

FOCUS A GUIDE TO AIDS RESEARCH

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AIDS and Spirituality

Fr. Richard Dunphy, SJ

The crisis of living with AIDS precipitates physical, psychological, social and spiritual needs. It is important for health care providers to be attentive to the full spectrum of these needs, for when they are not heard or acknowledged, the overall health and well-being of the person with AIDS can be affected significantly. This holds true especially for spiritual needs; these are present and real, and understanding them will help the health care professional respond in an appropriate manner.

This article will explore some of the spiritual needs caregivers may encounter during their work with people with AIDS. First, the article will discuss the difference between spirituality and religion, a distinction that has helped a number of individuals engage key issues that they otherwise might have repressed or ignored due to their previous experience with organized religion. The second part will discuss the spiritual issues that I have encountered most frequently when counseling people with AIDS.

Spirituality and Religion

When spiritual issues surface in the life of someone with AIDS, he or she may mistakenly assume that these issues can only be confronted by returning to an active participation in organized religion. Such a prospect can often be quite problematic for the individual, since a significant number of people with AIDS have found organized religion unresponsive to their needs or a source of oppression and alienation in their lives. As a result, these needs may be dismissed as either irrelevant or oppressive, or they may be ignored out of fear of an anticipated rejection by a representative of organized religion. However, when individuals recognize that spirituality and religion are not necessarily one and the same, they are able to acknowledge and engage a dimension of their lives that is central to their health and well being.

In this discussion the term "spiritual" refers to that dimension of the human experience which transcends the immediate awareness of one's self. It is manifest in a variety of experiences: when someone questions the purpose of existence, when someone is filled with a sense of personal limitations and an awareness of the need to depend on a greater power, or when someone feels the joy of loving a friend unconditionally.

Spirituality is concerned with issues of meaning, hope, freedom, love, one's image of a Supreme Being, and forgiveness and reconciliation. The experience of spirituality is most fully realized through self-transcendence in love. It is reflected in the way an individual understands his relationship with a Supreme Being (or the absence of one), other persons, the world in which he lives, and himself. More simply, spirituality can be expressed as the way in which an individual lives his life in accord with basic values.

Organized religion on the other hand attempts to objectively structure spirituality in the forms of creed (an established set of beliefs), cult (a form of worship and religious practices), and community (authority, laws, and institutional structures). As such, organized religion is a human creation and is subject to sin and distortion. In fact, organized religion can be even more susceptible than other human enterprises to a variety of abuses, because in religion one can be tempted to justify prejudices by appropriating the power of the holy. Unfortunately, the history of organized religion has shown that religious leaders and institutions often intertwine sanctity and self-interest. At its best, organized religion truly serves the spirituality of its members; at its worst, it can alienate an individual from that which is most deeply human: the freedom to love.

When spiritual needs do surface, they may be dismissed as either irrelevant or oppressive, or they may be ignored out of fear of an anticipated rejection or inappropriate response by a representative of organized religion.

Religion should exist to serve the spirituality of its members, not the other way around. As Jesus told the religious leaders of his day, "The Sabbath was made for the human person, not the human person for the Sabbath" (Mark 2:27). The elements that constitute each organized religion are meant to contribute to the spiritual growth of its members. Religious legislation and practices that serve this growth should be respected and followed, but those that compromise or block it, for example, attitudes often attributed to religious teachings such as "AIDS is a punishment for being gay," should be challenged and disregarded.

Many people with AIDS who choose to participate in a religion (whether Judaism, Buddhism, or a Christian denomination) have found elements that have contributed significantly to their spiritual growth, whether a particular belief, a visit from their minister, prayers offered by their congregation, or receiving the sacraments. There are many people with AIDS who have no desire to associate with organized religion and they have found it possible to live lives of significant spiritual depth without it.

The Spiritual Needs

The crisis of living with a diagnosis of AIDS can bring spiritual needs to conscious awareness. Faced with the physical as well as the psychological and social impact of the disease, people with AIDS often engage spiritual issues such as meaning, hope, love, one's image of a Supreme Being, forgiveness and reconciliation in a new and frightening context, frequently with a depth and intensity that is greater than what they have previously experienced.

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AIDS and Spirituality . . .

