness progresses, Coleman [1986] notes that "[s]tigma often results in a special kind of downward mobility" wherein the stigmatized "...lose their place in the social hierarchy" [p. 214]. Persons with AIDS are likely to become increasingly isolated over time with fewer opportunities for unfettered social interaction. As illness becomes increasingly more difficult to conceal, the opportunity for enacted stigma is accentuated. Having experienced the downward decline, the individual is aware of the isolation and withdrawal of others who were, in less troubled times, willing interactants and providers of support.

During this phase, the disease process, as much as the internal psychological processes, may disrupt social interaction. Central nervous system symptoms are increasingly manifest in late stage AIDS with early symptoms being memory loss, difficulty concentrating, mental slowness, confusion and apathy, withdrawal and depression. Moynihan, Christ and Silver [1988] report patients fear these symptoms and may attempt to conceal them from their physician, an indication that they are still, in a sense, trying to "pass" as a means of denial and normalization. More importantly, there may be the increasing loss of control experienced by the terminal AIDS patient [Stulberg and Buckingham, 1988]. For some patients, avoiding physicians may be a form of asserting control over their emotional well-being despite the physical consequences. For others, suicide may seem a way to alleviate uncertainty and maintain control [Weitz, 1989].

Individuals without ties to the gay community where AIDS is more accepted, are more likely to continue to try to conceal their AIDS diagnosis [Powell-Cope & Brown, 1992, p. 573] and are less likely to associate with others or become involved in situations (e.g., support groups) in which their status may be identified. Those wishing to pass may be concerned about guilt by association [Gibbons, 1986], or, persons with AIDS (gays and others) may engage in downward comparison and thus avoid the more stigmatized of their lot [Gibbons, 1986].

During late stage HIV infection, many individuals will continue to struggle with internalized blame. Moulton, Sweet, Temoshok and Mandel (1987) found that attributing the cause of AIDS to one's self was positively correlated with dysphoria (a combined measure of depression, anxiety, and negative mood). While such mood states may negatively impact on health/illness outcomes [Solomon & Amkraut, 1981], society offers few resources to enable individuals to come to terms with a sense of personal responsibility for their own increasingly unfortunate circumstances.

It is noted [Kaya?, 1992; Moynihan, Christ and Silver, 1988] that the risk behaviors contributing to HIV/AIDS generally distance the individual from organized religion and the value and meanings of life associated with religion. Yet, the distance and alienation experienced by persons with AIDS evoke primitive fears of being outcast and a longing for formal reconciliation, contrition and acceptance. In addition, individuals may desire religion as a means to search for meaning in the fate they will come to experience.

Religion, while providing explanation, may extend little needed comfort. In going to religion, the HIV-infected persons must again accept the perspective of the condemners; that God may be punishing them for their behaviors [Kaya?, 1992; Stahly, 1988; Weitz, 1989]. Rather than promoting tolerance, religion may in fact reinforce stigma [Kaya?, 1992]. The sympathy and forgiveness engendered in religious institutions is not constant and may depend on the particular

clergyperson encountered [Moynihan, Christ and Silver, 1988]. Similar to matters relating to physicians, treatments and regimens, the individual may be forced to shop for religious acceptance.

Individuals may find solace in social support groups. Support groups provide a context which enables the stigmatized person to feel normal [Saylor, 1990]. Gibbons [1986] points to the accepting nature of self help and support groups where the issue of morality, and perhaps contrition, is not stressed and the promotion of a "shared stress" may serve as a respite from felt and enacted stigma. Support groups are comprised of others who share the same symptoms or disability and provide "tricks of the trade" and sanction [Saylor, 1990]. Support groups provide a community of "own" [Goffman, 1963] in which members share a stigma and demonstrate that they are accepting and accepted people. Support groups additionally provide forum for the individual to act as a "hero of adjustment" [Goffman, 1963].

As the patient becomes more isolated, either because of a desire not to interact or an inability to do so, a close family member, friend, or partner (the caregiver) will typically begin to operate as a surrogate in terms of dealing with daily interactions and social encounters. For example, Bennett [1990] found the phrase "bumper guard" was used by one AIDS patient to depict the protective stance of his lover. Thus, the AIDS patient's "moral career" [Goffman, 1963] may be influenced by the ability of a caregiver to provide a protective, insulating capsule.

