



## STIGMA, HIV AND AIDS: AN EXPLORATION AND ELABORATION OF A STIGMA TRAJECTORY\*

ANGELO A. ALONZO<sup>1</sup> and NANCY R. REYNOLDS<sup>2</sup>

<sup>1</sup>Department of Sociology, The Ohio State University, Columbus, OH 43210, U.S.A. and <sup>2</sup>School of Nursing, University of Rochester, Rochester, NY 14642, U.S.A.

**Abstract**—Stigma is a social construction which dramatically affects the life experiences of the individuals infected with the human immunodeficiency virus (HIV) and their partners, family and friends. 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 a single illness. In this paper, HIV/AIDS is analyzed in terms of a stigma trajectory. The primary purpose is to conceptualize how individuals with HIV/AIDS experience stigma and to demonstrate how these experiences are affected by changes in the biophysical dimensions of HIV/AIDS. Four phases of the HIV/AIDS stigma trajectory are depicted: (1) *at risk*: pre-stigma and the worried well; (2) *diagnosis*: confronting an altered identity; (3) *latent*: living between illness and health; and (4) *manifest*: passage to social and physical death. The essential processes through which individuals personalize the illness, dilemmas encountered in interpersonal relations, strategies that are used to avoid or minimize HIV-related stigma, and subcultural networks and ideologies that are drawn upon to construct, avow, and adapt to an HIV identity are considered across the stigma trajectory.

*Key words*—HIV, AIDS, stigma, trajectory, coping

### INTRODUCTION

Since its recognition in 1981, the Human Immunodeficiency Virus (HIV) has aroused deep human responses. In the United States, where the HIV epidemic emerged among gay men and intravenous drug users, a persistently negative societal response has played and continues to play a critical role in the experiences of individuals infected with the virus [1]. While the significance of the stigmatizing aspects of HIV is widely acknowledged [2], little consideration has been given to how social stigma interacts with HIV disease† components in the illness experience of HIV infected persons. In this paper, HIV is analyzed in terms of stigma, deviance and illness perspectives, and disease course and illness trajectory perspectives [3]. The goal is to conceptualize how the interaction of social, psychological, cultural and biophysical dimensions of HIV/AIDS produce and shape the illness trajectory and, what we will term, the stigma trajectory. Further, this analysis considers the various dimensions of stigma which must be reconceptualized or specified to take into account the unique nature of

the HIV/AIDS trajectory. No-one to our knowledge has elaborated the relationship between HIV and stigma in terms of specifying the nature of the HIV/AIDS disease trajectory and the social processes of experiencing stigma or a 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 illness course where stigma may be differentially experienced and managed.

This paper is informed by extant literature, conceptualizations and research concerning the experiences of HIV infected persons and their informal caregivers. Our analysis of these sources is consistent with current analytic efforts to bring synthesis to diverse bodies of literature. A brief background on the nature of stigma is followed by a discussion of illness and stigma, an examination of stigma and HIV/AIDS, and finally an elaboration on the stages of the HIV/AIDS illness course in relation to stigma. The focus of attention in this analysis is upon the stigma confronting HIV positive gay males. The analysis also extends, where appropriate, to other 'at risk' groups, namely, injection drug users, bisexual males and others placed at risk for having HIV disease in the United States.

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†The term 'HIV disease' is used in this analysis to refer to the discrete biophysical dimensions of HIV/AIDS, whereas 'HIV illness' is used to denote the subjective, and social constructive aspects of HIV/AIDS and their interaction with the biophysical dimensions. That is, HIV illness is used heuristically to delineate how biophysical and psychosocial and cultural dimensions interact in the social construction of the HIV/AIDS stigma trajectory.

### 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 [4] offer a useful definition. 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" [4] (p. 33).

In general, there is consensus in the stigma literature that stigma represents a construction of 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 [5] perspective, is a powerful discrediting and tainting social label that radically changes the way individuals view themselves and are viewed as persons. When individuals fail to meet normative expectations because of attributes that are different and/or undesirable, they are reduced from accepted people to discounted ones. Thus, the discrepancy between what is desired and what is actual, 'spoils' the social identity, isolating the individual from self, as well as, societal acceptance [5].

As Goffman [5] notes, stigma is not merely an attribute, but represents a language of relationships. An attribute that stigmatizes one type of possessor can confirm the usualness of another, and therefore is neither creditable nor discreditable as a thing in itself [5] (p. 3). Individuals are devalued less because they display attributes that violate accepted standards than because some communities have chosen to call certain attributes deviant [6]. Thus, a given attribute that is stigmatized is not inherently pathological, immoral, or 'deviant' but derives from culturally imbedded meanings. Thus, various forms of 'deviance' are stigmatized in the context of a particular historic period and cultural context.

