SEXUALITY AND THE HIV-POSITIVE INDIVIDUAL

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As the HIV/AIDS epidemic enters its second decade and persons with HIV/AIDS are living longer, it is becoming increasingly evident that quality of life issues — including sexuality — have been inadequately addressed. One's sexuality is not lost, nor necessarily diminished, due to illness. Yet, to date, most HIV studies have focused on drug therapy, viral transmission, epidemiology, attitudes, and prevention. Only one study, *HIV-Positive Gay Men: Sexual Dysfunctions*, has examined sexual functioning. This study found multiple sexual problems among asymptomatic men with HIV: diminished sexual satisfaction, negative feelings during sexual activity, sexual aversion, erectile failure, and retarded or premature orgasm.

Healthy sexuality signals life energy and well-being. This contrasts with the apathy and weakness many people feel when they or their partners learn they are HIV-positive. People with HIV often fail to ask their health care provider about diminished libido and often the health care provider fails to inquire about possible issues surrounding sexual health. Early identification and treatment of sexual problems may help to improve mood, energy, life satisfaction, and partner relationships as well as decrease overall suffering. Human sexuality, as an integral part of one's health and well-being, is a vital area of future study in the HIV-positive population.

Issues for the Person with HIV

John* has been HIV-positive for six months and he has no physical manifestations of the virus. His weight is normal and he continues to work as a computer programmer. His lover is HIV-positive, John has experienced erectile dysfunction since learning his HIV status. He is terrified that he has infected, or could infect, his partner. He fears becoming a burden and has considered leaving his partner in order to avoid this. His father, who John has not seen in 20 years, is his only living relative. John is not well-connected in the gay community and avoids what he calls "those depressing AIDS groups." He has been depressed since learning his HIV status.

Ann is a 40-year-old HIV-positive woman married to an HIV-positive man. Her husband, who was formerly an injection drug user, infected her. He refuses to use condoms because, as he says, "We're both infected anyway," and Ann has been unable to convince him otherwise. She feels angry with him for re-exposing her to the virus, but she is currently unable to assert herself and is unwilling to leave him. She feels exhausted and experiences frequent vaginal yeast infections, which cause intercourse to be painful.

In the asymptomatic person with HIV, sexual apathy may be related to anxiety about one's ability to transmit the virus to one's partner, as well as one's own anxiety regarding harboring the virus. Multiple fears, which may dampen sexual interest, include: fear of conception due to contraceptive failure, fears of the future, fear of death, fear of stigma, and fear of loss of friends or family. These fears compound anxiety for the newly diagnosed person in particular and contribute to sexual malaise. Myths abound regarding viral transmission — one person thought others had to wear gloves if they touched him so they would not get the virus! This person was fearful of being involved intimately again. Another person believed that because he had not been diagnosed as having AIDS, he could not really infect others. Education remains an invaluable and integral part of encouraging responsible sexual activity.

Depression, a common initial reaction upon learning that one is HIV-positive, also contributes to diminished sexual desire. A hopeless and negative view may contribute not only to loss of desire but also to loss of satisfaction and pleasure from sexual activity. Feelings of guilt, regret, loss, and anger may become overwhelming for some people. Counseling should be considered an important option to assist in working through these feelings and allowing positive feelings to emerge.

Symptomatic persons with HIV may experience fatigue, swollen and tender lymph glands, intermittent fevers, headache, severe and sudden mood changes, and weight loss. Such somatic experiences coupled with the psychological impact may contribute to sexual apathy and

*All names used in case examples are fictional.*
sexual performance problems. The person may feel less desirable and less lovable as well as less loving. Body image changes affect one's total self-image — the alteration in one's body disturbs one's integrity and forces that person to acknowledge the reality of the illness and the loss of one's usual state of health and vigor. This psychic stress naturally impairs sexual interest.

Social stresses also can contribute to alterations in one's self-image. Such stresses include: lifestyle changes with respect to recreational activities, finances, and job and family roles. Certain recreational activities might be either too expensive to continue — such as travel, or too physically demanding — such as contact sports. Recreational use of drugs and alcohol needs to be addressed among necessary lifestyle changes in order to improve one's physical health and not further debilitate the immune system. Although this is a positive step, it can also be very stressful and anxiety provoking, and thus likely to interfere with sexual functioning. Loss of one's job creates major financial upheaval as well as changes in role function. One's career is an integral part of one's identity and persona, and loss of the ability to work often contributes to feelings of guilt. Many people speak of feeling that they are a burden to their loved ones and to society. These feelings all impact on sexual desire and interest — there may even be feelings of being unworthy of sexual pleasure if one is no longer able to contribute financially within a relationship.

Self-concept is partially derived from the acceptability of one's physical appearance — both to the individual and to others. Feeling less attractive on a basic physical level is a powerful inhibitor of sexual interest. Weight loss contributes to one's self-concept, because weight is viewed by many people as an indicator of one's health and "normalcy." Weight loss usually ignites a person's fear of disease progression. For the HIV-positive person, weight loss usually ignites a fear of imminent disease progression, and also may be accompanied by weakness and fatigue. These all contribute to sexual apathy.

Bob is a 36-year-old gay male with AIDS. He has known his HIV status for four years and he has Kaposi's sarcoma, lymphadenopathy, and oral candidiasis. The Kaposi's sarcoma lesions have spared his face, but are visibly scattered over his trunk and legs. His oral thrush is medically controlled with medication. Bob is an injection drug user in recovery and is supported by public assistance. He is actively involved in several AIDS community support groups. Bob is worried that he can transmit the virus or thrush by kissing. Three years ago, his lover died and Bob has not been sexually involved with anyone since then. Recently, he met someone he feels he could be interested in, however, he says he feels like a "leper," and that the lesions makes him feel "like a marked man — like the 'A' in the Scarlet Letter." He has little sexual desire, but does masturbate to insure that "everything still works."

When one is diagnosed with AIDS, many more physical changes may occur. Patients often cite hair loss due to various medications as a concern. Insertion of a central catheter to allow permanent venous access can be devastating to one's self-image — it becomes a permanent, visible mark of one's illness. Disfiguring lesions of Kaposi's sarcoma can be a formidable obstacle to retaining one's self-image as desirable — both for the person and for their partner. For women, the loss of menses, which commonly occurs in advanced HIV disease, may be accompanied by feelings of regret, loss, and being less feminine.

In addition, women may experience vaginal dryness that persists during sexual arousal. Little is known regarding the effect of the HIV virus in women and the reproductive system. For men with neuropathy, erectile difficulty — either related to neuropathy or to the tricyclic medications used to treat the neuropathy — is common.

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In persons with pulmonary processes, coughing and breathing difficulties can interfere with enjoyment of or sexual activity. In addition, pain related to AIDS will generally interfere with libido or functioning and make changes where needed. Partners of people with HIV/AIDS often encounter additional issues. They often fear aggravating the pain or causing discomfort and may withdraw physically; they may be disturbed by the changes they are witnessing and lack of mobility are all compelling reasons for diminished sexual activity. Nausea, vomiting or diarrhea may also interfere with the ability to fully express one's sexuality for obvious reasons. Many medications taken by people with HIV/AIDS can inhibit sexual functioning. These medications include: tricyclics, medications for the treatment of depressions and/or neuropathy; opiates, used to control pain; cimetidine, used to manage peptic ulcer disease; such as antihistamines used to control allergic reactions or itching; and antihypertensive drugs, used to control blood pressure. It is not known if antiretrovirals, such as AZT and ddi, affect sexual functioning. Partners of people with HIV/AIDS often encounter additional issues. They often fear aggravating the pain or causes discomfort and may withdraw physically; they may be disturbed by the changes they are witnessing and withdraw emotionally. Or, partners may feel overwhelmed and drained of any physical desires. Partners who themselves are HIV-positive struggle to cope with similar physical, social, medical, and psychic issues. For some the struggle to simply survive requires immense amounts of energy, so that sexual functioning falls low on their priority list. Frequent medical appointments, recurrent hospitalizations, keeping track of multiple medications combined with possibly devastating physical sequelae may amount to leaving little room and interest in their sexual self. When asked, some say "that part of my life is over, now I just want to stay alive." This response may signal depression or it may simply reflect the reality of living with HIV/AIDS.

Conclusion

For people with HIV, the goal is not just survival, but optimal quality of life in coping with both diagnosis and treatment. Quality of life — a vital aspect of which is sexuality — needs to be recognized as an important part of the approach to HIV disease. The human need and desire for sexual warmth and expression is not negated by illness or pain, however, changes in sexual patterns of expression may occur. Health care providers need to assess sexual health as they do physical health — with sensitivity and willingness to help. Sexual problems need to be fully evaluated and appropriately treated. Counseling about sexuality should not be limited to discussion of safer sex practices. Rather, it should be provided within the context of an ongoing, educationally oriented counseling program in which a variety of issues can be discussed, such as those concerns and feelings addressed above. Because the nature of sexual dysfunction remains poorly understood in persons with HIV/AIDS, much research is needed to answer the unknowns and provide direction for successful interventions. First, however, the sexuality of the HIV-positive individual needs to be recognized as positive, healthy, and life-affirming.

References

HIV is sexually transmitted. That fact has determined in large part society's view of the illness, the slow public health response to it, and the stigmatized experience of HIV-infected people. The AIDS epidemic has in turn had a profound effect on sexual attitudes in this country. More liberal attitudes of the 1960s and 70s have faded. AIDS has been seen as punishment for sexual behavior that is outside of conventional norms, and sexuality has become associated with illness and death, something to be feared and curtailed. This complex relationship between AIDS and sexuality affects the sexual lives of all at risk of HIV infection. Some people with HIV seem to adjust well sexually, i.e. sexuality continues to be an important and positive aspect of their lives, and they avoid risk to themselves and others by practicing safer sex. Others are conflicted about sexuality, and tend to withdraw, and blame sexual activity for their illness. My clinical experience suggests that a major determinant of an individual's sexual adjustment to HIV disease, or the threat of it, is the extent to which one has accepted and integrated one's own sexuality as a positive aspect of life, prior to exposure to HIV. For some, HIV disease seems to exacerbate unresolved sexual conflict and guilt, while others can accept their HIV-positive status and maintain a satisfying sexual life.

This article will address the effects of HIV disease on sexual attitudes, feelings, and behavior, based upon my experience in the clinical practice of psychotherapy in New York City. My HIV-positive patients are primarily white, middle class gay men. Some were diagnosed as HIV-positive during the course of general psychotherapy. Others sought psychotherapy for adjustment to being HIV-positive. I will present extensive clinical material in support of observations based on my practice, which may be relevant to others with HIV infection.

### Four Stages of HIV Progression

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**Stage One: At Risk**

With the recent revelations of Magic Johnson and Arthur Ashe, and with all the controversy about condom availability programs in the public schools, it is difficult these days to be unaware of HIV/AIDS. The question is whether one sees HIV as a threat to oneself, and whether one is willing to adopt behaviors necessary to protect oneself from infection. Some who see themselves at risk of HIV infection are anxious. These tend to be people at particular risk such as men who have sex with men and who are informed about HIV, but have not always adhered to safer sex guidelines. They are often vigilant about their health, anxious at the first sign of a physical problem. Others are in denial. A person who only engages in unprotected sexual activities with those s/he loves is denying the risk of infection.
In my practice, I have found that a primary issue for people at risk of HIV disease is how to protect themselves from infection. Abstinence from sexual activity as a means of preventing HIV infection has not been considered a viable option by my clients. Rather, they have altered their behavior to comply with safer sex guidelines, and the extent to which many of my clients have changed their behavior to protect themselves from infection has been very impressive. It is important to note, however, that for them sexual behavior is neither safe nor unsafe, but occurs along a continuum of risk from low to high, and the level of risk of different sexual activities is not always clear. For example, oral sex is considered to be relatively low risk by many, although transmission is possible in oral sex. Clearly, decisions about safer sexual behavior are complex with several determinants, including knowledge of relative risk of various sexual activities, the importance of that activity to the individual, and the nature of the relationship in which sexual activity occurs. My counseling about safer sexual behavior has involved helping individuals decide for themselves what is an acceptable level of risk, given their own unique values and beliefs.