In serving in this capacity, however, the AIDS caregiver may experience an enacted "courtesy stigma" [Goffman, 1963]. Initially there may be considerable felt stigma. Later, the manifest nature of AIDS may elicit either rejection and enacted stigma, or, particularly in the terminal stages, progressively evoke sympathy. Powell-Cope and Brown (1992), found that AIDS caregivers tended to disclose more information about their caregiving relationship to more people as



the patient became increasingly ill. Disclosure was most common following the diagnosis of AIDS, during a hospitalization, or during a significant illness crisis. The major personal benefit of "going public" reported by the study participants was the gaining of support and assistance from others.

The caregiver and the person in late stage HIV-infection may receive more sympathy for several reasons. First, while family estrangement and rejection may sometimes exist during the at risk and asymptomatic stages, family members may find it unacceptable to be angry with a patient [Moynihan, Christ and Silver, 1988] who is suffering, particularly one who is dying. During the end stage, negative attitudes and feelings may thus be suppressed and not communicated either verbally or behaviorally to the stigmatized person. Further, as the therapeutic focus changes from HIV focused antiviral therapy to more specific conventional therapies for opportunistic infections and chronic diseases, the nature of the stigma may also change to more benign feelings associated with cancer treatments, and other more sympathy evoking diseases, especially those associated with great discomfort.

Manifestations of AIDS herald loss and may thus invoke sympathy. For example, when the individual begins to experience central nervous system disorders, such as memory impairment, changes in cognitive functioning with personality changes, inability to concentrate and generalized confusion, family members and partners may initially respond negatively in terms of the disrupted interaction. However, they may also begin to experience the social loss of the patient and the beginnings of social death [Coleman, 1986]. In a process similar to what occurs in alzheimer's disease, families, partners and/or friends will begin to mourn the social loss of the patient and attempt to come to terms with them before they are gone.

While physical manifestations of AIDS, such as the wasting syndrome or Kaposi's sarcoma, may evoke sympathy since they are visible signs of physical

decline, they may also arouse fear because they are constant reminders of one's contagious and tainted status. Actually, such individuals begin to pose less of a threat or peril in terms of contagion because as the illness becomes manifest, the individual not only becomes increasingly isolated and physically less capable of infecting others, but he or she is no longer able pass as uninfected. However, the individual may be still be regarded by others as an extreme threat with visual cues enhancing a perception of contagion and a "leper-like" status. Goldstein (1990) observe; that in television, the person with AIDS is rarely portrayed as innocent, "It is not the person with AIDS who is victimized, but those threatened or affected by the disease. Family and community occupy center stage, and the issue is not survival but cohesion: how to deal with a breach in the safety net" (p. 299).

Goffman [1963] argues stigma itself breaks the claim on us for sympathy that we might otherwise give a terminally ill individual. The individual's perceived responsibility for his illness may further serve to reduce our feelings of compassion and sympathy. As Herek and Glunt [1988] point out, it is ironic that when the AIDS patient needs our social support they are burdened by societal hostility and generally shunned. However, Jones et al. (1984) and Katz (1981) assert that stigma reactions are essentially ambivalent, rather than uniformly negative with feelings of revulsion, hostility, and avoidance coexisting with feelings of sympathy, nurturance and awareness of social norms against bigotry.

To a large extent these conflictive feelings may account for the variability of enacted stigma. It is possible to interpret the release of the individual from normal role expectations, in the Parsonian [1951] sense, and therefore lowered expectations, as a form of sympathy. However, as Coleman [1986] points out, sympathy is merely an expression of stigma, and fundamental inferiority and social control. In addition, Gerhardt [1985] points out that treatment agencies in general, when dealing with stigmatizing illnesses,

encourage the acceptance of a deviant identity, dependence and irresponsibility. Thus, the expression of sympathy itself, while frequently well intended, could represent a variety of ambivalent and conflictive feelings. Sympathy is likely to be regarded as preferable to rejection, yet sympathetic responses do not necessarily reflect acceptance. Persons with AIDS, while desiring acceptance, may thus come to regard sympathetic responses warily [Sandstrom, 1990]. Crocker [1991] argues that the stigmatized in general, typically exist in a chronic state of ambiguity regarding the causes of the responses they receive. Negative responses may be due to a true lack of deservingness, or they may be due to prejudice and/or discrimination. Positive responses may be due to deservingness, or they may be due to prejudice, pity, or the desire to avoid the appearance of prejudice. In fact, Crocker [1991] reported that the results of her experiments suggest that attributional ambiguity surrounding negative responses protects the affect and self-esteem of stigmatized persons, while the attributional ambiguity surrounding positive outcomes (e.g., sympathy), has a variety of negative consequences for feelings and self-evaluation.