Katz [7], 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 we often try to avoid interaction with individuals whose bodily and psychological characteristics deviate from our own group norms [7] and those who are different wish to avoid situations where their difference may be problematic for themselves and others. Stigmas also have a temporal dimension in that they are ineradicable and irreversible as the terms ex-mental patient or ex-convict imply [8, 9]. In fact, stigmas may follow us through the life cycle [10].

It is ironic, as Goffman [5] suggests, that the stigmatized tend to accept the norms that actually disqualify them from comfortable and equal participation in social interaction. Self hatred, and we might add shame, develop from internalizing negative values and repressed anger from discrimination [11]. The individual "stands a discredited person facing an unaccepting world" [5] (p. 19) all the while internalizing the perspective of the rejecters. This is not to say that stigmatized groups can not develop ideological defenses to account for their plight or

strategies to avoid or minimize discrediting social attributions. For example, stigma theories and "sad tales" [12] may be developed to attenuate the process of self-stigmatization and correct misinformation and its consequences in terms of fear, prejudice and discrimination. As Gassow and Tracy 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" [13] (p. 317). 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 [7].

Goffman further suggests that no matter how small or bad off a particular stigmatized group is, they are generally given some kind of public presentation and an "intellectually worked-up version of their point of view is thus available to most stigmatized persons" [5] (p. 25). Television and films, aside from newspapers and magazines, are voracious consumers of human interest 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 relational 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 'out' group by reinforcing norms of the 'normal' community.

Ultimately, stigma creates outsiders and social boundaries between normals and the stigmatized, with the stigmatized doomed to "eternal stigmatization in their own eyes as well as those of society" [8] (p. 8). In so doing, the life chances of the stigmatized are reduced [5]. Thus, the essential meaning of stigma which guides this analysis, drawn from the previous discussion, is that *the stigmatized are a category of people who are pejoratively regarded by the broader society and who are devalued, shunned or otherwise lessened in their life chances and in access to the humanizing benefit of free and unfettered social intercourse*. Given this definition, it is necessary to now briefly consider how diseases and illnesses lend themselves to stigmatization and why HIV/AIDS fits into a stigmatic framework.

#### STIGMA AND ILLNESS

Societies have several means of controlling deviant behavior or behavior which is pejoratively regarded. Medicine is one of these means and provides both a judgment as to the cause of the disease or behavior, as well as a means of hopefully curing or at least controlling the disease. More importantly, however, being placed in the hands of medical practitioners and

having one's deviation medicalized and reconstructed as a disease, allows one to disavow inferiority by appealing to the randomness of disease and the potential medicine offers for absolution from responsibility [9].

Illness 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 socially problematic to the extent that it interferes with the pursuit of life in its biophysical, social and psychological, or generally human manifestations. Disease is essentially a deviation from what we expect or what we have been told to expect by medical authorities. However, some diseases are imputed and laden with additional meaning and significance or become as Sontag [14] notes, metaphors for sinfulness and evil.

With stigmatizing illnesses "disreputability and even evil" may adhere to the person so afflicted [11] (p. 137) and, as Goffman [5] notes, to his family and friends in the form of a courtesy stigma. Conrad [15] 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. Thus, some individuals stigmatized by illness are devalued, shunned, or otherwise lessened in their life chances because the illness they have, or are suspected of having, discredits their claim to be "moral characters" [5] and one of 'us.'

#### STIGMA AND HIV

HIV and AIDS are manifestations of an extraordinary illness in terms of its potential for multidimensional stigmatization. To further explore the nature of HIV stigma, three sources that propose schemas for understanding variations in the construction of stigma and strength of negative response are considered; these include: (1) Goffman [5], who defines three basic types of stigma: character blemishes, abominations of the body and tribal stigma; (2) Katz [7], who distinguishes four dimensions of stigma: threat, responsibility, visibility and sympathy; and (3) Jones *et al.* [16], who distinguish six dimensions of stigma: concealability, course, disruptiveness, aesthetic qualities, origin and peril.

Merging the types and dimensions of stigma as delineated by Goffman, [5], Katz [7] and Jones *et al.* [16], 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 [15];

- (2) viewed as the responsibility of the individual [17];
- (3) tainted by a religious belief as to its immorality [18, 19] and/or thought to be contracted via a morally sanctionable behavior [17] 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 health care providers [20, 21].

In fact, while other illnesses or character blemishes can be said to differentially stigmatize, HIV infection and AIDS are rather universal in their preponderant negative evaluation.