Once individuals have established their own personal guidelines for safer sexual behavior, they must have the confidence, assertiveness, and sobriety to bring up the subject of safer sex and to set limits on the sexual interaction. Many people at risk find it awkward to bring up the subject. Talking about sexuality is difficult for most people, and here it must happen early on in the relationship, before sexual activity occurs. Some of my patients fear that they will be rejected if their limits are different from their partner's. Perhaps the most challenging aspect of safer sex counseling is helping individuals develop the confidence and skills to implement their own decisions.

Tim

Tim is a bright, attractive, precocious, and sincere high school student who lives at home with his parents and two siblings in Manhattan. He does very well academically and is active in extracurricular activities, especially art, in which he is quite talented and successful. Tim in under a great deal of pressure from family and peers to excel, particularly in anticipation of admittance to the Ivy League college of his choice, his father's alma mater. He was referred to me by another therapist to whom the parents had turned for counsel after their maid had found gay-oriented sexually explicit materials in Tim's room. On advice from the therapist, the parents confronted Tim who revealed that he was confused about his sexuality, and hoped he was not gay.

Tim revealed to me that he was not so much confused about his sexual feelings (he was quite sure that his preference was for men,) but that he was very anxious about what the implications might be of his being gay. He believed that it would mean social ostracism, disappointment to his family, and a life of failure and unhappiness. The only homosexual men he had ever known were his parents' decorator and the decorator's lover, whom his parents entertained socially on occasion, yet were derisive of in private. Tim feared the disdain of his family and friends.

Tim had been very enterprising in finding information about homosexuality in the library and in finding other similarly inclined young people of high school age through an underground gay newsletter. In fact he had been sexually active with some of these young men and with some "older men" (in their early 20's.) Tim was already sexually active and chose to continue to be. For him, sexual abstinence was not an option. Before dealing with his sexual identity as it was evolving, I wanted to be certain that Tim was aware of HIV, how the virus is transmitted, and how he could protect himself from infection. Tim actually was quite informed about HIV/AIDS and safer sex guidelines, however, he lacked the assertiveness and in some cases the self-control to implement his better judgment. Much of the initial hours of treatment were devoted to developing the skills necessary to bring up the subject of safer sex and to negotiate limits on his sexual interactions. This was quite successful with Tim, since he was a very confident and articulate young man. He simply was inexperienced sexually and shy about discussing sexual issues, therefore likely to let his partner set the agenda. He recognized the importance of safer sex, and responded well to counseling.

Maintaining safer sexual behavior is an ongoing process of reassessing risk based on the latest information, and reaffirming one's own commitment to avoid risk. In an insightful discussion of factors which contribute to lapses in safer sexual behavior, DeMayo lists several: a partner's HIV antibody status, being too turned on to stop, being in love, stress, depression, embarrassment, a partner's request, low self-esteem or an inability to formulate a positive gay identity. Further, he points out that individual decisions to maintain safer sexual practices are facilitated by a supportive community in which such practices are accepted and respected. "The challenge is thus to generate a culture which accepts and encourages safer sexual behaviors for all people, regardless of sexual orientation, socioeconomic status, age, ethnic origin, religion, or any other social or political descriptor."21

Another important issue for people at risk is testing for HIV antibody status. In my practice, I encourage individuals who are at risk and who are concerned about their HIV status to be tested. Knowing early that one is HIV-positive affords greater opportunity to prevent major infections and to prolong life. Testing is extremely anxiety provoking and needs to be accompanied by counseling, which is mandated by law in New York State. Pretest counseling should include discussion of the meaning of the antibody test, the benefits of knowing, what the individual expects the test to show, and what effects the result may have. If the result is positive, posttest counseling should deal with the emotional impact of the test result, discussion of further testing and monitoring of the immune system, the issue of disclosure to family and friends, notification of sexual partners, the issues of safer sex, and the impact of HIV status on relationships. As a therapist, I am actively involved in the support and counseling of my patients during this emotionally traumatic and confusing time. I find the adjustment to being HIV-positive and all the implications this has for a client is an ongoing process that can affect the overall emotional adjustment to HIV.
Testing for couples can be particularly tricky. Often one member of the couple is more ready for testing than the other. The couple must decide whether to proceed with testing together or individually, each course of action having implications for the relationship.

Ben and Sam

Ben and Sam are a couple who have been living together for about two years. Ben was a long term psychotherapy patient of mine whom I had seen in therapy for perhaps two years prior to his meeting Sam. Though there were problems in communication and control, this seemed a very positive relationship for both partners. Ben had been hoping for a long time that he would meet someone, and Sam seemed to him ideal in many ways.

Neither Ben nor Sam had been tested for HIV antibodies. I had encouraged Ben to be tested, but he had avoided it as it caused him a great deal of anxiety. Ben and Sam had discussed the issue of testing and how they might go about it, in particular whether they would be tested together. One evening Sam took Ben out to dinner, ordered an expensive bottle of wine, and announced to Ben that he was HIV negative. Ben was shocked, pleased that his lover was not infected, but hurt that Sam had gone ahead without him. Sam claimed that he had been tested "by mistake", that his physician had run the test without his knowledge and then informed him of the good news. Ben doubted this, since informed consent is required in New York City for HIV testing. He felt deceived and betrayed, and pressured now to be tested and forced to encounter the test alone, with the added fear of what a positive result for himself might do to the relationship. Sam was angry at Ben's response, that he didn't take more pleasure in his own good news, and that he made such an ongoing issue of the way the test was done.

It was indeed an ongoing issue for the couple for several months. Anger and hurt feelings persisted on both sides, and their sexual relationship suffered as a result. At one point Ben reported that Sam had jumped away from him, to avoid contact with Ben's ejaculate on Sam's skin. Ben withdrew sexually. The couple sought therapy together for this and other conflicting issues in the relationship. In the meantime, Ben dealt privately with me about testing and how he wanted to go about it. He considered not telling Sam and just finding out for himself. Finally there seemed no real reason to avoid testing any longer. He told Sam and proceeded with the test, which to everyone's relief, was negative.

Testing for HIV-antibody status often creates a great deal of anxiety for individuals being tested and those close to them, and this anxiety can sometimes cause people to behave erratically. The period of time leading to the decision to be tested, the drawing of the blood, waiting for the results and receiving the news, are all stressful and are best negotiated with counsel. Often counseling is available from the testing center if the individual is not in some ongoing therapy. The experience of testing, and certainly the results, can have a lasting effect on the lives of the people involved. Counseling around testing should be handled with great care.

A true story, which I have recounted many times to professionals who deal with clients around HIV testing, is of a client of mine who for months had discussed testing with his best friend who also had not yet been tested. They were not lovers, but for 11 years they had been the closest long term relationship that each had had. Finally they decided to go for testing together. Bloods were drawn and they were told to return in two weeks for their results. Upon return, they were told by their counselor at the lab that there was a "mix up" regarding their tests. All she knew was that one was positive and the other negative, but they didn't know which was which. More bloods were drawn, and the friends were told to return in another two weeks. Of course they were devastated, with two weeks of wondering "what if." They became afraid of one another and of themselves. Each wanted to be negative, and wanted his partner to be negative too. Finally, they returned together, and the results were known. The relationship was never the same after that. The friend who was positive withdrew, and sought greater intimacy with a mutual friend of theirs who was also positive. The negative partner felt hurt and abandoned. Irrevocable damage had been done with one moment of professional carelessness. Testing must be handled with sensitivity to the anxiety involved in the process, and the implications the results have for peoples' lives.

Believing that one is at risk of HIV raises anxiety about dating and forming relationships. I have observed sexual withdrawal among patients at risk of HIV infection, sometimes with complete abstinence for several years. One patient would not undress completely with his ongoing partner. He was generally obsessive with unresolved issues around control, exacerbated by the risk of exposure to HIV. In dating, when do you inquire about HIV status, and when do you bring up the subject of safer sex? How do you negotiate a safer sexual experience, set limits, and risk conflict and rejection? In ongoing relationships, couples may not agree on monogamy, citing the low risk of safer sex. Individuals feel that they are putting their own lives in the hands of their partners, which raises the issue of trust early on in the relationship.

Bisexuality raises anxiety for persons who have not thought of themselves as being at risk. Men who have incidental sexual experience with other men, while married or primarily involved sexually with women put themselves and their partners at risk if they are not practicing safer sex. There are no reliable figures citing the extent to which men who define themselves as heterosexual also have sex with other men, but from clinical experience it appears to be substantial. Gay men may also have more sexual contact with women than was previously thought. In the 800 Men Study (see sidebar), participants were self-defined as gay men. It was remarkable to learn, however, that 15 percent had been sexually involved with one or more female partners in the previous five years, a total of 210 different women.

Chris

Chris is a 36-year-old married man with two children, who lives in a suburb of New York City where he has his own business. Chris was referred to me in a major depressive episode with suicidal ideation. He was hospital-
The 800 Men Study

In *The 800 Men Study*, funded by the New York State AIDS Institute from 1984-86, I directed an investigation of what aspects of health education programs work in encouraging people at risk of HIV infection to change their sexual behavior. Specifically, we asked whether just informing people of safer sex guidelines caused them to alter their sexual behavior, whether anxiety is an effective motivator for change, whether presenting an alternative safer behavior helps and in particular whether presenting that desired behavior in an appealing way using sexually explicit videos would reduce high risk behavior, and promote low risk sexual behavior. It was thought that an effective HIV/AIDS prevention program had to do both to be effective, because just eliminating high risk behavior without substituting low risk behavior was not thought to be a durable change.

The study found that a program which raises anxiety about HIV/AIDS is effective in causing persons at risk to reduce their high risk sexual activity. However, a program which presents safer sexual activity in an appealing way, using explicit visuals, was the most effective in motivating participants to adopt safer sexual activity. Simply informing people about HIV/AIDS and safer sex guidelines was not associated with change in sexual behavior. It was concluded that effective HIV/AIDS prevention programs do not just take away, they must give back an alternative, and make the alternative behavior as appealing as possible.

The spirit among participants in *The 800 Men Study* was high, with a sense of commitment to protect themselves and their partners from infection. While it is not documented statistically, this sense of community may have been important in facilitating individual change. Safer sexual behavior gained status among participants. People who practiced it were respected and these were important behavioral change motivators for the group. Safer sex, like not smoking, will become pervasive, as it is seen as socially desirable, self-respecting behavior.

Stage Two: Minimal Or No Symptoms

As long as one remains HIV-negative or unaware of one’s HIV status, one will remain in Stage One. Stages Two through Four occur only in those who know they are HIV-infected.

