

A Model for Psychosocial Issues in HIV Disease

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The progression of human immunodeficiency virus (HIV) infection from exposure to active acquired immunodeficiency syndrome (AIDS) involves a complex interplay between medical stages and psychosocial factors. Common initial reactions to the diagnosis of HIV infection are shock, denial, and anger. Depression can occur soon after diagnosis and often worsens with the onset of disease symptoms. The relative risk of persons with AIDS committing suicide is many times greater than that of the general population. Both patients and their families often experience feelings of acute suffering and prolonged grieving throughout the illness.

A model of the interrelationship between the medical stages and common psychosocial issues during HIV progression is provided to assist family physicians and other health care providers in counseling their patients (Figure 1). The usual disease progression from infection to death has been estimated to occur over a 10-year or longer period.¹ The authors have found the proposed model helpful for training medical students, residents, psychologists, and primary care physicians in the psychosocial dynamics associated with HIV disease.

The at Risk, "Worried Well"

It is well known that exposure to HIV is greatest among individuals who are currently or have been in the past 10 years involved in high-risk behaviors. The behaviors that place individuals at greatest risk are unsafe sexual practices between homosexual men and intravenous drug abuse that involves sharing unclean needles. As of August 1989, approximately 90% of the total number of AIDS cases fall into one of these high-risk groups.¹

Individuals who are concerned about their past or

present high-risk behaviors and have not yet been tested for the HIV infection have been described as the "worried well."² Many of these people become preoccupied and increasingly anxious about their infection status and find it difficult to decide whether or when to be tested. Instead of the patient revealing his or her true concern, the anxious patient often presents to the physician with somatic complaints. Patients may arrange a complete physical examination to verify their well-being. The physician will not discover the reason for the examination without direct, sensitive questioning about the patient's sexual history and possible high-risk behaviors.

Crisis

Testing positive for HIV is usually very traumatic for patients. They frequently experience a crisis reaction that includes feelings of severe shock, a sense of unreality, and some form of denial. Feelings of anxiety and guilt can often be overwhelming.^{3,4} Depression may occur during this crisis period, especially if the patient has a premorbid history of depressive episodes. Common symptoms of depression characteristic of patients who test positive for HIV include feelings of helplessness and worthlessness. These are provoked by the terminal nature of the illness, by fear of social stigmatization, and loss of friends or family support. Personal fears are often compounded by the patient's direct knowledge of friends and acquaintances who have died of AIDS. This may lead the patient to suicidal ideation.^{5,6}

After the initial crisis period, most patients begin to reestablish a sense of personal equilibrium and accept their HIV-positive status. Depending on their personality and coping styles, patients will respond in various ways.⁷ It is important for primary care physicians to discuss "safer" sexual practices with their patients who are HIV positive and to refer them to local AIDS service organizations for support and assistance.

Patients who have a strong need for control and have learned to meet that need in a cognitive manner will

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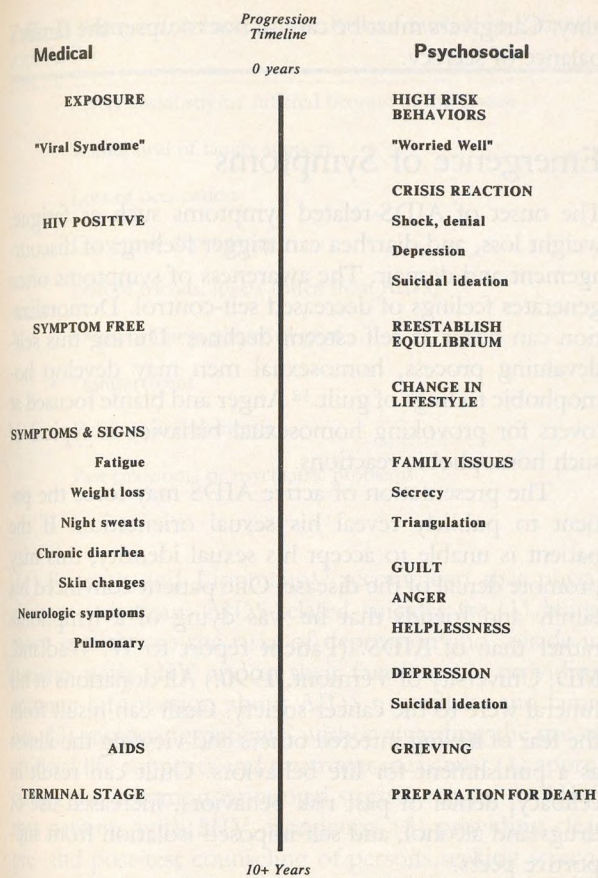


Figure 1. The interrelationship between the medical stages and common psychosocial issues during HIV progression.

acquire a great store of information about the disease and treatment options. They sometimes surpass their physician's own clinical knowledge about the disease. While this can be unsettling or disconcerting, it is important for physicians to recognize and support patients who need to master their diagnosis in a cognitive manner, and to work with them in a collaborative partnership.