Although the stigma associated with HIV/AIDS is overpowering, individuals with the illness do not necessarily experience the same degree of stigma. Differentials in stigma experience can be explained, to a large extent, by variation in individual social identities and attitudes confronted in one's social networks and reference groups. For example, an individual with strong ties to the gay community may perceive less and experience less gay and HIV-related stigma than an individual with stronger ties to non-gay communities. In addition, it has been noted that gay related stigma and rejection most often come from fathers, men, blue-collar workers, fundamentalists, and the less educated, than by the opposites of these [22]. Some population groups are also more likely to be regarded by the broader society as 'innocent' victims of HIV/AIDS [2, 17], for example, transfusion recipients and infants of HIV positive mothers, and may thus be viewed and treated less harshly. However, it is suggested here, that variation in the experienced stigma trajectory may also be related, to a significant degree, to biophysical changes in the HIV disease trajectory. A social construction which addresses both the social and biophysical basis of the stigma is thus considered.

#### THE HIV/AIDS AND STIGMA TRAJECTORIES

The concept of trajectory, deriving from the work of Strauss and Corbin [3, 23], is central to understanding the unfolding, discovering and controlling or working which occurs over the course of experiencing an illness. While Corbin and Strauss [23] stress the 'work' involved in shaping the trajectory, what is stressed here is the experience of both the course of the illness and the experience of the course and development of the shape of the stigma trajectory. The shape of the stigma trajectory is intrinsically entwined with the disease course but is uniquely tied to the responses of the broader society, family, peers, strangers, health care professionals and the identity of the individual who is

potentially stigmatizable. As Corbin and Strauss note, the concept of trajectory subsumes from Dewey [24] aspects of "undergoing and experiencing." These are central to the stigma trajectory as the individual and others undergo pejorative responses, experience devaluation and abridged social interaction as a consequence of being HIV positive.

Our current understanding of HIV/AIDS disease trajectory suggests that it can be understood as a continuum, at one end of which is an intact immune system while at the other a severely damaged system. Undergoing and experiencing HIV infection 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 [25]. 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. Disease progression varies widely among individuals, and, while the overall HIV/AIDS disease trajectory is downward, the slope is often barely perceptible for extended periods of time. However, 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 9–13 months for treated and untreated individuals combined and 21.3 months for those receiving antiviral medical treatments [26].

This biophysical disease trajectory underlies the individual's psychosocial reality. The HIV illness trajectory represents the interaction of the biophysical dimensions of HIV infection and psychosocial and cultural processes and is shaped by the trajectory 'work' carried out over time [3]. Considering the four stages of HIV disease discussed above and the multidimensional nature of stigma discussed previously, the nature of the HIV stigma trajectory is

conceptualized within the context of four essentially distinct biopsychosocial phases:

- (1) At Risk;
- (2) Diagnosis;
- (3) Latent;
- (4) Manifest.

While it is acknowledged that there is no single illness trajectory for HIV/AIDS and that at the individual level each trajectory, whether disease or stigma, has unique features, it is also evident, that by moving to a higher level of abstraction, common themes can be distinguished as to how individuals simultaneously address the intersection and interaction of both the stigma and HIV/AIDS trajectories. In addition, we are suggesting that disease and stigma trajectories may vary independently, but not too independently, and that stressing convergence of trajectories and commonality at this more abstract level provides greater insight than focusing on the independence and divergence of trajectories. The developed stigma trajectory is an ideal type and is not meant to disregard the variety of human and trajectory experiences.

In the following elaboration of the HIV stigma trajectory phases, we will consider: the essential processes through which individuals personalize the illness; the dilemmas encountered in interpersonal relations; the strategies that are used to avoid or minimize HIV-related stigma; and the subcultural networks and ideologies that are drawn upon as they construct, avow, and adapt to an HIV identity. While the views of society toward the individual across the stigma trajectory are not emphasized, it must be stressed that because stigma is a constructive/interactive phenomenon, the experiences of individuals over the stigma trajectory do, as Goffman [5] stresses, reflect internalized pejorative assessments of the broader society. We open each phase elaboration with interview excerpts from a study of HIV/AIDS caregivers\* to illustrate essential qualities and processes occurring in each phase.

#### AT RISK: PRE-STIGMA AND THE WORRIED WELL

Jim: I haven't been tested. I would rather not know than know for sure that I was HIV positive.

Michael: It took me quite a while to decide to get the test because I thought if I have to care for Jim it wouldn't do me any good to worry about myself. Finally, I became convinced that it could be useful if I could begin an earlier treatment if I were positive.

The 'at risk' phase does not correspond with an actual stage in the HIV disease course, however, it specifies a period of uncertainty in the stigma trajectory when an individual fears behaviors or contacts have placed him or her at risk for HIV, or fears that others regard him or her to be at risk for HIV

\*Data in this study were collected in 32 in-depth, focused interviews with persons primarily responsible for providing care to an HIV positive individual. Several of the participants were at risk or diagnosed as HIV positive at the time of the interviews. All interviews were tape recorded and later transcribed verbatim. Data were analyzed using a constant comparative method. See Ref. [71] for a more detailed description of this study.