A positive test result, the beginning of Stage Two of my delineation, is a crisis. Even if not seen as a death sentence, it is frightening and dreadful news. The threat of illness begins at this time. I encourage my patients to develop an ongoing relationship with a specialist in infectious diseases for regular monitoring of the immune system. Some patients develop a sense of the body as a problem, something to be feared. In more extreme cases, the person may see the body as contaminated, threatening, and unlovable. They are vigilant about their health—a cold is no longer just a cold, fatigue just fatigue, diarrhea just diarrhea. A positive test result can precipitate a major depressive episode, particularly when there is a history of depression. There may be a sense of hopelessness and shame. One must decide whom one is going to tell, family, friends, associates at work. Some persons remain quiet, telling almost no one, and becoming isolated with their worry and dread, while others quickly inform persons close to them and avail themselves of the many support programs for HIV-positive persons. The latter seem to fare better emotionally, and can often proceed with their lives normally for several years.

HIV-positive people, who are often young and rising in their careers, must face the question of whether they can make job moves because of the difficulty of obtaining insurance. Their desire for financial and health care security is pitted against their sense of limited time in which to realize their career goals. As a therapist, I try to facilitate a process of values clarification in which individuals question how they want to spend their time, if that time is to be foreshortened. Relationships are questioned for their
importance, some dropped and others cultivated for greater intimacy and intensity. This can be a time of great personal growth and intensity of living, a desire to make every minute count.

A positive test for antibodies to HIV causes many sexual issues in psychotherapy. My patients universally feel responsible for protecting their sexual partners from infection. But how one goes about this varies from one person to another. It also varies with the nature of the relationship. Sero-discordant couples usually decide together how they want to protect one another, and what level of risk they are willing to assume in their relationship. Interestingly I find that it is often the HIV-positive partner who is most concerned about protection, fearing the possibility of infecting the HIV-negative partner. I have often observed that my patients, following an HIV-positive test result, lose interest in sexual desire. This news is frightening and depressing. There tends to be confusion about sexuality. Is sexual activity bad? Did I bring this upon myself by being sexual? Sexual desire usually returns, but how rapidly and how completely seems related to the level of unresolved sexual conflict present before learning one is HIV-positive.

**Sally and Will**

Sally and Will, each in their late forties, met through an ad in New York Magazine in 1987. They liked one another immediately and found that they had much in common. They were strongly attracted to one another and the sexual interaction was very satisfying to both. Each had been married once before and had been divorced some years earlier. Each had been dating and sexually active prior to their meeting. After dating for more than a year, they decided to marry. In anticipation of their marriage, they were tested and learned that Sally was HIV-positive, while Will was negative. Will was very supportive of Sally who was shocked by the news. They decided to go ahead with the marriage. They did not tell their friends or Sally’s grown children about her HIV status.

Sally and Will were referred to me for couple counseling focused on a sexual problem. Since learning that she was HIV-positive, Sally had completely lost interest in sexual activity; in fact, she would not allow intercourse at all. Will desired sexual intimacy and was frustrated. It was obvious that Sally blamed sex for her HIV infection and that she wanted no part of it. Her history revealed a repressive sexual environment throughout much of her life, first in a strict Jewish home where she was warned about the “evils of sex,” and later in a marriage where an active sexual life was avoided and problematic. It was only when Sally was divorced, in her 40s, that she began to enjoy a sexual life. She was exposed to the virus during this more liberated time. One could hardly miss her sense of punishment for what she had been warned about years before.

In therapy, we initially focused on the sexual issue, with on-going attempts at physical closeness. The couple enjoyed this, but attempts to move further to genital activity were rebuffed by Sally. Will became increasingly frustrated and angry. Sally became angry with Will, finding him awkward and insensitive. Conflict spread to other areas of the relationship, and the focus of the therapy switched to general communication and conflict resolution. As communication improved, the sexual relationship did also, with occasional sexual intercourse using condoms which both enjoyed. However, this remained infrequent, and their sexual relationship never returned to what it had been prior to her positive test result. Will never lost his sexual desire; he still found Sally attractive and desirable. Gradually he accepted much reduced frequency and limited activity, but there was a strong sense of loss and sadness for him.

Most people who are HIV-positive decide for themselves what is an acceptable level of risk to them since they, as well as their partners, are vulnerable to infection. They must decide when and how to disclose their HIV status, and these questions are often addressed in psychotherapy. Is it necessary if I am only going to have safer sex? Do I reveal before any sexual activity, or some time later in the relationship if it develops? Is it up to me to bring it up, or wait for my partner to ask? Will I be rejected? Some people, particularly HIV-negative persons at risk, feel strongly that partners should decide together how to proceed, with all the relevant information on the table. Other people believe that as long as they practice safer sex, disclosure is not required.

As a therapist, I try to help individuals arrive at behavior that is emotionally and morally acceptable to them. Some HIV-positive people avoid sex and relationships altogether, fearing disclosure and the risk of rejection. They experience the stigma of being HIV-positive, with a loss of self-esteem. They feel less appealing and desirable. As symptoms develop, there may be a loss of muscle tone, eruptions of the skin, and weight changes, which cause a reluctance to be seen or touched. Sexual guilt is common. Positive HIV status may exacerbate long term, underlying shame and conflict about one’s sexuality. People may believe that they brought the illness on themselves, that they deserve it, that they are being punished. Psychotherapy to relieve such guilt and shame can be difficult and sometimes only marginally effective.

**Mike**

Mike is a 36-year-old gay man. He is a physician who studied medicine in Germany where he met his lover, whom he sees two or three times a year on vacations. Mike is not open about his homosexuality at work; his family knows that he is gay, although it has never been discussed. His relationships with men have always been kept separate from his work and family life. His sexual activity had consisted primarily of encounters in bath houses. This activity, which was not always safe, continued to 1985, despite the fact that Mike was well informed about HIV. Mike believes he knows the actual experience in which he was infected. (This is not unusual among the HIV-positive people I have seen in my practice.) He has a great deal of regret and self-blame about his exposure. He feels guilty about the pain his illness will cause his family, particularly his sister, his only sibling, and her two children, with whom he is close. Family members had not been told of his HIV status, though he did tell his sister and brother-in-law during the course of psychotherapy, however, there is no dialogue with his sister about his HIV status and its effect on his life. Mike avoids talking
about his condition in part because of his discomfort with his homosexuality. Discussing HIV is avoided as it brings up the shame associated with being gay.

For two years, Mike had been extremely anxious about being tested, believing that he would test positive. He had ongoing somatic symptoms of anxiety, including pain in his arms and shoulders and difficulty swallowing, causing him to avoid certain solid foods and public dining. After testing, his anxiety was unabated. (Sometimes individuals experience relief with confirmation that they are positive. They no longer have to wonder about it, and can begin the active pursuit of maintaining their health.) Now it took the form of vigilance and obsessive monitoring of his body. Periodic testing of immune function created extreme anxiety.

Mike does not feel sexually attracted to his lover and does not initiate sexual activity, which occurs only occasionally. Mike's sexual life consists primarily of safer sexual encounters with other men, which are most satisfying when they include hugging and holding as well as genital contact. They are inevitably followed by guilt about the nature of the encounter, which he considers depraved and pathetic.

Group therapy seemed to have a positive effect initially. The group of seven gay men was approximately equally split in serostatus. Mike revealed his positive HIV status during his first session in the group. It was the focus of his concern throughout his two year tenure in group therapy. Mike was compelled to confront his sexual and social withdrawal, his homophobia, and his resistance to making changes. He saw first hand from two other group members that life with HIV could still be full emotionally and sexually. His anger was mobilized and at times he seemed more hopeful. However, for the most part, he was unable to take positive steps for himself, such as attending social gatherings for HIV-positive people, talking more openly with loved ones about his condition, or being more assertive at work. He has terminated therapy, both individual and group, and as far as I know, remains physically well to date.

With Mike, self blame and recrimination never abated. He obsessed about his HIV infection, and was unable to experience any real pleasure in his life. His self punishment was a recurring theme related to his lack of acceptance of his homosexuality and a general sense of inadequacy and failure. He believed he was a disappointment to his family, and he certainly was a disappointment to himself. Being HIV-positive seemed to confirm his shame and guilt which the treatment was unable to alleviate. Psychotherapy helped Mike identify issues raised by his HIV infection, and increased his insight into underlying conflicts about sexuality and intimacy. However, his anxiety and depression continued, with occasional periods of abatement and he remained socially and emotionally isolated.

Some individuals make a good adjustment and are able to continue an active and satisfying sexual life following a positive HIV test result. For them, there is an absence of blaming and self-recrimination; rather the attitude is more that one was unlucky, in the wrong place at the wrong time. Sexuality is not seen as something evil, responsible for illness or death. For my clients, this positive sexual adjustment to HIV seems to be associated with a pre-existing positive attitude about their sexuality. These are people who have been comfortable with being gay, are generally open about it, have been sexually active, and have found satisfaction in their sexual lives.

Rick

Rick came to me for general psychotherapy in 1987. A 27 year old gay man, he is a very talented designer who has already risen to a very high level of responsibility and respect in his profession. Rick had been involved with a lover for six years, also successful in a related profession. Despite his success, Rick lacked confidence in himself socially and lived much in the shadow of his moregregarious and socially ambitious lover. Over the course of the relationship, Rick became increasingly dissatisfied, losing interest in sexual activity with his partner and became sexually active outside the relationship. This activity consisted of safer sexual encounters.

It was not long into psychotherapy that Rick gained the emotional strength to end the relationship and live on his own for the first time in his life. Things went very well. He made friends readily, and had a series of short-term romantic involvements. Success at work continued and Rick's life was taking off in every way.

An infection unrelated to HIV caused Rick to seek a physician. Both his physician and I encouraged Rick to be tested for HIV antibodies, since it was important to know and to monitor the immune system if the result was positive. Rick was anxious, so the decision was made to test T cells, an accurate measure of immune function, without actually revealing HIV status. His T cell count was high, but with a ratio that suggested abnormality. His physician was concerned and pushed for an HIV antibody test. After some weeks of preparation, Rick agreed. The test result was positive.

Initially Rick denied the significance of the finding. He had thought he would be positive, nothing was changed, his health was fine, no big deal! Gradually, however, he began to think that he would not likely live to age 40, or perhaps even 35. He was alternately panicked and sad. Initially he was reluctant to tell anyone, but soon he told his family and close friends, and he sought a support group for HIV-positive persons. He adjusted well to his HIV status. Now it is something that is always in the back of his mind, but he does not allow it to overwhelm him, or keep him from going on with his life.

He has had a new lover for the last year, and he is currently contemplating a job change. His current lover is HIV-negative but knowledgeable about HIV due to experience with friends. He is a very supportive and loving partner, and the sexual relationship with Rick is safe, stimulating, and satisfying to both.

Stage 3: A Series of Opportunistic Illnesses

Stage Three begins with the long awaited and dreaded arrival of serious opportunistic illnesses. This can mean hospitalization for treatment, greater awareness among friends and coworkers of one's illness, and an ongoing feeling of greater vulnerability. With a series of illnesses due to a decline in immune function one gradually be-
comes weaker and less energetic. A depressed mood is common as one recognizes the loss of mobility and options, as well as the hopelessness of the situation. This gradual decline in physical health and mood may be accompanied by a loss of interest in sex. When and how this occurs depends on the extent of body changes as they contribute to one’s sense of self as a sexually appealing partner, physical energy and strength, depression, attitude about sexuality, and in particular, whether sexual activity is blamed for illness. The availability of a partner is particularly important. If there has been an ongoing sexual relationship, it is likely to continue throughout Stage Three, though the type of sexual activity may become less vigorous physically.