### CONCLUSION

Stigma is a social construction which dramatically impacts the experience of HIV/AIDS for the infected individual and his partner, family and friends. It devalues individuals who possess the mark and substantially reduces life chances by reducing the humanizing benefits of free and unfettered social intercourse. While it has been generally recognized that the nature of stigma varies across illnesses, it has usually not been considered as changing and emerging over the course of the illness trajectory. We have considered three stages in the HIV/AIDS trajectory. Each one carries its own unique stigmatic qualities and characteristics.

The unique nature of HIV/AIDS with its acute, latent and manifest stages,

lends itself to many dynamic changes in the manner in which the individual and others must address issues of stigma construction and management. Initially the individual must address the constructive nature of HIV/AIDS stigma, concealed identities, and stresses of information control and management. As the manifest nature of HIV/AIDS begins to make itself evident, stigma as an "abomination of the body" [Goffman, 1963] is revealed and this revelation is accompanied by severe feelings of stigma [Coleman, 1986]. The individual's world now centers around changes in bodily sensations [Strauss, 1984] which may portend opportunistic infections and a certain decline in health status. Whereas early manifestations bring increased sensitivity to bodily changes, each change and sensation in late-stage AIDS heralds multiple problems that must be coped with above and beyond initial, secondary and tertiary manifestations of opportunistic infections.

As the individual is experiencing and coping with bodily changes he must also manage the expanding stigma as it become his "master status." The issues raised by Jones et al. [1984] and Katz [1981], such as, responsibility, peril, aesthetic qualities and concealability, impact the nature of the stigma experience and will vary over the course of the illness. To study HIV/AIDS, stigma and illness, we must be sensitive to the delicate and emergent interaction of the disease trajectory, the constructive nature of stigma, and the struggles of individuals who are living through this socially and physically fatal illness experience. Stigma as we have described is not static, but is emergent. Sometimes it is expansive, prevading all corners of one's life and identity. At other times, relative to the disease trajectory, it is containable, limited and controllable in terms of consequences and, more importantly, personal and social identity.

### The HIV Continuum

CD4 1000		CD4 500		CD4 <200	
Stage I	Stage II	Stage III			
At Risk	Latent	Manifest			
	Acute Phase	Asymptomatic Phase	Early Manifest Phase	Full Blown AIDS Phase	

Figure

## REFERENCES

- Aboulker, Jean-Pierre and Ann Marie Swart. 1993. Preliminary analysis of the Concorde trial. *Lancet*, 341, 889-890.
- Ainlay, Stephen C., Gaylene Becker and Lerita M. Coleman. 1986. Stigma Reconsidered. In Ainlay, Stephen C., Gaylene Becker and Lerita M. Coleman, eds. *The Dilemma of Difference: A Multidisciplinary View of Stigma*, pp. 1-13. New York: Plenum Press.
- Albon, Joan. 1981. Stigmatized health conditions. *Social Science and Medicine*, 15B, 5-9.
- Bayer, Ronald. 1989. *Private Acts, Social Consequences: AIDS and the Politics of Public Health*. New York: The Free Press.
- Becker, Howard S. 1963. *Outsiders: Studies in the Sociology of Deviance*. New York: The Free Press of Glencoe.
- Bennett, Marsha J. 1990. Stigmatization: Experiences of Persons with Acquired Immune Deficiency Syndrome. *Issues in Mental Health Nursing*, 11, 141-154.
- Birenbaum, A. and Edward Sagarin. 1976. *Norms and Human Behavior*. New York: Praeger.
- Brown, Marie A. and Powell-Cope, Gail M. 1991. AIDS Family Caregiving: Transitions Through Uncertainty. *Nursing Research*, 40, 338-345.
- Center for Disease Control. 1992. The second 100,000 cases of acquired immunodeficiency syndrome-United States, June 1981-December 1991. *MMWR*, 41[2], 28-29.
- Coleman, Lerita. 1986. Stigma: An Enigma Demystified. In Ainlay, Stephen C., Gaylene Becker and Lerita M. Coleman, eds. *The Dilemma of Difference: A Multidisciplinary View of Stigma*, pp.211-232. New York: Plenum Press.
- Conrad, Peter. 1986. The Social Meaning of AIDS. *Social Policy*, 17, 51-56.
- Crocker, Jennifer and Major, Brenda. 1989. Social stigma and self-esteem: The self-protective properties of stigma. *Psychological Review*, 96, 608-630.
- Crocker, Jennifer. 1991. Social stigma: The consequences of attributional ambiguity. The Ohio State Social Psychology Colloquium Series. October 3.
- Fischl, M., Richman, D., Nansen N, et al. 1990. The safety and efficacy of zidovudine in the treatment of subjects with mildly symptomatic HIV-1 infection: A double blind placebo-controlled trial. *Annals of Internal Medicine*, 112, 727-737.
- Forstein, Marshall. 1984. The Psychosocial Impact of the Acquired Immunodeficiency Syndrome. *Seminars in Oncology*, 11, 77-82.