(e.g. bisexual and homosexual men; heterosexuals with multiple sexual partners). While 'at risk' individuals may have no laboratory or clinical evidence of HIV infection, they are cognizant of their risk or perceived risk [2], and the meaning and consequences of HIV/AIDS is present in terms of a potentially felt stigma for being at risk and therefore suspect in the eyes of others. Individuals at risk live with the ideation of what might happen to them, in essence, a pre-stigmatic fear.

Individuals 'at risk' for HIV represent the 'worried well' or 'socially worried well', that is, individuals whose initial concern of being in an at risk group is not entirely with the disease itself, but with the social risks of being perceived as being in an at risk group [27]. As Sontag notes, being in the at risk group reflects the "archaic idea of a tainted community that illness has judged" [17] (p. 46). The individual fears moving into the stigmatized category because of the social consequences, however, in so doing, he begins to take the perspective of the condemners or broader society 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 this sense, 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.

#### *Managing risk*

An individual may use different strategies to manage one's 'at risk' status. Denial is one of the primary coping mechanisms discussed in the literature describing behavior of 'at risk' individuals (see Refs [28, 29]). Denial is a form of avoidance by which individuals may diminish their perceived risk and perhaps discount relevant educational information. 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 [30] 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" [30] (p. 273). Thus, they suspend the possibility of HIV because they are not one of the above types of people. In essence, "AIDS occurs only elsewhere" [30] (p. 273). More importantly, as Moynihan, Christ and Silver [31] point out, treating individuals at risk for HIV in categorical terms, for example, homosexuals and injection drug abusers, rather than in terms of risk behaviors, reduces perception of risk and encourages, what we term a suspension of possibility.

#### *The reality of HIV*

Being 'at risk' may end with the result of testing among individuals who find their way into the health care system and test positive. Actions to evaluate HIV status and the issues raised in testing are similar to those raised by the Health Belief Model [32, 33] 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 regarded as too stigmatizing and threatening in terms of a potential for rejection by family, partners, friends and co-workers [34]. In addition, at risk individuals may believe that testing will jeopardize civil liberties [35] and encourage many forms of discrimination [36]. Quam 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" [37] (pp. 31-32). Individuals may thus spend considerable time grappling with the decision of whether or not to be tested, sometimes preferring an ambiguous HIV status and opportunity to merely flirt with the possibility of a stigmatized HIV identity. As Mishel [38] notes, ambiguity or uncertainty may offer the possibility of more hope than does certainty.

To varying degrees and in specific locales, support for being at risk is available to gay, bisexual and non-gay segments of the population. However, bisexuals may have more tenuous ties to the gay subculture and therefore are often neither encouraged to get tested nor supported in a decision not to get tested. Bayer [36] noted the initial absence of support for testing in the gay community for fear of civil liberty infringements and potential for labeling 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 most likely, a certain degree of fear, anxiety and self-loathing. As Cassel [39] suggests, fear is future oriented. Individuals who regard themselves 'at risk' may look into the future and fear the loss of personhood or sense of self as formerly known. For some the fear and ideation of what might happen to them becomes a reality as they move from the pre-stigmatic risk status to diagnosis or HIV positivity.

#### **DIAGNOSIS: CONFRONTING AN ALTERED IDENTITY**

Brad: I don't have any first hand experiences with it (HIV related stigma) but I pick it up in conversations. I see people's reactions when the word (HIV) is mentioned. I see people's reactions and misconceptions in conversations when they start talking about something they suspect. I see it in the newspapers and all this other kind of stuff. It's there.

An individual may be diagnosed as being HIV positive once 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 approx. 95% of infected persons can be expected to seroconvert (test positive for the HIV antibodies) [40]. The initial acute infection with HIV is generally characterized by a mononucleosis-like syndrome, usually appearing 2 to 6 weeks after seroconversion [41]. 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 [42]; 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.

The individual may be diagnosed as HIV positive early or late in the HIV disease trajectory. Whether late or early there are specific issues and stresses surrounding a positive diagnosis. As Moynihan, Christ and Silver [31], Sandstrom [43] and Pierret [2] all note, it is a profoundly disturbing realization, especially for a young adult and his family, to have to address the possibility of a significantly shortened life span as a consequence of HIV. Further, Quam points out that "(d)earth at an early age is itself stigmatized" [37] (p. 37), for family as well as the individual. As Lang [44] suggests, 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. For the young mother, a positive diagnosis may be even more disturbing with the possibility of having infected her infant and/or the knowledge that she may eventually need to place young children in the hands of others for care.