Ken

Ken is a 48-year-old gay man who has taught in the New York City School system for nearly 25 years. He is a good teacher, very well-regarded by his students and colleagues. Ken’s life was completely changed by the AIDS epidemic. From 1981 to 1987 when I met him, he had lost over a hundred acquaintances, close friends, ex-lovers, colleagues, even a cousin and a nephew, to AIDS. He had been closely involved in establishing some of the early programs in New York to care for people with AIDS. As soon as the test for HIV antibodies was available, Ken took it, and learned, as he expected, that he was positive. In 1987 he sought therapy for depression related to his many losses, and in particular for the loss of a very close friend with whom he had cared for daily throughout the end stages of his illness, and to look at the meaning for him of his own HIV infection.

Ken had had a full and satisfying sexual life. He was comfortable being gay, and was open about his lifestyle with his family and at work. He had had three long term significant relationships during his adult life, but when I met him his sexual life consisted primarily of occasional encounters. He practiced safer sex and was always aware of the need to protect himself as well as his partners from infection. Sometimes he disclosed his HIV status; sometimes he did not. He was not eager to become involved in an ongoing romantic relationship. His occasional sexual experiences seemed satisfying and enough for him as he attempted to deal with all of the illness around him, and with his own HIV infection.

In 1991, Ken began to experience major opportunistic illnesses. He developed Kaposi’s sarcoma, persistent diarrhea, occasional high fevers. He had a variety of skin problems related to HIV. He had bouts of weakness and fatigue, when it was all he could do to make it back to his apartment after school and get into bed. Gradually, as his energy level decreased markedly and maintaining his health became almost a second full-time job, Ken no longer experienced sexual desire. He masturbated very rarely, as he said, "occasionally just to see if it still works!" Ken had always taken a great deal of pride in his appearance. He associated his loss of interest in sex with not wanting his body to be seen. The Kaposi's sarcoma lesions and the loss of weight and muscle tone made him feel unattractive as a sexual partner. He feared that he would be repulsive, and the fear of rejection seemed to overcome what sexual desire he did experience.

Ken is a good example of someone who was uncomfortable with his sexuality prior to HIV illness, and who maintained an active and safer sexual life for several years of being HIV-positive. Ken believes that the physical changes in his body caused him to lose interest in sex. He simply does not feel well enough much of the time. I believe that Ken might have continued to be sexually active longer, if he had an ongoing partner involved with him sexually during the course of the illness. Such a partner would be able to accommodate gradually to the changes in Ken’s body and would likely want to continue to express love and affection sexually.

Stage Four: End Stage of Illness; Physical Deterioration

Stage Four, the end stage of HIV disease, is characterized by nearly complete loss of immune function, constant serious illness, loss of weight and muscle tone, loss of body functions such as sight, mental faculties or ability to move around independently. Much time is spent in hospital or hospice. For some this is a time of preparing emotionally for death and accepting its inevitability, for others it is a fight to stay alive. For long term lover relationships, this can be a time of extraordinary closeness and intensity.

As a therapist, I continue to see patients in their homes or during hospitalization, as long as they want. I also see family members at this time, if requested. In some cases I have lost contact with patients during Stage Four, due to their moving away or to a decline in mental function, which eventually makes psychotherapy impossible. Visits then consist of simple conversation, holding a hand, or just being there in silence.

Sexual expression changes with the physical condition of the individual. While genital sexual interest can continue right to the time of death, often sexual activity takes the form of holding and caressing more than genital stimulation. Touching can be very reassuring to both partners of the other’s presence and love. Massage can ease the pain and discomfort of being bedridden. Just holding hands or running fingers through hair is very comforting. It seems to be that couples who have been physical and sexual throughout their relationship tend to continue this physical closeness up to the time of death. It is a natural evolution.

Robert and John

Robert was referred to me by his physician for anxiety regarding an AIDS diagnosis, a very common referral situation for me over the last ten years. His first awareness of his HIV disease resulted from a case of oral candidiasis. He had avoided testing, suspecting that he was positive. Confirmation precipitated increased anxiety, but also a sense of relief. He went to work, in his obsessive style, on maintaining his health. Throughout the course of his illness, which lasted about three years, he was compulsive about his medical care, which increased the quality and extended the length of his life.

Robert had a lover, John, with whom he had lived for approximately three years prior to diagnosis. John was extremely devoted to Robert and very dependent upon him. Robert had always provided the primary financial support in the relationship, as well as being the more so-
cially comfortable and gregarious partner. He tended to take control and responsibility for most of the couple's life together. Their sexual life was monogamous, active and generally satisfying to both partners. Both were open with family and friends about their sexuality and their relationship. They were quite inseparable. Where you saw Robert, you would see John.

During the course of his illness, Robert was very concerned about whether John would have the emotional strength to care for him, and what would happen to him after John died. John too was anxious about what would happen to him after Robert's death. I referred John to a colleague for psychotherapy, and over the course of Robert's illness, John became stronger and more independent. He was an excellent care partner, providing emotional as well as physical care for Robert.

Robert and John's sexual life continued throughout the course of Robert's illness, although the activity and the significance of their sexual relationship changed. John tested negative for HIV antibodies. Both partners were very concerned about the issue of transmission, and practiced safe sex consistently. As Robert's illness progressed in duration and severity, he lost a great deal of weight, he developed Kaposi's sarcoma lesions, his sight was severely diminished, and he became weak. Their sexual life gradually changed from a physically active and arousing experience to a more affectionate, supportive and reassuring experience of touching and holding. For the last year or so of Robert's life, John no longer found his body appealing, but both enjoyed physical closeness. A sexual relationship that had always been active continued throughout the course of illness, changing and adjusting as the needs of the individuals changed, but remaining satisfying and important to both partners.

Conclusion

The fact that HIV is sexually transmitted has a profound effect on the sexuality of those infected and those at risk. In my clinical practice with HIV-positive gay men in New York City, sexuality has been an important concern in psychotherapy. For those at risk of HIV infection, there is the issue of how to protect oneself from exposure. My role here has been to see that my patients are informed about safer sex and to help them develop assertiveness and self confidence to negotiate safer sexual interactions. Maintaining safer sex over the long term is an ongoing process of updating information, values clarification in terms of the level of risk an individual is willing to assume, and openness in communication about sexuality. These issues are addressed repeatedly in psychotherapy. Also as a therapist, I have been very involved with my patients' decision of whether and when to be tested for HIV antibodies, a process which involves weighing the advantages of knowing one's status, the meaning of a positive finding, and dealing with the intense anxiety commonly found to exist around testing.

For people in Stage Two through Four of HIV infection, sexuality is an ongoing issue in psychotherapy. Attitudes about sexuality, guilt, and blame are important elements. While some tend to see HIV infection as a stroke of bad luck, others tend to blame themselves and their sexuality. Often there are underlying, unresolved conflicts about sexuality and homosexuality that become manifest in feelings about HIV. Clinically, I have observed that these people adjust less well and tend to have more emotional and sexual problems throughout the course of their illness. Psychotherapy to resolve underlying conflict can sometimes be helpful, though in some cases, as with Mike above, therapy did not produce significant behavioral or mood change regarding HIV.

A number of other factors affect the sexual adjustment of people with HIV: bodily changes, a decrease in strength and energy, and depression. Availability of a partner is a very important factor, particularly during stages Three and Four. If there is an ongoing sexual relationship, it is likely to continue in the latter stages of HIV, with the form of sexual expression becoming more affectionate and supportive.

When I recall my first experience in 1981 with a person with AIDS (it was called GRID then, Gay-Related Immune Deficiency), I remember how frightened I was, and how pressured I felt to do something for this man. He was too scared. He knew he was going to die, and that there was little that could be done. The situation is very different now. More has been learned about HIV in the last ten years than any other disease in history. Physicians can do a great deal now to prolong life and improve the quality of life for those infected with HIV. Mental health professionals know much more about the emotional and psychological aspects of HIV. And yet there are many of us who are still uncomfortable with AIDS, not sufficiently informed, and uneasy about how to treat someone with HIV infection in psychotherapy.

The best antidote is information and experience. As psychotherapists, we need to be informed about the emotional and sexual issues that arise for HIV-infected people. We need to know about safer sex, and the problems people encounter when they attempt to implement their own efforts to protect themselves from infection. We need to know about testing for HIV antibodies, how to help a patient prepare for testing and interpret the meaning of test results. We need insight into the issues underlying guilt and shame about sexuality in relation to HIV. Most important of all, perhaps, is that we as psychotherapists have to keep an open mind about HIV disease and each person's individual response to it. We cannot assume that we know how HIV affects them. We cannot project our attitudes and fears onto them. HIV and AIDS raise strong feelings in all of us, and it is up to us to be aware of these feelings and not allow them to interfere with our effective and compassionate treatment of people with HIV/AIDS.

References


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Very little is known about Human Immunodeficiency Virus (HIV) in women. Studies of women with HIV have primarily been focused on their role in transmission of the virus to sexual partners or to offspring, not on the course of illness or response to therapies for the women themselves.

What we do know about HIV disease is largely based upon the experiences of gay men, the first population identified with this syndrome of immune system disorders. In addition to gender differences between males and females, race and socioeconomic status also create differences. It would seem unlikely that we can merely extrapolate what we know from one population to understand another.

As of April 1992, more than 22,000 women have been reported with AIDS. The majority of HIV-infected women are found in inner city areas on the East Coast. Although HIV infection occurs among all races and classes, urban women of color are disproportionately affected by HIV disease. Black women have 13 times, and Latinas six times higher rates of HIV infection than white women.

In spite of the alarming statistics of HIV among women, there is still a misperception among health care providers and policymakers that women are not affected by this disease. Symptoms reported by women are more likely than those of men to be overlooked or attributed to other causes. Women with HIV/AIDS become sicker and die sooner than men. Delayed diagnosis leads to increased mortality, but there may be additional social or biological factors influencing this trend. The societal role of women has always been as caregivers. HIV affects women as mothers, lovers, sisters, and daughters. Priority is often given to others while one's own needs are neglected.

Infectious disease specialists and other providers of HIV care do not generally perform pelvic examinations, let alone provide women's health care services. OB/GYN health practitioners, on the other hand, are not typically versed in HIV detection or management. Despite this, HIV appears to have an effect on gynecological conditions, such as genital infections and cervical disease. It may impact on sexual relationships, pregnancy, and contraceptive choices.

**Gynecological Manifestations**

Recent studies and many anecdotal reports by patients and health care providers indicate that HIV infection may alter the course of certain gynecological conditions. Genital ulcers, abnormal cervical cytology, pelvic inflammatory disease (PID), refractory vaginal candidiasis, and menstrual cycle changes all may indicate signs of HIV disease in women.

- Genital ulcers caused by herpes, chancroid, and syphilis have all been implicated as a transmission mode for HIV infection. The course of these diseases in an individual with HIV are frequently more fulminant, taking longer to resolve. Often, they require greater doses or alternative therapeutic regimens than the standard treatments effective in immunocompetent patients.