- Friedman-Kien, A. E., R. Ostreicher, B. Saltzman. 1989. Clinical Manifestations of Classical, Endemic African, and Epidemic AIDS-Associated Kaposi's Sarcoma. In A.E. Friedman-Kien, ed. *Color Atlas of AIDS*, pp. 11-48. Philadelphia: W. B. Saunders Co.
- Freidson, Eliot. 1971. *Profession of Medicine*. Dodd, Mead & Company.
- Freund, Peter E. S. and Meredith B. McGuire. 1991. *Health, Illness, and the Social Body*. Englewood Cliffs, New Jersey: Prentice Hall.
- Fullilove, Mindy T. 1989. Anxiety and Stigmatizing Aspecto of HIV Infection. *Journal of Clinical Psychiatry*, 50, 5-8.
- Gerhardt, Uta E. 1985. Stress and Stigma Explanations of illness. In Uta E. Gerhardt and Michael E. J. Wadsworth, eds. *Stress and Stigma: Explanation and Evidence in the Sociology of Crime and Illness*, pp. 161-204. New York: St Martin's Press Inc.
- Gibbons, Fredrick X. 1986. Stigma and Interpersonal Relationships. In Ainlay, Stephen C., Gaylene Becker and Lerita M. Coleman, eds. *The Dilemma of Difference: A Multidisciplinary View of Stigma*, pp. 123-144. New York: Plenum Press.
- Goffman, Erving. 1959. *The Presentation of Self in Everyday Life*. Garden City, New York: Doubleday & Company, Inc.
- Goffman, Erving. 1961. *Asylums*. Garden City, New York: Doubleday & Company, Inc.
- Goffman, Erving. 1963. *Stigma: Notes on the Management of Spoiled Identity*. Englewood Cliffs, New Jersey: Prentice-Hall, Inc.
- Goldstein, Richard. 1990. The Implicated and the Immune: Cultural Response to AIDS. *The Milbank Quarterly*, 68, 295-319.
- Gorman, Christine. 1993. Are Some People Immune to AIDS? *Time*, March 22, 49-51.
- Grady, Christine. 1992. HIV Disease: Pathogenesis and Treatment. In Jacquelyn Haevk Flasherud and Peter J. Ungvarski, eds. *HIV/AIDS: A Guide to Nursing Care*, pp. 30-54. Philadelphia: W. B. Saunders Co.
- Gussow, Z. and G. S. Tracy. 1968. Status, Ideology and Adaption to Stigmatized illness: A Study of Leprosy. *Human Organization*, 27, 316-325.
- Hammersmith, Sue Kiefer. 1987. A Sociological Approach to Counseling Homosexual Clients and their Families. *Journal of Homosexuality*, 14, 173-90.
- Herek, Gregory M. and Eric K. Glunt. 1988. An Epidemic of Stigma: Public Reactions to AIDS. *American Psychologists*, 43, 886-891.
- Heyer, D. M., J. O. Kahn and P. A. Volderbing. 1990. HIV-Related Kaposi's Sarcoma. In P. T. Cohen, M. A. Sande and P. A. Volberding, eds. *The AIDS*