#### *Response to diagnosis*

A stress response characterized by disbelief, numbness and denial, followed by anger, acute turmoil, disruptive anxiety and depressive symptoms is typically seen after the diagnosis [1]. 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 issues concerning 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 potential for enacted stigma associated with their newly emerging and disreputable status as being HIV positive.

As with any secret, and especially a stigmatizing and discrediting one, the individual must engage in "information management" [5]. 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" [5] (p. 42). Siegel and Krauss [26] 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. Among individuals whose gay identity has remained private, the revelation of HIV positivity may mean having to cope with the identity of also being gay, a prostitute or an injection drug user. This potential for simultaneously acquiring a double stigma is exemplified among hemophiliacs who have been encouraged to deny their hemophilia, and are later encouraged to deny their positive HIV status for fear of being associated with homosexuality and injection drug abuse [45].

The primary process in this stage in the stigma trajectory is dealing with identity consequences of discovery or disclosure of HIV positivity. Individuals at this stage may have already seen and felt the consequences of the HIV/AIDS stigma among others and must manage information carefully and prudently, usually under much stress and tension [43]. The interaction and intersection of disease, social and stigma trajectories is manifest because individuals must simultaneously come to terms with their shortened life span, inevitable death and what they now symbolize to society. While this stage is not necessarily highly symptomatic, the next stage is even less so and makes denial and normalization even more inviting, feasible and possibly threatening to society.

#### **LATENT: LIVING BETWEEN HEALTH AND ILLNESS**

Lon: I don't tell anybody. It is not because I'm ashamed or anything, it's because of the reaction. I know people's ignorance of it so I don't even bother to say anything . . .

Steve: I can't go into work talk about it . . . I worry I'll say something to someone by mistake and everyone will know. I don't have a job where I can be open about it . . . I'm not really proud of not talking about it. I wish I could be open. I just wish I could be more open about it.

'Latent' refers to the time in the trajectory when the disease is asymptomatic, concealable and presumably the least overtly disruptive in general; however, it may still be covertly quite disruptive in terms of internal feelings of anxiety and stress. While the disease process has the quality of being quiescent, there is a high potential for felt stigma experienced in terms of fear of rejection and isolation. The uncanny retrovirus nature of HIV has created, according to Goldstein, "... a new class of 'patients,' forced to live between sickness and health, giving a tangible twist to the old medical term, 'worried well' " [46] (p. 316).

#### *Concealing the diagnosis*

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 conceal their diagnosis, normalize and,

to some extent even deny their HIV positivity. Triplet and Sugarman [47] suggest there is good reason to attempt to conceal HIV status, as AIDS patients have the lowest interactional desirability among several chronic diseases. Likewise, Yedidia *et al.* [21] report that physicians also express negative attitudes toward patients with HIV infection or AIDS. Thus, concealability becomes a defense against enacted stigma and it has been noted that people who can, generally will conceal their stigma [16]. But concealing may not be an entirely adequate strategy to avoid the discomfort that accompanies illness-related stigmas. Individuals in the asymptomatic phase harbor feelings of shame, self blame and fear of rejection or abandonment by friends, neighbors, co-workers and employers [48, 49] and the dread of enacted stigma [50]. Having crossed a boundary [37] or feeling different from the rest, the individual begins to experience isolation, alienation, denial and the building of an identity as a stigmatized person despite opportunities for normalization (see: Refs [43, 51, 52]).

By concealing one's HIV status, the individual attempts to protect his or her self-esteem [16] by avoiding episodes of enacted stigma [53], but there may be other negative consequences in so doing. 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 . . ." [49] (p. 357). The stress of living a double life is a heavily felt burden [26, 30], especially if interacting in both straight and gay settings.

Second, by keeping the diagnosis secret, the individual is deprived of social support from his or her social network that presumably would normally be available to him/her [49]. Third, by failing to disclose the individual also risks engendering the hostility of others when they finally learn that the individual is HIV+ and they were not informed previously.

Fourth, the individual may be motivated to refrain from activities that signal diagnosis, such as delay in seeking appropriate health care or participation in HIV support groups. Suspicion may adhere to any individual of known risk who deviates in terms of health status. Thus, some may jeopardize their health status to appear normal or to be "moral characters" [5] when early health status evaluations and support would be beneficial.

Lastly, 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. The individual may engage in activities that dismiss and deny the diagnosis, such as unprotected sex with unknowing partners [35, 54] or sharing needles. In so doing, the individual essentially disavows his HIV positivity but this will necessarily come at the cost of placing others at risk.

### *Revealing the diagnosis*

While the consequences of concealment are potentially detrimental, the consequences of revelation at this stage may be no less costly. Individuals view the diagnosis of HIV positivity as potentially exposing them to the "...harsh and injurious realities of lay ignorance, intolerance, and discrimination" [53] (p. 214). There may be an oppressive fear of the enacted stigma [53] of being rejected by family, friends and companion. Quam [37] argues that this fear may be well founded as HIV+ individuals report being shunned by friends and family and removed from housing and employment.