- Several studies have shown an association between HIV, Human Papillomavirus (HPV), and cervical disease. Different strains of HPV are thought to be responsible for most genital warts and for cervical cancer. The more immunosuppressed a woman is, the greater the susceptibility to HPV and neoplasia. There is an five- to eight-fold increased incidence of abnormal Papanicolaou (Pap) test results among women with HIV when compared to other women within the same community. These findings may actually be an underestimation of the problem: infected women may have a higher incidence of "false negative" Pap smears than uninfected women. Cervical cancer progresses more rapidly in HIV-infected women, with a median time to death of less than half that for HIV-negative women. It is advised that women with HIV receive Pap smear screening every six months. Colposcopy and aggressive treatment is warranted in the presence of any abnormality.

- PID has been associated with HIV infection. At King's County Hospital in Brooklyn, New York the rate of HIV infection among women treated for acute PID was found to be nearly 14%, compared with a 2% seroprevalence rate among women delivering babies at the same hospital during the same time period. PID is more fulminant in the HIV-infected woman, more fre-
quently requiring hospitalization and surgery. At this time, treatment regimens are not based upon HIV serostatus, although some authorities recommend that infected women with PID are hospitalized during their initial course of treatment.

- Immunocompromise predisposes one to candidiasis — thrush in the mouth and so-called “yeast” infections of the vagina. Although vaginal candidiasis is a common affliction among all women at some point in their lives, an immunosuppressed woman may suffer from chronic, recurrent or resistant candida vaginitis. She may need longer courses of the standard topical remedies, or may need treatment with oral, systemic medications.3

- Many women with HIV have reported menstrual cycle changes. The use of medications, such as AZT, are anecdotally reported to influence the interval and duration of menstrual periods. These changes may impact on contraceptive options and confound pregnancy detection.

Safer Sex and Birth Control

Power imbalances in relationships between women and men can lead to sexual risk-taking in an effort to preserve social and financial status. Women may be unable to negotiate condom use for fear of rejection, abandonment or even abuse by their partners. Abstinence and safer sex practices, such as non-penetrative sexual activities, are often considered unacceptable options. This is particularly true for those for whom sexual intimacy is defined as vaginal penetration resulting in male orgasm. For others, loss of sexual freedom and spontaneity may cause a reaction of grief and an inability to experience pleasure. Empowering women to have fulfilling and safer sexual encounters cannot be achieved without equal efforts to encourage men to take responsibility for engaging in safer sex practices.

It is irrational to solely place the burden on women to get their partners to use condoms.

HIV-positive women who wish to avoid childbearing need to be offered safe, reliable, and acceptable contraceptive methods. Barrier methods such as latex condoms and spermicide with nonoxynol-9 that combine birth control with disease prevention are only effective if used properly, however, method failures are known to occur. There is no clear contraindication against the use of hormonal contraception such as birth control pills, Depo Provera or Norplant. However, it is not known if estrogen and progesterone affect the immune system or impact on other medications taken by the infected woman. Intrauterine devices may increase susceptibility to pelvic infections and should therefore be avoided. Abortion and sterilization procedures are options that should neither be mandated nor prohibited for women with HIV infection.3

Pregnancy

The HIV-infected pregnant woman may be in a state of emotional crisis, particularly if she only first learns about her serostatus as a result of prenatal-based HIV testing services. Many are faced with difficult choices, such as whether to continue or terminate the pregnancy. Reproductive choices are influenced by a host of factors. The perinatal transmission rate of one-third or one-quarter may seem an acceptable risk to some women for whom other life experiences offer worse odds. Religious beliefs, psychological and cultural factors, and previous experience with loss of children to illness or the foster care system may additionally influence reproductive decisionmaking.9 Society often inappropriately views the infected woman’s medical and social problems in moral, or even criminal terms. Information should be provided in a non-directive fashion and individual decisions supported fully.

Two Women’s Experiences

Sandy busily spends her days between medical appointments for her two HIV-infected children and caring for the rest of her family. Although her own prescriptions have needed to be refilled for some time, she has not been able to attend the clinic for herself. Appointments are scheduled months in advance and require a four to five hour time commitment for clerical processing, awaiting evaluation by the physician, and going to the lab and pharmacy. No provision for child care is offered at the clinic, and as Sandy cannot afford to hire a babysitter, she must take along her preschool children. The medical visit itself is perfunctory: blood work is ordered and prescriptions renewed. In spite of Sandy’s recurrent complaints of vaginal irritation, she is told, “You’ll have to go to the GYN clinic for that.”

Marie has been on medications for HIV disease since she was first diagnosed with pneumocystis carinii pneumonia (PCP) three years ago. The diagnosis of her pregnancy came as a surprise as she had been experiencing irregular and infrequent menstrual periods for several years, and had been using birth control faithfully. In spite of the unplanned nature of the pregnancy, and the pressure she felt by her health care provider to have an abortion, Marie decided she wanted to have the baby. The policy at the AIDS clinic Marie attends is to terminate care for the duration of pregnancy. However, she was referred to another clinic for prenatal services within the same facility. All medications were to be discontinued until she received obstetric evaluation. The following month at the first prenatal clinic appointment, Marie was advised to find a hospital that was better equipped to provide health management for her high-risk pregnancy, now at six months’ gestation. No medications were prescribed and no followup appointment was arranged. Marie, like many other HIV infected pregnant women, could find no place to receive marginal, let alone comprehensive, medical care.
Pregnant women commonly desire information about the effect of HIV on the pregnancy, and the effect of pregnancy on their disease. Perinatal transmission accounts for 85% of the pediatric AIDS cases nationwide. Although special blood tests are being researched which could aid diagnosis of HIV disease in children as young as three or six months of age, standard HIV antibody testing on children will reflect the positive antibody status of their mothers for as long as 18 months.10 There has been some speculation that the degree of the mother's disease may correlate to the risk of transmission to her baby. Unfortunately, it cannot be predicted whether a particular pregnancy will result in an infected or healthy child. The Mothers are frequently stricken with feelings of guilt and grief about having a child who may develop AIDS or become orphaned.

Ideally, women who elect childbearing should receive combined HIV management with prenatal care. Although there is no evidence that pregnancy accelerates HIV disease progression, T cell counts tend to decrease during pregnancy among HIV-positive as well as HIV-negative women. Health management requires greater vigilance by the woman and her care provider to assess complaints such as fatigue and headaches, which may be attributed to typical signs of pregnancy, or may indicate underlying HIV-related problems.8

It is often difficult to find willing and experienced ob/gyn providers to care for infected women. Moreover, HIV clinics typically discharge pregnant women from their care for the duration of the pregnancy, out of concern that medications may adversely affect the fetus.

Experience with the use of many medications in pregnancy is limited, and not without theoretical or unknown risks.9 However, an illness suffered by the mother may be more damaging to the fetus than medications taken to prevent or treat disease. For example, if a woman should develop PCP during the course of her pregnancy, both she and the fetus are deprived of adequate oxygenation. But PCP can be prevented with certain medications, such as Bactrim, which is considered generally safe for pregnant women, or Aerosolized Pentamidine, a less effective medication that also appears to be safe in pregnancy, but has not been adequately studied. Care should be taken to assist a woman in making informed decisions about the use or avoidance of any therapies while pregnant.

Clinical trials of experimental treatments have begun to recognize the need to include pregnant women or those "at risk" for pregnancy, defined as any woman who has not been sterilized. Injection drug users may be excluded from most clinical trials because researchers are concerned that they will be unreliable participants or that there may be chemical interactions between the experimental medications and the drugs used. Substance abuse treatment services are woefully inadequate. A survey in New York City found that 87% of all drug treatment facilities refuse Medicaid patients who are pregnant and addicted to "crack" cocaine.11

Although there is evidence that perinatal transmission frequently occurs during the birth process, labor and delivery management differs only in that obstetric staff are advised to practice universal precautions and to avoid procedures which theoretically could increase risk of transmission to the fetus from the mother. For example, the use of an instrument such as an internal monitor should not be used since the skin barrier of the fetal scalp is broken permitting exposure to its mother's infected vaginal secretions with the placement of this device. Cesarean section deliveries do not prevent HIV infection in the newborn, and should only be performed when medically indicated.8

Breast feeding is generally not recommended where safe alternatives to breast milk exist. Although a comparison study of HIV-infected children has shown that those who were breast fed fared better than those given formula, breast feeding has been implicated as a mode for HIV transmission.12

Conclusion

The incidence of HIV among women continues to rise at an ominous rate. Further research on the biological, psychological, social, and sexual affects of HIV on women's lives would help us to better understand the scope of this disease. If we are to meet the many needs of women and their families, we must develop community-based facilities to offer primary care, including gynecological services. In addition, education, counseling, drug treatment, and social services as well as child care, transportation, and food are essential components of an enhanced and comprehensive care system.

References

PATHFINDERS AWARDS WINNERS

The National Partners, a consortium of 18 organizations including SIECUS, recently organized the first Pathfinders Awards to recognize outstanding individuals for their unique and vital contributions to the fight against HIV/AIDS. The 131 nominees represent a broad spectrum of American society and include health care workers, educators, business leaders, union members, AIDS activists, legislators, religious leaders, and volunteers. The finalists (listed below) were brought to Washington, DC on June 9-11 to be honored in an awards ceremony, which included special recognition from Congress.

Bill Cole
Teacher, Chairman of the Gloucester AIDS Task Force
Wenonah, New Jersey
Kathleen Geros
Co-chair, Women's Outreach Network, National Hemophilia Foundation
Sterling, Michigan
Judith A. Hargis
Nurse, Founder of the New Hope Clinic for PWAs
Yakima, Washington
Janet McMahon
Founder, Mothers of AIDS Patients (MAP)
Torrance, California
James McWilliams
Educator, South Philadelphia High School
Philadelphia, Pennsylvania
Stephen T. Moskey
Director, Office of Consumer Issues, Actna Life & Casualty
Hartford, Connecticut
Genie Quincy
Founder, Buddy Program for PWAs and "Healing Wings"
Arlington, Texas
Jorge and Mariana Serrano
Grassroots AIDS Activists
Luquillo, Puerto Rico
Richard Scott
Union Agent, AFSCME (American Federation of State, Country and Municipal Employees) Local 2187
Philadelphia, Pennsylvania
James Shimmel
Member, American Red Cross HIV/AIDS Task Force
Bay City, Michigan
Darlene Titus
Outreach Worker, Hoopa Health
Hoopa, California
Sandra Vining-Bethea
Outreach Worker, Bridgeport Women's Project
Bridgeport, Connecticut
Sterling Alexander White
Founder, STARR (Street Team AIDS Risk Reduction)
Atlanta, Georgia

HIV/AIDS RECOMMENDED RESOURCES

AMERICA RESPONDS TO AIDS (ARTA) PUBLIC SERVICE ANNOUNCEMENT MATERIALS (1/2" VHS videocassette, magazine and newspaper ad packet, poster packet/individual posters/brochures, 1992) are part of the public information campaign created by the U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control (CDC), and directed by CDC's National AIDS Information and Education Program (NAIEP). The 1992 phase of the ARTA campaign is entitled, "Americans Working Together to Prevent HIV and AIDS." The television public service announcements (PSAs) feature individuals in large cities and small towns, at home and in the workplace, coming to grips with HIV/AIDS for the first time, correcting misconceptions about HIV transmission, and learning that education about HIV/AIDS is crucial for everyone. The presentation tape contains new ARTA television and radio PSAs, in 60- and 30 second format (with a 30-second segment of each in Spanish). The radio PSAs include four live announcer scripts that provide the CDC AIDS Hotline number 1-800/342-AIDS, which also appears on each television PSA. Although the Psas never use the term safer sex, in one television voiceover a woman with HIV states: "What's bad is that most women still don't protect themselves...and I don't want anyone else getting AIDS." CDC National AIDS Clearinghouse, PO Box 6003, Rockville, MD 20849-6003, 1-800/458-5231. Prices: single copies of the videocassette, ad packets, and poster packet are available free of charge. Multiple copies of individual posters and brochures are available for postage and handling charges: 2-10 copies/$5, 11-25/$6, 51-l00/$7.25. Catalog available free of charge.