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Many people with AIDS have expressed the need for meaning and hope in their lives as they have tried to cope with the traumatic losses associated with their disease. Many of us give our lives meaning and hope by creating a sense of identity and self-worth through our personal and professional relationships, through the acceptance and respect received from these relationships, through the personal and material satisfactions received from our work, through our state of health and physical well being, and perhaps through our participation in an organized religion or our experience of a Supreme Being. When any one or all of these aspects of a person's life is changed, threatened, or lost, one can experience the partial or complete collapse of meaning and hope. After the initial shock and devastation of receiving an AIDS diagnosis, the individual may feel a pressing need to re-establish that life still has value and purpose and that there is a worthwhile future in terms of quality of life and relationships.

Obstacles to Renewed Spirituality

The process of re-establishing meaning and hope can include a number of obstacles, and it is important to be attentive to them when they arise. One of the major external obstacles is the social stigma associated with AIDS. Because of this stigma, at precisely the time when a person needs support and a sense of belonging, the person with AIDS frequently encounters prejudice, discrimination, condemnation and abandonment. As a result, the atmosphere of acceptance and love that can facilitate the rediscovery of meaning and hope is often missing or severely compromised. Health care professionals who are sensitive to the impact of this stigmatization can help reduce the sense of isolation and abandonment that results. Practitioners who accept their AIDS patients unconditionally and try to adapt to their differing temperaments and needs can have a significant influence on creating an atmosphere of love that is essential for breaking through to new levels of meaning, hope and a sense of personal worth.

Unfortunately, a number of people with the disease internalize the negative social images associated with AIDS and experience another major obstacle to re-establishing meaning and hope in their lives. This internalization can produce a profound sense of alienation and can cause the individual to withdraw and become more isolated. There are a number of factors that can foster this internalization of the AIDS stigma.

For gay men, one important factor is internalized homophobia. In the face of a catastrophic illness like AIDS, latent homophobia, even in a previously well-adjusted gay man, can reassert itself and take the form of accepting society's negative judgements about gay men who have AIDS: for example, "Maybe God is punishing me for my lifestyle." The end product of this internalized homophobia is the reaffirmation of a poor self-image, self-hatred, and alienation from one's self. It is important to recognize such homophobia for what it is and to challenge it, for it is a serious obstacle to finding the acceptance and love of other people and rediscovering meaning and hope in the face of AIDS.

Another factor involved in the phenomenon of internalizing the stigma of AIDS is guilt. When faced with the largely chaotic nature of a life-threatening illness such as AIDS, it is not unusual for individuals to try to re-establish some control over their lives. An unhealthy and unproductive way of attempting to do this is through guilt. AIDS patients addicted to heroin may be filled with guilt and remorse over the addiction and thereby try to create the illusion that they really chose to become addicts and get AIDS. Hemophiliacs with AIDS may feel the disease is a punishment for some past unresolved moral failure and thereby rationalize the illness through the guilt still felt about the past. Guilt can lock people into themselves, closing them off to the acceptance and love of others, and can block any breakthrough

toward finding meaning and hope in the midst of their illness. In situations such as these, it is imperative not to reinforce such guilt, but to make a referral to a competent pastoral minister or therapist.

The need for unconditional acceptance often intensifies in an individual faced with an AIDS diagnosis. Providing support for the individual during these times does not mean allowing oneself to be manipulated by unacceptable behavior; rather, one should try to understand and love the person behind such behavior in a consistent and accepting manner.

The model for this unconditional acceptance and love in the West is the God of the Hebrew and Christian scriptures: the God who accepts and loves us as we are; who calls us from personal, social and religious bondage; and who leads us through the darkness of suffering and death to the bright promises of immortality. Unfortunately, many people with AIDS have had experiences with organized religion that have presented them with a harsh, judgemental god who condemns and rejects. As a result, there is a need to discover an image of God who is unconditional love. In the final analysis, it is this experience of spirituality that is based on an appreciation of a divine love, mediated through our human love, that can heal the isolation and alienation so often occasioned by a diagnosis of AIDS.