In this stage, the individual does have the advantage of choosing the time to disclose, which, in some cases, may soften the potential for rejection by giving the individual an opportunity to first demonstrate their 'worth' and 'humanity' to others [16]. Individuals with HIV do often employ 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 the situation. Yet, in a study of caregivers, Powell-Cope and Brown [55] noted that disclosure in relationships ranging from the most intimate to the most public usually involved intense emotions such as embarrassment, pain, confusion and anger. And Stulberg and Buckingham [49] note that the devastation of revelation for the heterosexual spouse of a person who is HIV+ may be profound because of the implied double life one's partner has led and the now terminal prognosis.

During the latent phase the greatest independence between the HIV disease trajectory and the HIV/AIDS illness trajectory may be expected. Yet, in essence, and consistent with our definition of stigma, the individual's access to the humanizing benefits of free and unfettered social intercourse begins to be impaired, as is their immune system. Because of the potential for revelation, the realization of stigma and the potential to 'pass,' HIV positivity continues to be disruptive in terms of internal feelings of stress, anxiety and matters relating to information management. However, passing is also problematic as Schneider and Conrad [56] point out in their study of epileptics, since it can isolate the concealer who is patently aware that he or she is secretly different from others. On the other hand, even when immediate disclosure would seem reasonable, fear, anger and anxiety associated with it are major constraints. However, when the transition is made to manifest HIV/AIDS, the nature of coping and the illness and stigma trajectories significantly change.

### MANIFEST: PASSAGE TO SOCIAL AND PHYSICAL DEATH

Jack: But when his T cell count dropped real significantly and he had to go on medicine, that's when we told his Mom. And pretty much since he went into the hospital in the last few months we told all our other friends . . . for practical reasons . . . (S)ome people I just don't want to deal with. I don't need their sympathy or pity.

Michael: I didn't let him (HIV-infected partner) know, but I got upset with so called friends that decided they didn't want to be involved. They didn't call or come to see him or anything like that. Prior to the beginning (of illness) they would call two or three times a week.

#### *The manifest disease trajectory*

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 [41]. These early manifestations indicate significant immunologic impairment and can precede acquisition of an AIDS-defining condition [25, 41]. 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 [57, 58, 59, 60].

Despite the apparent 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 and AIDS-related conditions and can affect virtually every organ/system of the body. The conditions that are most visible, have the greatest implications for individuals in terms of the stigma trajectory. For example, Kaposi's sarcoma is most typically manifested as nodules that are usually pigmented and violaceous (red to blue) and difficult to conceal [61]. Distinct patch-stage lesions appear quite early in some individuals and may be initially mistaken for bruises [62], 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 [61]. 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 [63]. 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 [64].

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 [64].

#### *Disease and stigma trajectory interaction*

In the early manifest phase, the interaction of social identity issues, stigma and the biophysical disease process become intensified. Rather than remaining potentially independent, as in the diagnostic and latent phases, the emerging manifestations of HIV disease, noted above, thrust the disease and stigma trajectories toward convergence. 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 previously. In terms of the stigma trajectory, issues of enacted stigma must now be fully addressed. The psychological isolation that may have begun during a latent period is now reinforced by early, potentially revealing, 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 later phases in the disease trajectory.

Issues concerning information control, which tend to stabilize during 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 treatment. Early acknowledgment of HIV infection and a willingness to accept the identity of HIV positivity will likely increase 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 be inclined to postpone anti-viral treatment, especially if they are largely 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 normalization or denial reinforced by the previous latent, asymptomatic phase and the hope of being one of the long-term HIV positive survivors who could escape AIDS [65].

While anti-viral treatment may biophysically enhance the individual's immune system, it may not entirely overcome other anxieties related to the body. Moynihan, Christ and Silver report that early in this phase individuals feel like a "walking time bomb," just waiting for the first medical crisis or "explosion" to occur" [31] (p. 384). They often experience a great deal of uncertainty as to the meaning and purpose in their lives. Many individuals cope with the unpredictable nature of the HIV trajectory by closely monitoring 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 [3].

As opportunistic infections become more numerous and manifest, it is the biophysical trajectory that begins to drive coping behavior as the HIV continues to suppress the individual's immune system. The transition to an AIDS identity may be in the form of a "sharp rite of transition" to AIDS as a "master status" [66]. The 'normal' identity of the individual is essentially worn down and the stigmatic AIDS identity becomes fixed by multiple opportunistic infections, repeated hospitalizations, physical changes, weakness, dependence on others, increased contact with medical practitioners, and sometimes either increased contact with estranged family and friends or essential rejection and increased social isolation.