CONDOM EDUCATOR'S GUIDE (8½"x11" booklet, 1991, 40pp.) written by David Bao & Beowulf Thorne, is an entertaining and fact-filled resource about condoms with powerful graphics and sidebars that communicate both the fun side and the serious nature of condom awareness. The booklet begins with an outline of five areas of education needed to create intellectual and behavioral change: awareness, personalization, nitty gritty, personal and social factors, and continuation, and charts the model with goals and questions to answer in order to reach them. The topics covered address a wide range of issues, including peer education as a state of mind, explicitness vs. accuracy in educating about condoms, prophylaxis vs. contraception, and negotiating safer sex. A sidebar on condom anxiety advises, "Condom anxiety can be a serious problem with many people. It's critical for you, as a condom educator, to be completely comfortable with educating and using condoms. If you are the slightest bit nervous, you will communicate this nervousness to your audience." Although this excellent resource is geared toward educators, it is useful for anyone interested in gaining further knowledge about condoms and their use. The Condom Resource Center (CRC) is a project of the Men's Support Center and coordinates National Condom Week, held annually in February since its inception by Berkeley University students in 1978. CRC provides up-to-date information, educational materials, and referrals about condoms and offers resources and ideas to support community-based programs on all aspects of condom information. The Men's Support Center, CRC, PO Box 30504, Oakland, CA 94654, 510/891-0455. Price: $10.

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A View from the Field

MANY VOICES, ONE WORLD

Carolyn Paticrno
Director, National AIDS Initiative

I am writing this on the third anniversary of the death of one of the most important people in my life, my friend Joseph. Joseph's lover, my best friend, lamented that he could not quite remember Joseph's voice anymore. Yet I remember his voice so clearly. I hope that his particular voice will be heard in this article as well.

Call me a cock-eyed (albeit rather cynical) optimist, but every time I have a discussion on sociopolitical issues affecting the AIDS crisis that sounds eerily enough like ones I had four or five years ago, I ask myself "Why are we still having these discussions?" And I wonder why we still debate whether or not discussions on homophobia belong within an HIV/AIDS education program, why the case definition does not include symptoms affecting only women, and why we are still having to convince people that racism is one of the causes of the relentless growth of this epidemic.

And then something changed.

When the Rodney King verdict was announced, my partner said, "L.A. is going to burn to the ground." The injustice was incomprehensible. At the same time, I sensed intuitively that something had changed irrevocably in terms of HIV/AIDS education and prevention work. This stemmed partly from my conviction that everything is connected — all oppressions, all injustices. Several years ago during an HIV/AIDS training, an African-American woman spoke about cultural issues that affect sexuality and HIV/AIDS education. She began talking about poverty and racism, and then launched into a lengthy and challenging discussion about teenage pregnancy. Having coordinated many trainings and read hundreds of evaluations, I braced myself for what I thought would be the inevitable audience response. "I didn't come here to hear opinions, I came to learn about HIV/AIDS," "I didn't come here to hear about teenage pregnancy, I came to learn about HIV/AIDS," "I didn't come here to hear about racism and poverty in the black community, I came here to learn about HIV/AIDS." This woman had done a lot of training herself and probably began to anticipate the same response, because suddenly she stopped and said, "In case you're wondering what teenage pregnancy has to do with AIDS, I'll tell you — everything — everything has to do with AIDS."

And so it does. What I so strongly sensed was that the events in Los Angeles and the subsequent response throughout the entire country, would change the framework in which HIV/AIDS education must be done. My next experience out in the field proved this theory to be true.

Our first two day sexuality and HIV/AIDS training since the Rodney King verdict and subsequent riots included a session on culture and the different messages we receive from particular cultures on various sexuality-related issues. First, we asked participants to identify all of the cultures that inform the person they are. For example, one might identify as a Jewish, gay Southerner — these being three very distinct cultures that influence who this individual is in the world. There was a heavy feeling as we began. I emphasized that in light of the national climate, and certainly the climate at a gathering of people working in HIV/AIDS, these discussions would surely take on a different level of intensity. Anger arising was certainly possible, however, as the facilitator of this discussion, I chose to embrace anger as a means of creating change. Discussions ensued regarding the assimilation of both newly immigrated peoples and those who have been in this country for generations. One participant questioned at what price individuals sacrifice their original culture in order to assimilate into the predominant culture. Several participants were adamant in feeling that assimilation was essential in order for a community to progress economically. Others still believed that many non-Anglo citizens had the desire to, in fact, acculturate, but do not know how to begin that process. With barriers that include differences in language and communication, resentment and racism, it is an overwhelming task. An African-American, Christian woman from upstate New York proclaimed that we as a nation must be patient and that individual peoples must state their needs clearly to their neighbors at the ground level. She went on to emphasize that change takes time. Listening to her comments, this Italian, lesbian New Yorker thought, "But how long? How long must we wait?" Until how many are dead from AIDS-related illnesses, violence, neglect, and moreover injustice, unemployment, poverty, and despair?

There were uncomfortable moments but they were not passed over. As a group we focused on each of those moments and questioned what they were all about. It was important, and difficult...and exciting. I felt like something was being accomplished.

The training moved into a session on heterosexism and homophobia. As I always do, I presented an often used formula to demonstrate the making of heterosexism. The formula states that as power + prejudice = racism, so power + prejudice = heterosexism. What followed was an emotionally charged discussion regarding what I later heard Suzanne Pharr call the "hierarchy of oppression." There were some impassioned exchanges. One African-American man recalled his grandfather being lynched by the KKK, and then stated that gay men and lesbians are not lynched. A white woman responded by sharing a story about her uncle, beaten within inches of his life with "faggot" spray painted on the outside of his store-
vices Center. Her book, *Homophobia: Weapon of Sexism*, should be required reading for individuals working within all liberation movements. She connected these oppressions in a brilliant speech, “Divisions that Kill: The Enemy Without and Within,” in which she succinctly outlined how the those on the far right have successfully and methodically undermined and divided oppressed communities. She shared her personal experiences as a white, lesbian, Southerner, and describes growing up in the south in the 1950s as an excruciatingly isolating experience. While still a very young woman, she heard about an African-American woman in Arkansas who, with other African-American students, began to demand equal and quality education. This act of courage, and ultimately, revolution, gave hope to Pharr and connected her with the world. She joined the civil rights movement and began to develop the means to become the gay and lesbian rights activist she is today. All liberation movements are united.

The AIDS crisis has forced us to consider oppression like no other health issue has. And communities with histories of oppression — women, people of color, lesbians and gay men, the poor — are beginning to dialogue with each other. It is imperative that this dialogue continue to grow in scope, despite difficulties that will certainly arise. Those of us working within the HIV/AIDS movement are continually made aware that to be successful, we must be inclusive and competent around these issues. In fact, we can always be sure that there will always be someone in the wings (read: “right in our faces”) reminding us of the importance of speaking with all communities. It is important — now more than ever — that we pull together and challenge those who oppose equality and justice for all. Our opposition is formidable and works insidiously on many fronts to strip away democracy while attempting to distract attention from their true intention. They insist on focusing on what they believe is the “demise of traditional family values.”

The point is that we must all focus our collective energy to work against both alienation from each other and alienation from others who face discrimination Carter Heyward is a lesbian Episcopal priest. In her book, *Touching Our Strength: The Erotic as Power and the Love of God*, she writes, “Those of us emerging from the underside of history today also may fail to see that our problems — be they AIDS, loneliness, gay-bashing, rape, racist violence, or intolerance — are not simply ours, but belong to the whole society, in which the dynamics of alienation set the terms and construct the conditions for who’s to live, who’s to die, and how. The fear in which this alienation is fastened, however, is remarkably personal. We feel it and often we know that we do. But we have learned to feel it toward the wrong enemy. Rather than fearing our alienation from one another, we have learned to fear one another.”

The images that bombarded us of a terrifying beating on a dark Los Angeles street must impel us to move forward, to heal ourselves, and to make peace with each other. There are too many unseen and unexposed occurrences of oppression and violence that happen every day. We must go forward together — without fear, without a hierarchy of oppression, and without alienation.

*Continued from page 15*

**DEGRASSI HEALTH EDUCATION CURRICULUM**

(11 1/2 x10 1/4" looseleaf binder, 1992, 72pp., with six videocassettes) developed by Robin J. Kirsch and The Educational Print and Outreach Department of the WGBH Education Foundation, is based on the popular public television shows *Degrassi High* and *Degrassi Junior High*. The curriculum is composed of six stand alone units, each of which uses an episode from the series that focuses on a particular adolescent health issue. The topics covered, marked with tabs for easy reference, are: Alcoholism, Relationships, HIV/AIDS, Date Abuse, Sexual Orientation, and Teen Pregnancy. Each unit contains background information on the topic, three to four lesson plans, reproducible handouts, and suggested Readings and Resources. The first lesson of each unit focuses on the television episode that covers the topic and requires viewing of the video, however the following lessons of each unit can be taught on their own. The episodes and their corresponding topics are: “Great Expectations” (Relationships), “It’s Late” (Teen Pregnancy), “One Last Dance,” (HIV/AIDS), “Nobody’s Perfect” (Date Abuse), “He Ain’t Heavy,” (Sexual Orientation), and “Bottled Up,” (Alcoholism). *Health Curriculum, Box 2222, South Eastern, MA 02375, 617/492-2777, ext. 4299. Prices: Curriculum, $5; videocassettes, $50 per program or $300 for all six programs.*

**HIV/AIDS: FACTS TO CONSIDER, FEBRUARY 1992 UPDATE**

(8 1/2”x11” report, 1992, 12 pps.) compiled by Tracey Hooker & Lucinda Bryant, HIV/AIDS: Facts to Consider, is an important compilation of current factual information and statistics on HIV/AIDS in the United States. The update, published by the National Conference of State Legislatures (NCSL) with the CDC, is part of the HIV/AIDS Information and Education Project for State Legislators, which provides legislators and their staffs with information resources and a forum to communicate with legislative colleagues, experts, and government officials around the country. Services offered at no cost through the HIV/AIDS Project include an information clearinghouse, publications, technical assistance, and meetings and workshops. The update begins with a valuable background description of HIV and AIDS, and includes the following sections: Caseload Trends, Transmission, Women, Infants and Children, Adolescents and Young Adults, Costs, HIV Drug Treatment, Medicaid/Medicare, Testing, Reporting, Confidentiality, Partner Notification, Health Care Workers and Patients, Blood Supply, Criminal Penalties, Sex Offenders, Discrimination, Education and Awareness, Needle Exchange and Injecting Drug Use, and Worker Notification. A chart outlines misleading vs. more accurate phraseology about HIV/AIDS, such as AIDS virus (miseducating) vs. HIV (more accurate), HIV virus vs. HIV, AIDS test vs. HIV antibody test, and AIDS victim vs. PLWA (person living with AIDS). An evaluation questionnaire is also included. For further information about the project, contact: Tracey Hooker, Policy Specialist, National Conference of State Legislatures, 1500 Broadway, Suite 700, Denver, CO 80202, 303/830-2200, fax 303/863-8003. Price: Copies of the update are available free of charge.
AMONG FRIENDS: Hospice Care for the Person with AIDS
Robert W. Buckingham, DrPH

In Among Friends: Hospice Care for the Person With AIDS, Dr. Robert W. Buckingham invites the reader's conscience by identifying hospice as a "moral notion...addressing the issues of quality of life and how people ought to die." Intrinsic to this moral notion is the concept of choice; choice only exists when there are options. The contemporary AIDS movement has struggled for a decade now to create care and treatment options for people living with AIDS. Buckingham details what the hospice option offers for people with AIDS who are approaching the final stage of their illness, although it is a care alternative that seems to be reaching fewer than one-quarter of the people who die of AIDS. While presenting a wide range of information about hospice and AIDS, Buckingham's book is diminished by failing to adequately embrace important elements of the struggle to live with AIDS, through topics he has failed to emphasize and language he has chosen.