A final spiritual need concerns forgiveness and reconciliation. All individuals have histories of relationships which include misunderstandings, self-destructive behavior, mutual hurts and injuries, resentments, pride, and self-centeredness. In the face of our histories each of us needs forgiveness and reconciliation with ourselves and with our fellow human beings. When individuals face life-threatening illnesses, the need to deal with their unfinished business, including its moral dimension, often intensifies. People with AIDS often express the need to be forgiven by God for whatever injuries they may have inflicted on others; and, when possible, they have sought reconciliation with family, friends and past associates. It is not uncommon for them to stay alive long enough to bring about the most significant of these reconciliations. This desire for forgiveness and reconciliation is markedly different from internalized homophobia or the experience of guilt, although the words that express it may sound similar. When this need is spiritual, it arises from an understanding and compassion for oneself and is based upon what Paul Tillich described as the act of faith: "the courage to accept acceptance."

Conclusion

Obviously there are other spiritual issues and needs — such as prayer, the "dark night" of faith, and personal immortality — that may surface in the lives of people with AIDS as they try to understand and live the spiritual dimension of their existence. Whatever these may be, it is crucial to be attentive to them so that the individual can find the support and encouragement needed to grow along spiritual lines. By responding in a sensitive and compassionate manner to the spiritual dimension of the people with AIDS in our care, we can contribute significantly toward their efforts to live a life that has quality and purpose and to die with dignity and a sense of completion.

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RESOURCES

The author has addressed this topic at greater length in a previously published article, "Helping Persons with AIDS Find Meaning and Hope," *Health Progress* (May, 1987) pp. 58-63. Other relevant works include John E. Fortunato, *AIDS: The Spiritual Dilemma*, San Francisco: Harper and Row, 1987; Richard L. Schaper, "Pastoral Care for Persons with AIDS and For Their Families," *The Christian Century* (August 12-19, 1987), pp. 691-694; Leo J. Tibesar, "Pastoral Care: Helping Patients on an Inward Journey," *Health Progress* (May, 1986), pp. 41-47; and Klaus Wendler, "Ministry to Patients with AIDS," *The Journal of Pastoral Care* (March, 1987), pp. 4-16.

Diagnosis/Treatment/Prevention

Countertransference Reactions of Female Health Care Providers to Women With HIV Infections (part two)

Judy Macks, LCSW

Countertransference reactions refer to the provider's conscious or unconscious behavioral, cognitive or emotional reactions to the circumstances, emotions or behavior presented by the client. These responses are among some of the most rewarding aspects of providing care to people with HIV-related concerns.

In the first part of this article, we discussed how health care providers have begun to work with greater numbers of women who are concerned about their risk for HIV infection or who are already infected with HIV. Several reactions to this work by female providers were discussed in part one, including fear of contagion, denial and magical thinking, discomfort with sexuality and sexual behavior change, and combating helplessness and despair.

In this second part of the article, we will address three additional responses experienced by female health care providers:

- (1) anger and blaming the victim,
- (2) blurring of ethical and professional boundaries, and
- (3) fear of professional inadequacy.

Anger and Blaming the Victim

Female practitioners may feel anger toward women infected with HIV for many reasons and express it in multiple ways — including blaming those who are already ill. The desire to blame may be directed toward a woman who did not know her partner was having high-risk sex outside of the relationship. Providers may respond incredulously, "How could you not know . . . ?", reflecting the practitioner's fear that she may not be absolutely confident in the fidelity of her own partner. Or, feelings of anger may emerge as a defense against feeling helpless, guilty, fearful of working with clients who are facing death and other uncomfortable feelings. They also usually result in emotionally distancing from the client because of the practitioner's inability to tolerate her own reaction.

Blurring of Ethical and Professional Boundaries

The most significant psychosocial concern for women with HIV relates to pregnancy and children and decisions about these issues often generate strong feelings in female providers. The woman who chooses to terminate or postpone pregnancy indefinitely will experience profound grief and loss, related both to the loss of her child and her role as mother. The woman who chooses to continue a pregnancy or become pregnant may not only experience opposition from providers, family members and others in her community, but also will have to endure the long wait to know if her child will be healthy. The wait is filled inevitably with anxiety and self-doubt.