As the illness progresses, Coleman notes that "(s)tigma often results in a special kind of downward mobility" wherein the stigmatized "...lose their place in the social hierarchy" [67] (p. 214). Persons with AIDS are likely to become increasingly isolated over time with fewer opportunities for unfettered social interaction, and, as the illness becomes increasingly more difficult to conceal, the opportunity for enacted stigma is enhanced. Having experienced the downward decline, the individual is aware of the isolation by and withdrawal of others who were, in pre-manifest times, willing interactants and providers of support.

Interactions between the 'discredited' [5] and 'normals' reflect a general decrease in spontaneity and increase in tension [68]. During this phase, the disease process, as much as the internal psychological processes and social tension, may disrupt social interaction. Central nervous system symptoms are increasingly manifest in the later stages of AIDS with early symptoms being memory loss, difficulty concentrating, mental slowness, confusion and apathy, withdrawal and depression. Moynihan, Christ and Silver [31] report that patients often fear these symptoms and they may attempt to conceal them from their physician, an indication that they are still, in a sense, trying to 'pass' as a means of normalization and denial. More importantly, there may be an increasing sense of loss of control by the terminal AIDS patient [49]. Some patients avoid physicians, as a way of asserting control over their emotional well-being despite the physical consequences. For others, suicide may seem a way to alleviate uncertainty and exert control [30].

During late stage HIV infection, the stigma of HIV again forces individuals to struggle with internalized blame. Moulton *et al.* [69] 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 have a negative impact on health/illness outcomes [70], society offers few resources to enable individuals to come to terms with a sense of personal responsibility for their own increasingly unfortunate circumstances.

Although early signs and symptoms are concealable, the 'wise' [5] 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 early manifest AIDS. 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 [37]. Thus, stigma is enacted as others shun the person with AIDS, and/or abridge social interaction with him or her. At the same time, 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 [71].

#### *The search for meaning, support and acceptance*

It is noted [19, 31] that the risk behaviors that make a person vulnerable to HIV/AIDS generally distance them 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 [68]. In addition, individuals may desire religion as a means to search for meaning in the fate they will come to experience. However, religion, while providing explanation, may extend little needed comfort. In seeking religious support, the HIV-infected persons may again have to accept the perspective of the condemners; that God may be punishing them for their behaviors [19, 30, 72]. Rather than promoting tolerance, religion may in fact reinforce stigma [19]. The sympathy and forgiveness engendered in religious institutions is not constant and may depend on the particular clergyperson encountered [31]. Just as he or she may have had to search for nonjudgemental health care providers, and acceptable treatments and regimens [73], the individual may be forced to *shop* for religious acceptance and support.

Some individuals find solace in social support groups, which can provide a context which enables the stigmatized person to feel normal [74]. Gibbons [75] points to the accepting nature of self help and support groups where the issue of morality, and perhaps contrition, is not stressed and the sense of a 'shared stress' may serve as a respite from felt and enacted stigma. Because support groups are comprised of others who share the same symptoms or disability and they can provide "tricks of the trade" and sanction [74]. Support groups thus may constitute a community of 'own' [5] in which members share a stigma and demonstrate that they are accepting and accepted people, and at the same time provide a forum for the individual to be a "hero of adjustment" [5] demonstrating triumph in the face of the adversity visited upon them over the course of the stigma trajectory.

However, individuals without ties to the gay and other communities where AIDS is more accepted, are more likely to continue to try to conceal their AIDS diagnosis as a means of coping with stigma [55] (p. 573) and are less likely to associate with others or become involved in situations (e.g. support groups) where their HIV status may be identified or must be acknowledged. Those wishing to 'pass' may be concerned about guilt by association [75], and may engage in downward comparison and thus avoid the more stigmatized of their lot [75].

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 [50] 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" [5] may be influenced by the ability of a caregiver to provide a protective, insulating capsule [23].

In serving in this capacity, however, the AIDS caregiver may experience an enacted "courtesy stigma" [5] rather than support for their efforts and sacrifices. Initially, in assuming the caregiving role, 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 [55], found that AIDS caregivers tended to disclose more information about their caregiving relationship to more people as the patient became increasingly ill and they needed to seek support. 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 of HIV-infection may receive more sympathy for various reasons. First, while family estrangement and rejection may sometimes exist during the at risk, diagnostic and latent stages, family members may find it unacceptable to be angry with a patient who is suffering [31], particularly one who is dying. During the end stage, negative stigmatic attitudes and feelings may thus be suppressed and no longer communicated either verbally or behaviorally to the dying person. Second, as the therapeutic focus changes from HIV focused anti-viral treatment to 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 distress and great discomfort.