The book draws upon Buckingham's work with more than 1,700 terminal cancer and AIDS patients, beginning with his participation in founding the first hospice in the United States. The book is intended as a resource particularly "for caregivers, for people with AIDS, and for health professionals." The diverse topics covered include the history of hospice, why hospice is needed, its philosophy of care and advantages, the hospice approach to medical treatment, emotional and social issues, the cost of care, and how to develop hospice programs. Special focus on children (2,789 cases of AIDS in children under 13 were recorded through 1990) and on suicide (the rate for men between the ages of 20 and 59 is 36 times greater when AIDS is involved than when it is not) provides valuable information about two increasingly important concerns in AIDS care.

The treatment of these topics ranges from intimate, life-affirming lessons gleaned from the author's "patients-teachers," numerous insightful case studies, and first-hand accounts, to technical discussions of opportunistic infections and their treatment. He succinctly describes what hospice has to offer and the barriers that need to be overcome — both by hospices and the larger community — in order to best meet the needs of people with AIDS.

Buckingham identifies the most unique and compelling elements of hospice "...[H]ospice is primarily a philosophy of care and a program for the terminally ill. It is not necessarily a facility." Misconceptions of hospice as a place to die when everyone has given up can lead to its preemptory rejection by people with AIDS and their caregivers. As he points out, it is a "flexible concept" of care that can be brought into any setting, i.e. at home, in a residential facility, or in a nursing home. Hospice uniquely offers the strategy of using a multidisciplinary team that brings the insights and resources of medicine, nursing, social work, physical therapy, pharmacology, and pastoral care to focus on the needs of not only the person who is ill but also the larger family unit, whether biological or chosen. Hospice is patient-oriented, not disease focused. Underscoring the importance of choice, hospice empowers the patient who "must be considered the key member of the team," even if the patient is a child. There is an emphasis on bereavement care for family members, which with AIDS can mean ongoing support services, such as those for orphaned children. Hospice is a cost effective alternative to acute hospitalization, which, as Buckingham points out, is 10.5 times more expensive. The value of hospice is that at a particular moment it offers a humane alternative to costly, unneeded and/or undesired acute hospitalization. Hospice is a form of treatment that emphasizes comfort, symptom and pain control, and the goal of maintaining the quality of life until it ends.

Buckingham explores why many of the 1,800 hospice programs in the United States and people with AIDS are not a comfortable match. In their short history, hospices have developed traditions and protocols that are obstacles to serving people with AIDS well, and the nature of AIDS brings demands for service changes and expansions. Buckingham confirms that "hospices now serve only a small percentage of terminally ill patients" and refers to obstacles that particularly affect the participation of people with AIDS. These include the expectation of a primary care provider in the home, the limited number of hospices that are Medicare certified, the need for certification that the patient only has a six month life expectancy — a prognosis extremely difficult to make about AIDS, concerns about reimbursement for the high cost of medications, and the lack of awareness about hospice in the larger community as well as among medical practitioners.

Buckingham gives special attention to the problem of inadequate reimbursement rates from Medicaid, an increasingly important issue as more people with AIDS come under its coverage due to limited or no private insurance. Defining palliative care — hospice's medical approach — is particularly problematic in light of the range of aggressive treatments that would normally be prohibited in hospice but are available to people with AIDS. He stresses the right of patients to make decisions about their medical treatment and provides a philosophical base for a flexible hospice approach, affirming that "even the most aggressive medical treatments are merely palliative," however, he does not fully address the administrator's fears about how to pay for such treatments.

Similarly, on most of these issues Buckingham leaves the reader uninspired. He cites few examples of those hospice programs that have successfully overcome these barriers and does not suggest or detail a strategy for change, instead he limply offers, "we can only hope for competent and caring professionals who can enable the dying to leave this world with dignity and who can lend support to those of us left behind," or discouragingly observes that "the obstacles inherent in developing a hospice program...loom large." Moreover, his claim that "hospice centers provide the best alternative for the care of people with AIDS," seems to negate the developing continuum of care in which hospice can play an important role.

The important message contained in this book suffers from language that can be insensitive and stigmatizing. Throughout the book, Buckingham uses fatalistic phrases such as, "The majority of people with AIDS...must resign themselves to the fact...they will die of this illness at a very early age," and "AIDS is a miserable disease; those afflicted with it know they are going to die." They belittle personal and community efforts to live with AIDS, to demand social and political commitment to seek solutions, and to affirm life while facing premature death. In addition, the author does not explore the painful and conflicting process of choosing hospice by patients who are young and struggling with the hope for curative treatments.

In one instance the author's language borders on the hysterical: "...caring for..."
the AIDS patient can be very deadly..."

In the chapter on children with AIDS he makes reference to "attitudes that normal children have about AIDS" (emphasis added). He writes that "due to its relationship to intravenous drug use, pediatric HIV infection is most often a disease of poverty" a statement that equates injection drug use with poverty and stigmatizes the poor as an agent of AIDS as has been done to homosexuals and Haitians.

Buckingham has given surprisingly little attention to the impact of AIDS on people and communities of color and the challenge that this presents to hospice, which largely is staffed by white professionals serving white middle-class patients. National hospice leaders call attention to the failure of hospice to adequately reach outside this population, a situation that is exacerbated by AIDS.

Buckingham fails to address the need for the development of socially and culturally sensitive services and the challenge to increase people of color on hospice boards and staff. Similarly, he fails to pursue the implications and challenges for hospice by the significant incidence of people with AIDS who are not current or former injection drug users, a reality that challenges medical treatment, social support, and case management efforts.

His advice about dealing with lifestyle issues recommends "putting aside one's personal feelings or prejudices about the patient's lifestyle or background" instead of promoting education programs that help hospice staff confront their feelings and prejudices so that they can truthfully and meaningfully deal with them. Who would want to receive personal and pastoral care in death by someone who has just "put aside" his or her prejudices about them?

Buckingham chose to devote a full chapter to first-person accounts from a hemophiliac family dealing with AIDS rather than the family of someone who is gay, a family of color, or the family of a drug user. The account in the book is intimate and revealing, however, as an account of an intimate and revealing, however, as an account of his personal and pastoral care in death by someone who has just "put aside" his or her prejudices about them.

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As such, it provides a unique, thorough, and explicit in this important "moral notion" that is hospice.

**If a Partner Has AIDS: A Guide to Clinical Interventions for Relationships in Crisis**

R. Dennis Shelby, PhD

If a Partner Has AIDS by R. Dennis Shelby is an excellent description of the process through which a gay male couple proceeds when one or both partners is diagnosed with HIV/AIDS. This book is primarily a clinical work that grew out of the author's private psychotherapy practice and doctoral research in Chicago and San Francisco. As such, it provides a unique, thorough, and practical account of the mourning process of gay male couples affected by AIDS.

The book is written in a classic academic format: introduction, a review of clinical literature on HIV/AIDS specifically related to mourning and grief and gay/lesbian relationships and a review of Self Psychology literature, research methodology, results, and clinical implications and applications. However, this is by no means a dry presentation of data. Shelby has written a book which is a captivating example of clinical research at its best and most applicable.

Shelby employs the conceptual framework of Self Psychology, an analytic approach that utilizes the theory of the development of the 'self' as that which is "the embodiment of self-esteem and develops through interactions with self-objects...in the direction of an entity that is able to internally regulate self-esteem, calm and soothe the self, and set appropriate but challenging goals." His explanations of Self Psychology often seem tedious, especially when juxtaposed against the captivating case presentations. Granted, this book grew out of the author's doctoral research and as an academic work necessitates such descriptions. However, to the degree included in this publication it seems somewhat overstated. Clinicians working with this population and others who may use this book to assist them in living with a partner with AIDS, would benefit perhaps from more expansion of intervention strategies as opposed to theoretical exposition.

The substance of Shelby's work is contained in his presentation of findings from the perspective of the gay male partners of men diagnosed with AIDS. He presents the experiences of these men as they progress through nine "categories of experience" which span the client's entrance into the stages of his partner becoming ill, from his adaptations to the progression of the illness and the death of the partner, to the singular journey of the surviving partner and, ultimately, his transition 'Back Into The World.'

By utilizing contemporary understandings of theory as a natural result of research, Shelby details the categories of experience by relating actual events of his clients' subjects' lives. Thus, he presents his research by telling the stories of the people with whom he worked. This is not an over-simplified, step-by-step approach to the loss of a partner to AIDS. Readers are led through the complex web of a partner accompanying his spouse through the course of initial diagnosis, physical decline and death, while simultaneously experiencing their own process of potentially, if not actually becoming HIV positive or contracting AIDS. Through these accounts, the categories of experience continually de-
velop and re-emerge more as descriptions of the experience rather than a strict format or process. Shelby continues this style of presentation through a reconsideration of mourning theory as well as specific intervention strategies which are practical as well as timely.

Ultimately however, this is a book about relationships irrevocably changed by a chronic, fatal illness. Shelby has fully captured this "immense journey" with a striking clarity of respect for his clients. Perhaps the most appealing aspect of this book is that it never falls into easy explanations or overly generalized assumptions about partners of people with AIDS. Many clinicians working with this client population have found that most attention is focused on the partner who has the illness at the expense of then having any effective way to address the needs of the surviving partner. This book provides effective strategies for the clinician to be more fully prepared to handle this crisis within a broader context of the many dimensions of a relationship that continues to develop and change, especially while the partner is still living, and not just focusing on what occurs after a partner has died.

Finally, it is profoundly significant that Shelby has presented his work from the perspective of gay male couples. He remains clear to his intent to simply present the observations of an incisively accurate observer. And in so doing, he accomplishes something that many professionals dealing with this situation have missed i.e., in being the first distinct group of people to be affected by AIDS in the United States, gay men have provided the entire health care community with a model for dealing with this disease. Much of the current education and non-gay media seem to be addicted to the so-called Minnesota Model. That in itself is perhaps the least satisfying of the six books on most counts. Marred by obsolete references (e.g., "ARC") and an overabundance of military metaphors describing the operations of HIV, the book feels like a hastily assembled collection of articles. Some of the information is unnecessarily timid, for example, Siegel notes that denying treatment to people with HIV is discriminatory, but fails to note that it also violates a host of state and federal laws and could subject the practitioner to litigation. He suggests that addicts ought to clean their works, yet fails to provide any detailed information — admittedly, a sticky topic for substance abuse counselors and addictionologists, but nevertheless essential.