- Knowledge Base*, pp. 713.1-713.19. Waltham, MA.: Medical Publishing Group.
- Heyward, William L. and James W. Curran. 1988. The Epidemiology of AIDS in the U. S. *Scientific American*, October, 72-81.
- Holland, J. C. and S. Tross. 1985. The Psychosocial and Neuropsychiatric Sequelae of The Acquired Immunodeficiency Syndrome and Related Disorders. *Annals of Internal Medicine*, 103, 760-764.
- Horsburgh, C. R., Ou C. Y., Jason, J. et al. 1989. Duration of Human Immunodeficiency Virus Infection Before Detection of Antibody. *Lancet*, 2, 637-639.
- Jones, Edward E., Amerigo Ferina, Albert H. Hastorf, Hazel Markus, Dale T. Miller and Robert A. Scott. 1984. *Social Stigma: The Psychology of Marked Relationships*. New York: W. H. Freeman and Company.
- Katz, Irwin. 1979. Some Thoughts About the Stigma Notion. *Personality and Social Psychology Bulletin*, 5, 447-460.
- Katz, Irwin. 1981. *Stigma: A Social Psychological Analysis*. Hillsdale, New Jersey: Erlbaum.
- Kayal, Philip M. 1992. Healing Homophobia: Volunteerism and "Sacredness" in AIDS. *Journal of Religion and Health*. 31, 113-128.
- Kelly, Jeffrey A., St. Lawrence, Janey S., Smith, Steve, Hood, Harold V., and Cook, Donna J. 1987. Stigmatization of AIDS Patients by Physicians. *American Journal of Public Health*, 77, 789-791.
- Kirscht, John P. 1988. The Health Belief Model and Predictions of Health Action. In David S. Gochman, ed., *Health Behavior: Emerging Research Perspectives*, pp. 27-41. New York: Plenum Press.
- Krieger, Lisa M. 1991. A Lost Generation of AIDS Activists. *San Francisco Examiner*, December 29, pp. A1 and B2.
- Lang, Norris G. 1990. Sex Politics, and Guilt: A Study of Homophobia and the AIDS Phenomenon. In Douglas A. Feldman. *Culture and AIDS*, ed, pp.169-182. New York: Praeger.
- LaVey, Simon. 1991. A Difference in Hypothalamic Structure Between Heterosexual and Homesexual Men. *Science*, 253, 1034-1037.
- Macklin, Eleanor D. 1989. *AIDS and Families*. New York: Harrington Park Press.
- Merz, David C. 1991. Clinical management of the acquired immunodeficiency syndrome. Unpublished manuscript.
- Moore, Richard D., Julia Hidalgo, Barbara W. Sugland and Richard E. Chaisson. 1991. Zidovudine and the Natural History of the Acquired Immunodeficiency Syndrome. *New England Journal of Medicine*, 324, 1412-1416.