Third, manifestations of AIDS heralds losses that invoke sympathy. That is, 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 [17, 67]. In a process similar to what occurs in Alzheimer's disease, families, partners and/or friends may begin to mourn the social loss of the patient, and may attempt to come to terms with them before they die [76].

However, sympathy for caregivers and/or the patient is neither without conflict nor ambivalence. 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 heightened fear because they are constant reminders of one's contagious and tainted status. Despite the fact that, as the illness becomes manifest, the individual not only becomes increasingly isolated, and physically less capable of infecting others, and, is no longer able 'pass' as uninfected, the individual may still be regarded by others as an extreme threat, with visual cues enhancing a perception of contagion and a 'leper-like' status. Goldstein observes 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" [46] (p. 299).

In addition, Goffman [5] 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 or her illness may further serve to reduce our feelings of compassion and sympathy. As Herek and Glunt [77] point out, it is ironic that when the AIDS patient needs our social support they may be burdened by societal hostility and generally shunned. However, Jones *et al.* [16] and Katz [6] assert that stigma reactions are essentially ambivalent and conflicted, 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 [78] sense, and therefore lowered expectations, as a form of sympathy. However, as Coleman [67] points out, sympathy is merely an expression of stigma, and fundamental inferiority and social control. In addition, Gerhardt [66] suggests 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 [43]. Crocker [79] 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 [79] 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. Thus, while sympathy may be initially desired, it also carries the stresses of ambiguity and ambivalence.

#### *Manifest phase summary*

During the manifest phase, while there may be no fixed HIV/AIDS illness trajectory, because the clinical course is very individuated and successful treatments are available for many of the above clinical manifestations and AIDS-defining conditions, it is still possible to analytically distinguish the intersection of the disease and stigma trajectories 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 to matters relating to disease and infection control and near the end stage, work on managing and coping with stigma, a concern that forcefully drives behavior at the initial HIV diagnostic and early manifest stages of the disease trajectory, might appear to lessen. In essence, during the manifest phase, behavior of the individual progressively becomes driven by the clinical manifestations of HIV/AIDS described above with matters of stigma changing in character and matters surrounding social and physiological death becoming dominant. The character of stigma for the individual, as ambiguous and ambivalent as it may be, drifts closer to intensely felt stigma as he/she experiences isolation and withdrawal as a means of concealing abominations of the body [5], and coping with compromised physical capacities. In addition, caregivers by way of the courtesy stigma experience the brunt of enacted stigma and also ambivalence. Yet, the stigma trajectory and its consequences while perhaps somewhat attenuated do not entirely relent, as even after death caregivers may struggle with and hesitate revealing the actual cause of death, funerals may not be as well attended as expected, and physicians may not reveal the cause of death on death certificates [27].

#### CONCLUSION

Stigma is a social construction which dramatically affects the life experience of the HIV infected individuals and their partners, 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 a single illness trajectory. For this reason we have attempted to delineate the phases of the HIV/AIDS stigma trajectory as they are undergone and experienced, suggesting that each phase carries its own unique stigmatic qualities, characteristics and struggles.

The unique nature of HIV/AIDS with its at risk, diagnosis, latent and manifest phases, lends itself to many dynamic and demanding changes in the manner in which the individual and others must address issues of stigma construction and management. At the onset of a stigmatic career the at risk individual must address matters relating to one's "guilty body" [2]. One must then address the constructive nature of HIV/AIDS stigma, concealed identities and stresses emerging from information control and management. As the manifest nature of HIV/AIDS begins to make itself evident, stigma as an "abomination of the body" [5] is revealed and this revelation is accompanied by severe feelings of stigma [67]. The individual's world now centers around changes in bodily sensations [3] which may portend opportunistic infections and an inevitable decline in health status. Whereas early manifestations bring increased sensitivity to bodily changes [2], each change and sensation in late-stage illness heralds multiple social, psychological and cultural problems that must be coped with above and beyond initial, secondary and tertiary clinical manifestations of opportunistic infections.

As the individual is experiencing and coping with bodily changes he or she must also manage the expanding stigma as it becomes his or her 'master status'. The issues raised by Jones *et al.* [16] and Katz [7], such as responsibility, peril, aesthetic qualities and concealability, have an impact on the nature of the stigma experience and will vary substantially over the course of the illness. To study the trajectories of HIV/AIDS, we must be sensitive to the delicate and emergent interaction of the disease trajectory, the constructive nature of stigma trajectory, and the human 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 and something that can be said to be undergone and experienced in the Deweyan [24] sense. Frequently, it is expansive, pervading all corners of one's life space and identity. At other times, relative to the disease trajectory or even independent of it, stigma is containable, limited and controllable in terms of

consequences and, more importantly, personal and social identity.

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