Siegel's perspective on addiction is muddled-of-the-road, a reflection of the so-called Minnesota Model. That in itself is not objectionable, however, because he fails to address the realities of women, people of color, and gay/lesbian/bisexual people, he reflects the limitation of that model. The people he addresses are white, probably male, and most likely heterosexual.

Nevertheless, there are some redeeming aspects to Siegel's book. He consistently refuses to treat HIV and AIDS as synonymous, and he contends that AIDS does not equal death. He includes an interesting and important discussion about differentiating between neurocognitive impairment due to AIDS and similar impairment caused by long-term drug use. His discussion of HIV antibody testing is particularly well-balanced, avoiding simple and thoughtless recommendations to test or not to test.

The Color of Light and Circle of Hope were written by Perry Tilleraas, a Minnesota AIDS activist and recovering alcoholic who recently died of AIDS. Both books seem to emanate from the
inside out and convey a consistently optimistic message. *The Color of Light* is a book of daily meditations, of which many variations are popular in the recovery literature, written for “all of us living with AIDS.” Throughout the course of a year’s reading, the daily meditations address almost every aspect of HIV or AIDS the reader might be facing. I have met recovering addicts with HIV or AIDS around the country who read Tilleraas’ daily readings for ongoing support and encouragement—a better recommendation could not be made.

*Circle of Hope*, the follow-up to *The Color of Light*, is patterned after the so-called Big Book of Alcoholics Anonymous: several short, introductory chapters that illuminate main issues and themes, followed by a much longer section of first-person stories of people in recovery with HIV or AIDS. It is a beautiful book, sometimes dark and painful as individuals recount the horrors of addiction, childhood abuse, sexism, homophobia, and racism, but always, in the end, bright with wisdom and light. Neither *The Color of Light* nor *Circle of Hope* are meant to be linear expositions of fact; they are forums for stories, tales of lives.

Especially important in *Circle of Hope* is Tilleraas’ discussion of “sober addiction”—the idea that recovering people can take medications for pain management without signifying “relapse.” He offers some strategies for successful pain management without relapse, but the topic deserves more, and more intricate, treatment.

I have only two reservations about Tilleraas’ work. First, his style is sometimes too “new-agey” for me (an admittedly personal bias). Although I realize that new age philosophies certainly have something significant to contribute to the experience of people living with HIV or AIDS, the assertion that the individual is responsible for her or his own disease, or that disease is merely a manifestation of internal spiritual imbalance, is dangerously punitive in its effect. Perry never quite crosses that border, but he straddles it frequently.

Second, all of the stories in Tilleraas’ books presume that the reader or subject is already in recovery, and more specifically, in a program of recovery that revolves around the Twelve Steps program model. Problems and issues of people with HIV or AIDS who, at least for the moment, have no interest in discontinuing chemicals are not addressed. Harm reduction models, for example, do not measure success by the presence or absence of chemicals in one’s body; they rather look at measurable indicators of quality of life, and whether they improve over time.

Despite those caveats, Tilleraas’ books are remarkable and beneficial—and if a friend in recovery is diagnosed with HIV antibody, they are the books I would most likely to offer as a source of practical wisdom and support. *Living in Hope* grows out of the same philosophical ground as Tilleraas’ work, with only minor variations. Sprung from the experience of the growing “HIV Anonymous” movement, which is based on the Twelve Steps of Alcoholics Anonymous rendered in the language of HIV/AIDS, the book has much to recommend it as a manual for emotional and spiritual healing. Like Tilleraas, the authors believe that “We must go beyond the Hollywood-inspired, simplistic view that healing means suddenly throwing away your crutches and walking off into the sunset.”

Not unlike the classic AA work, *Twelve Steps and Twelve Traditions, Living in Hope* is laid out one step at a time, and attempts to explore the meaning, implications, and practical benefits of each. Thus, the First Step becomes “Admitted that we were powerless over being at risk of or infected with the AIDS virus, and that our lives have become unmanageable,” and so on.

It is essential to view this book as what it is, and what it is *not*—which is sometimes problematic because of the terms the authors too casually employ. For those familiar with the sense and syntax of Twelve Step programs, and who view the experience of HIV infection as an opportunity to “take care of emotional and spiritual baggage” that may be preventing movement toward a higher ground of health, *Living in Hope* will probably prove an indispensable guidebook. For others, it may be alienating, since like so many Twelve Step programs, it relies on traditional, and culture-bound, notions of spirituality (e.g. the inclusion of a number of Christian prayers presented as aids to healing). Still, it is affirming, encouraging, and sometimes even liberating, and, unlike many “self-help” books, offers a wealth of practical strategies for confronting emotional traumas.

I submit to being somewhat uncomfortable with the authors’ fundamental assumption that alcoholism and HIV infection are much the same, and that therefore, the twelve steps are appropriate to each. (Even further, the authors are occasionally fervent about the steps, e.g., “we believe everyone on the planet could be helped in they lived their lives by the principles of the twelve steps.”) Even as an advocate of the twelve step philosophy, I am uneasy about admissions of “powerlessness” and “unmanageability,” especially as applied to HIV. And for many people—women, people of color, gay men, and lesbians—powerlessness is a condition to be rejected in the necessary reclamation of power and identity.

I have some linguistic quibbles with the book as well. HIV is not the AIDS virus, and only fosters the belief the authors claim to abhor: that HIV = AIDS = Death.

I predict that the “HIV anonymous” movement will grow rapidly in the coming years, especially as the proposition that “HIV is a chronic, but manageable illness” begins to replace current canons of inevitable fatality. As it does, this book will be an essential volume, and others, yet forthcoming, may surpass its shortcomings.

A fifth book, *The Caregiver’s Journey,* may not be an obvious candidate to review in a subset of volumes on HIV and substance abuse. It is not specifically concerned with the subject, but ends up being significantly so, if for no other reason that the principal author, Mel Pohl, was the former Medical Director at the Pride Institute in Minnesota, a substance abuse treatment program for gay, lesbian, and bisexual people whose client population is, on the average, 50% HIV-infected.

Pohl, Kay, and Toft propose that caregivers of people with HIV or AIDS, whether they are acting in a professional or non-professional capacity, typically pass through a series of “stages” in the “caregiver’s journey”: Discovering, Adapting, Coasting, and Colliding. Each stage demands that the caregiver travel through four phases. Learning, Working with Feelings, Taking Action, and Acceptance. If this topography of human experience already seems confusing, then one has already encountered the central deficiency of *The Caregiver’s Journey*—its mapping of stages and phases, while sometimes illuminating in the particular, is far too overwhelming and simplistic in the general. The catalogs of reality are neat and linear, life is more often messy and circular.

Many of the topical dilemmas outlined in the book involve substance abuse. In those cases, *The Caregiver’s Journey* is often helpful. It is in their discussions of the role of codependency and its affect on the caregiving relationship that Pohl, Kay, and Toft have the most insightful contributions to make. They offer broad cautions as well as concrete strategies to assist caregivers. However, the remaining discourses are forced into constructions of stages and phases that cannot support the weight of the argument, or the form of...
the feeling. There is a notable lack of specifics about the four stages. And this book will only be useful when buttressed with a number of other works: Tilleraas', for example, and the Los Angeles AIDS Project's AIDS: A Self-Care Manual.

Preventing AIDS in Drug Users and Their Sexual Partners is an invaluable resource for HIV service and education professionals, substance abuse counselors, and policy makers. Its tone overall is respectful of addicts and people with HIV (especially in underlining addicts' ability to adopt health-enhancing behaviors and to support those behaviors in other addicts), and is based on solid, reliable research and data. Preventing AIDS also displays considerable cultural and gender-sensitivity throughout (rather than merely treating women and people of color separately, apart from main themes), a characteristic that is still, unfortunately, uncommon in social science research.

Preventing AIDS is constructed in three main sections. The first outlines and summarizes background information on HIV, needle use, and sexuality. The authors make cogent cases for expanded drug treatment access, cultural sensitivity in the design and implementation of HIV/AIDS prevention programs, widespread condom and bleach distribution, and needle exchange (though they recognize the controversy surrounding it). The second section surveys intervention strategies, including primary substance abuse treatment, group counseling, and individual counseling. There is an impressive chapter about reaching women who are sexual partners of male injection drug users; it reflects a great deal of sensitivity to women's realities and conditions. The third section discusses social and policy implications derived from the presentations in part one and two.

This volume is targeted toward professionals, and as such, occasionally suffers from the absence of first-person viewpoints. It does not address some of the particular difficulties faced by recovering addicts with HIV disease (such as pain management); it concerns itself more with interrupting HIV transmission. Within those limitations, however, it is a balanced and progressive digest of current knowledge and research, and a call for essential change in social and political policy and practice.

Reviewed by Bart Pike, AIDS Guidelines specialist, Chemical Dependency Program Division, Minnesota Department of Human Services, St. Paul, Minnesota.
Conference and Seminar Calendar


VI INTERNATIONAL CONFERENCE ON AIDS EDUCATION, "THE SECOND DECADE OF HIV: PATHS TO PURSUE," August 16-19, 1992. Sponsored by The International Society for AIDS Education and The George Washington University Medical Center. Will focus on improving the effectiveness and inclusiveness of HIV/AIDS education through skills building workshops, presentations, and perspectives on HIV from people living with AIDS. Two preconference workshops will be conducted: an introduction to aspects of HIV, including biology and transmission, history, effects, and therapies; and a training institute for HIV prevention educators on dealing with issues of sexuality as they relate to risk reduction. Ritz Carlton Pentagon City, Arlington, Virginia. Contact: Daniel E. Reichard, Office of Continuing Medical Education, The George Washington University Medical Center, 2300 K Street NW, Washington, DC 20037, 202/994-4285.


BAY AREA PHYSICIANS FOR HUMAN RIGHTS' (BAPHR) & AMERICAN ASSOCIATION OF PHYSICIANS FOR HUMAN RIGHTS' (AAPHR) SYMPOSIUM 1992, "IN THE AGE OF AIDS: ISSUES AND DISCUSSIONS, HEALTHCARE PROVIDERS, STRETCHING THEIR LIMITS," August 20, 21, 22, 1992. Will include an Annual AIDS Update: "Strategic Planning for the Second Decade," a day devoted to the issues of healthcare workers with HIV, panels, two student workshops, and workshops covering ongoing as well as subjects new to the Symposium such as TB and homelessness. Will provide an update on current lesbian and gay health care issues in order to increase participants' knowledge base and to enhance their practices. In addition to its annual meeting, AAPHR will celebrate its 10th anniversary with a dinner and awards banquet on August 22nd. Cathedral Hill Hotel, San Francisco, California. Contact: BAPHR/AAPHR Symposium 1992, AAPHR, 2940 16th Street, #105, San Francisco, CA 94102, 415/255-4547.


NATIONAL COUNCIL OF FAMILY RELATIONS' (NCFR) 54TH ANNUAL CONFERENCE, "FAMILIES AND WORK," November 3-10, 1992. Will feature focus groups, workshops, speakers, posters, symposia, exhibits, and a video festival. Will offer an online publications database, Inventory of Marriage and Family Literature (IMFL), with topics that include: Reproductive Issues; Marriage/Family Counseling and Therapy; Family Sexuality; Marriage, Divorce, and Remarriage; and The Family and Human Development. Clarion Plaza Hotel, Orlando, Florida. Contact: Cynthia Winter, Conference Coordinator, NCFR, 3989 Central Avenue NE, Suite 550, Minneapolis, MN 55421, 612/781-9331, fax 612/781-9348.