Other patients will respond to their diagnosis by fighting back, vowing not to be a victim of the disease, and determining to become the first person to be cured of HIV or AIDS. In their struggle these patients frequently mobilize their strength and resources to take action (often political) against the disease, or they place intense and often unrealistic emphasis on nutrition, vitamin supplements, exercise, and "clean living." Some patients experiment with black market drugs in their search for an undiscovered miracle cure. Such experimentation may be allowable as long as patients are encouraged to inform their physicians of such drug use so that the physician can monitor potential side effects and discourage the use of drugs that have documented, dangerous toxicities. To

the extent to which they are able, physicians should encourage and support these efforts by their patients to grapple with their personal and social situation.

Patients who have previously relied heavily on other people to emotionally support them in their daily life will often respond by feeling increasingly helpless and dependent on their family, friends, and health care providers. When working with these patients, it is important for physicians to provide ongoing reassurance and constancy of care, carefully explaining major health changes to the patient as they occur.

Some patients are not able to accept the diagnosis and continue to deny their infection status. Denial can be a useful and adaptive defense for many patients with a fatal disease because it allows them to slowly and carefully filter into their conscious mind their own impending death. For persons with AIDS, it is harder to effectively block out reminders because the epidemic is so often discussed in the news media. For example, one patient described a dream she had in which Dan Rather came to her house and told her she had to pack up her belongings and children and move out of town because she was HIV positive. (Patient report to C. Gleeson, PhD, University of Vermont Medical Center, 1990.)

Some patients who adaptively try to deny their infection status continue to live as they had prior to the diagnosis. Other patients may begin to act out their fears and anxieties by engaging in high-risk and life-threatening behaviors, such as promiscuous sex or serious alcohol and drug abuse.⁸ Patients who demonstrate such self-destructive behaviors need to be closely monitored and either counseled in the office or referred for substance abuse or psychological assistance.

Research conducted on the three stages of HIV-related illness (asymptomatic, AIDS-related complex, and AIDS) shows that patients in the first two stages experience significantly higher levels of depression, mood disturbance, and anxiety than do those patients with AIDS.¹ It is postulated that fears of the unknown, coupled with worry about pain and suffering during the progression of the disease, and feelings of isolation and rejection may cause higher levels of stress during the early stages.

Infected But Well

During the asymptomatic phase of HIV progression, when patients are infected but feeling well, there is often a change in life-style. Many individuals, primarily in the male homosexual population, have modified their sexual activity to include safer sexual practices, resulting in a significant reduction in the incidence of new cases of

HIV infection in this population in the past several years.^{1,9}

Unfortunately, many intravenous drug abusers, both male and female, have not changed their life-style or needle-sharing activities. The numbers of new HIV cases among intravenous drug users from 1986 through 1988 increased over 230%. As of August 1989, intravenous drug users comprise over 22% of the population of persons with AIDS, up from 17% in 1986.¹

During the quiescent period (which can last up to 10 or more years), many patients share their HIV status with their families and close friends. For some homosexual and bisexual men this disclosure can precipitate their first discussion about their sexual orientation with the family of origin.

The combination of sharing the news of a fatal illness and disclosing homosexual or bisexual orientation can be very difficult and painful for both the patient and the family. Frierson et al¹⁰ found that communication was most strained between homosexual men with AIDS and their fathers, and least difficult between siblings. When a spouse of a bisexual patient was involved, their research showed that the spouse primarily focused on the patient's immediate health care needs and denied their own emotional reactions to the revelation of homosexuality.

Families of origin and orientation often react to the diagnosis in a similar manner.¹¹ They experience strong feelings of shock, denial, and anger. For some parents of patients with HIV, there are intense, often irrational, feelings of guilt about their son's homosexuality that are accompanied by a search for cause or blame. Families frequently begin to experience anticipatory grieving as they acknowledge the terminal nature of the disease.

Several patterns of reaction have been noted in families of origin.¹¹ Often a patient will tell only one or two members in the family about his diagnosis and instruct them not to tell anyone else until he or she begins to develop more serious symptoms. A pattern of secrecy and concealment from certain family members may begin to develop.

Another pattern that can occur is called *triangulation*.¹² This interaction involves focusing on a third person in order to reduce tension that exists between an original pair. This pattern is most likely to occur when the patient has a lover, and one or both parents use the third party as a scapegoat in an attempt to reduce their discord with their son.

When working with patients and their families of origin and orientation, it is important to find out from the patient whom he or she has chosen to tell about the diagnosis and to respect those boundaries of confidenti-

ality. Caregivers must be careful not to upset the family's balance of secrecy.

Emergence of Symptoms

The onset of AIDS-related symptoms such as fatigue, weight loss, and diarrhea can trigger feelings of discouragement and despair. The awareness of symptoms often generates feelings of decreased self-control. Demoralization can occur as self-esteem declines. During this self-devaluing process, homosexual men may develop homophobic feelings of guilt.¹³ Anger and blame focused at lovers for provoking homosexual behavior is typical of such homophobic reactions.