- Moss, A.R. and Bacchetti, P. 1989. Editorial review: Natural history of HIV infection. *AIDS*, 3, 55-61.
- Moulton, Jeffrey M., Sweet, David M., Temoshok, Lydia, & Mandel, Jeffrey S. 1987. Attributions of blame and responsibility in relation to distress and health behavior change in people with AIDS and AIDS-related complex. *Journal of Applied Social Psychology*, 17, 493-506.
- Moynihan, Rosemary, Grace Christ and Les Gallo Silver. 1988. Aids and Terminal Illness. *Social Casework: The Journal of Contemporary Social Work*, June, 380-387.
- Nardi, Peter M. AIDS and Obituaries: The Perpetuation of Stigma in the Press. In Douglas A. Feldman. *Culture and AIDS*, ed., pp. 159-168. New York: Praeger.
- Nelken, Dorothy and Laurence Tancredi. 1989. *Dangerous Diagnostics: The Social Power of Biological Transformation*. New York: Basics Books Inc.
- Parsons, Talcott. 1951. *The Social System*. New York: The Free Press of Glencoe.
- Powell-Cope, Gail M. and Brown, Marie A. 1992. Going public as an AIDS family caregiver. *Social Science and Medicine* 34, 571-580.
- Quam, Michael D. 1990. The Sick Role, Stigma, and Pollution: The Case of AIDS. In Douglas A. Feldman. *Culture and AIDS*, ed., pp. 29-44. New York: Praeger.
- Reynolds, Nancy R. 1991. "Effects of Nurse Case Management on HIV/AIDS Informal Caregivers." Agency for Health Care Policy and Research [R03 HS06971-01].
- Rogers, Paul and Henry Masur. 1989. The Immune System: Clinical Manifestations. In Richard A. Kaslow and Donald P. Francis, eds., *The Epidemiology of AIDS*, pp.48-67. New York: Oxford University Press.
- Sandstrom, Kent L. 1990. Confronting deadly disease: The drama of identity construction among gay men with AIDS. *Journal of Contemporary Ethnography* 19, 271-294.
- Saylor, Coleen R. 1990. The management of stigma: Redefinition and representation. *Holistic Nursing Practice*, 5, 45-53.
- Scambler, Graham and Hopkins, Anthony. 1990. Generating a Model of Epileptic Stigma: The Role of Qualitative Analysis. *Social Science and Medicine*, 30, 1187-1194.
- Scambler, Graham. 1984. Perceiving and Coping with Stigmatizing Illness. In Ray Fitzpatrick, John Hinton, Stanton Newman, Graham Scambler and James Thompson, eds., *The Experience of Illness*, pp. 203-226. New York: Tavistock Publications.
- Scheerhorn, Dirk. 1990. Hemophilia in the Days of AIDS. *Communication Research*, 17, 824-847.

- Schneider, Joseph W. and Conrad, Peter. 1986. In the closet with illness: Epilepsy, stigma potential and information control. In Peter Conrad and Rochelle Kern (eds.), *The Sociology of Health and Illness*. New York: St. Martin's Press.
- Siegel, Karolynn and Beatrice J. Krauss. 1991. Living with HIV Infection: Adapative Tasks of Seropositive Gay Man. *Journal of Health and Social Behavior*, 32, 17-32.
- Sontag, Susan. 1978. *Illness as Metaphor*. New York: Farrar, Straus, and Giroux.
- Stahly, Geraldine B. 1989. Psychosocial aspects of the stigma of cancer: An overview. *Journal of Psychosocial Oncology*, 6, 3-27.
- Strommen, Erik F. 1990. Hidden branches and growing pains: Homosexuality and the family tree. *Journal of Homosexuality*, 9-34
- Strauss, Anselm L. 1984. *Chronic Illness and the Quality of Life*. St. Louis: The C. V. Mosby Company.
- Stulberg, Jan and Stephan L. Buckingham. 1988. Parallel Issues for AIDS Patients, Families, and Others. *Social Casework: The Journal of Contemporary Social Work*, June, 355-359.
- Tiblier, Kay B., Walker, Gillian, Rolland, John S. 1989. Therapeutic issues when working with families of persons with AIDS. In Eleanor D. Maclin, ed. *AIDS and Families*, pp. 81-128. New York: Harrington Park Press.
- Tindall, B., Barker, S., Donovan, B. et al. 1988. Characterization of the acute clinical illness associated with human immunodeficiency virus infection. *Archives of Internal Medicine*, 148, 945-949.
- Triplet, Rodney G. and David B. Sugarman. 1987. Reactions to AIDS Victims: Ambiguity Breeds Contempt. *Personality and Social Psychology Bulletin*, 13, 265-274.
- Ungvarski, Peter J. 1992. Clinical Manifestations of AIDS. In Jacquelyn Haevk Flasherud and Peter J. Ungvarski, eds. *HIV/AIDS: A Guide to Nursing Care*, pp. 54-147. Philadelphia: W. B. Saunders Co.
- Volberding, P., Lagakos, S., Koch, M. et al. 1990. Zidovudine in asymptomatic human immunodeficiency virus infection: A controlled trial in persons with less than 500 CD<sub>4</sub> positive cells per cubic mm. *The New England Journal of Medicine*, 322, 941-949.
- Weiner, Bernard, Perry, Raymond P., and Magnusson, J. 1988. An attributional analysis of reactions to stigmas. *Journal of Personality and Social Psychology*, 55, 738-748.
- Weitz, Rose. 1989. Uncertainty and the Lives of Persons with AIDS. *Journal of Health and Social Behavior*, 30, 270-281.