The presentation of active AIDS may force the patient to publicly reveal his sexual orientation. If the patient is unable to accept his sexual identity, this may promote denial of the disease. One patient convinced his family and friends that he was dying of a lymphoma rather than of AIDS. (Patient report to W. Wadland, MD, University of Vermont, 1990.) All donations at his funeral were to the cancer society. Guilt can result from the fear of having infected others and viewing the illness as a punishment for life behaviors. Guilt can result in celibacy, denial of past risk behaviors, increased use of drugs and alcohol, and self-imposed isolation from supportive peers.

Physicians should be alert to the symptoms of depression in patients with HIV. Depression may manifest itself as forgetfulness, poor concentration, loss of interests, apathetic affect, and withdrawal. The symptoms may be difficult to differentiate from the AIDS dementia complex. Feelings of helplessness and worthlessness often result from the numerous personal losses experienced and the limited treatment and financial options available.⁵ Common fears are disfigurement, abandonment by lovers and family, and lack of self-control.

Risk for Suicide

Mazuk et al¹⁴ report a considerably increased risk for suicide in a New York population of persons with AIDS. The relative risk for suicide in men with AIDS aged 20 to 59 years was 36 times that of men the same age without the diagnosis, and 66 times that of the general population. There is a tendency for these suicides to occur early in the course of the illness. Primary care physicians should be aware of this increased risk for suicide, particularly among patients who have predisposing factors (Table 1). Significant others and family members are also at increased risk for suicide.

Table 1. Factors that Increase the Risk of Suicide in Patients with AIDS

Severe social stigma suffered because of the disease
Withdrawal of family support
Loss of occupation
Long-term dependency
Loss of friends, lovers (often from AIDS)
Overwhelming, perpetual grief
Disfigurement
Delirium and dementia
Past emotional or psychiatric problems

Frierson and Lippmann¹⁵ recommend that physicians can decrease AIDS-related suicides by (1) being more sensitive to the risks of depression and suicide in patients with HIV and in their families, (2) providing accurate information about AIDS to patients and families, (3) respecting patients' wishes regarding the use of artificial life supports and treatment measures, (4) appreciating the common emotional stresses related to AIDS that patients with HIV experience, (5) providing clear pre- and post-test counseling of persons seeking screening for AIDS, (6) discussing their thoughts about suicide frankly and openly with patients and their families, (7) referring the patient and family members to a pastoral counselor to enhance spiritual belief supports, (8) referring the patient and family members to local AIDS service organizations, (9) promoting support groups for family members of persons with AIDS, (10) assessing drug abuse and alcoholism by patients with HIV, and (11) recognizing dementia and delirium in patients with HIV as suicide risk factors.

Grieving

Health care providers can help patients with HIV infection, their lovers, and families with the mourning process, which often begins before death occurs. Lovers and families of persons with AIDS are at risk for complicated and prolonged bereavement. Persons with AIDS have often experienced the loss of numerous friends from the same disease. Grief reaction is often triggered by the physical impairment of symptomatic AIDS. Active bereavement counseling by the health care provider can decrease the risk of suicide. Worden¹⁶ describes four common tasks in mourning:

1. Accepting the reality of the loss (includes physical loss)
2. Experiencing the pain of grief
3. Adjusting to an environment in which the deceased (or physical capability) is missing
4. Withdrawing emotional energy and reinvesting it in another relationship.

Preparation for Death

The final stage of adjustment is the preparation for death. Many patients will try to make bargains as their disease progresses. For example, one patient who had recovered from severe cerebral toxoplasmosis and who was asked to speak at a conference by his physician jokingly remarked, "I will if you guarantee that I'll live until the conference." (Patient report to C. Grace, MD, University of Vermont, 1990.) Another common response to advanced AIDS is for the patient to accept his impending death, but express hope that it will be easy, quick, painless, and without suffering, which the attending physician cannot guarantee. Anxiety over the uncertainty of when and how they will die has become a major component of living with AIDS, especially as medical therapies become more effective.^{3,17} Health care providers should have discussions with the patient early in the progress of the disease concerning levels of care, life support measures, preparation for power of attorney or guardianship, and financial dispositions. One patient who lived longer than he expected had given his entire pottery collection away and was unable to enjoy it before he died. (Patient report to W. Wadland, MD, University of Vermont, 1990.)

Conclusions

The medical progression of HIV from exposure to active disease can be correlated with common psychological reactions. The interrelationship between the typical medical stages of HIV infection and the common predictable psychosocial behaviors and emotions of the patient are summarized in the model in Figure 1. Although individuals will vary in degree, timing, and response, this model can function as a guideline for primary care providers giving psychological support and counseling throughout the progression of HIV infection. Anticipating the medical management¹⁸ of HIV infection is clearly useful in initiating early intervention. Similarly, anticipating the common psychological reactions to HIV infection and AIDS should enhance early psychosocial interventions, particularly when there is a very real risk for suicide. The family physician is in a unique position to identify and

provide guidance for reducing the negative psychosocial impact of HIV infection on the patient, friends, and family.

Key words. HIV; acquired immunodeficiency syndrome; social support; behavioral medicine.

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