The effect of these decisions on female providers will often be influenced by the providers' own attitudes about abortion, risk-taking, and the proper role of motherhood. Most practitioners have little insight into how or why a woman infected with HIV would decide to continue a pregnancy or become pregnant and risk the life of her child. It is important to consider that the oft-quoted risk of a seropositive woman giving birth to an infected infant (50/50) has very different meanings to women with different experiences. For example, a woman who has a long history of intravenous drug use may feel these odds are very favorable, while female practitioners may view them as

irresponsible. Similarly, other issues such as losing a child either as a result of the child's or the mother's death, not being able to watch her child grow, the anticipated guilt in leaving a child motherless, planning for the time when the mother will not be able to physically care for the child, family conflict and upset as a result of the illness and the spectre of custody challenges are all concerns which may be viewed very differently by the provider. Every provider will be tempted to encourage clients to do what she thinks she would do in a similar situation. While the temptation may be strong, the practitioner needs to remain clear about her ability to assist the client free from her own personal opinions and reactions.

Fear of Professional Inadequacy

Feelings of professional inadequacy often reflect the underlying sense of powerlessness and helplessness that can accompany working with women with HIV infections. The multitude of complex and profound issues that are raised by this disease provides a backdrop against which any provider may feel uncertain about her skills. The wish to be helpful and to make things better may be particularly strong for female providers caring for women infected with HIV.

Conclusion

Providing quality care to women infected with HIV requires willingness to identify and confront these kinds of countertransference issues. Professional consultation and peer support are extremely important in this process of self-reflection and professional growth. Countertransference reactions can become a serious impediment to providing quality services. However, handled well, they can also teach the provider more about herself and serve as a vehicle for personal and professional growth.

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BRIEFS

Recent Reports

No Evidence for New Routes of HIV Transmission Found. Although more than 2000 cases of AIDS in the United States were not initially linked to known risk factors, a follow-up analysis reveals no evidence for new modes of transmission, according to a recent study from the Centers for Disease Control (*Journal of the American Medical Association*, March 4, 1988, pp. 1338-1342).

Follow-up investigations to determine possible risk factors were conducted through local health departments. Using standardized questionnaires, interviews were conducted informally in order to record sensitive information regarding issues such as sexual history and history of intravenous drug usage. A variety of other possible transmission routes were also investigated.

Through September 1987, 41,770 AIDS cases were reported to the CDC. Of these, 2054 were classified as having no identified risk factors (NIR). For 921 of these cases, follow-up

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Correction

In the January issue of **FOCUS**, Dupree and Margo stated in "Homophobia, AIDS, and the Health Professional" that the Diagnostic and Statistical Manual of Mental Disorders (DSM-III) makes only one reference to "ego-dystonic homosexuality" (referring to "those people who are poorly adjusted to their homosexuality"). The DSM-III was revised in May 1987 and the diagnostic category for ego-dystonic homosexuality was removed. The DSM-III-R now suggests a diagnosis of "Sexual Dysfunction Not Otherwise Specified."

BRIEFS

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information was not available. Information obtained for the remaining 1138 showed that 72% were reclassified with known risk factors; over 50% of these were linked to male-to-male transmission. Thirty-two cases did not meet the CDC definition for AIDS.

With the remaining 281 cases, 178 in-depth standardized interviews showed that a relatively high proportion (38%) had a history of having 1 or more sexually transmitted disease (STD) and 34% reported having contact with female prostitutes. There was no evidence that human plasma products, tattoos, acupuncture, renal dialysis, human bites, shared residence with individuals with HIV or at increased risk for HIV, or occupational exposure to AIDS were significant pathways for HIV infection.

The incidence of cases without identified risk factors may be attributed to several factors. First, the potential stigma associated with sexual activities and intravenous drug use may result in the denial of risk factors in initial interviews. Secondly, individuals with AIDS may not have complete knowledge about the infection status or risk factors associated with their sexual partners. In order for an AIDS case to be recorded as resulting from heterosexual transmission, the partner must also be reported to have AIDS, to be infected with HIV, or to be at increased risk for HIV infection. Without this information, an individual is classified as NIR.

The high incidence of STDs found among AIDS patients classified as NIR supports the hypothesis that infection occurs through sexual contact. It has been suggested that men may report that they have been with prostitutes in order to avoid acknowledging other possible risk factors. While studies on female-to-male transmission continue, the high incidence of sexual contact with female prostitutes in this study suggests that they may become a source of HIV infection. (Separate studies have shown that a high percentage of female IVDUs have engaged in prostitution, and that 57% of prostitutes in the Northeast United States tested HIV-antibody-positive.)

Since evidence supports that there are no new pathways for the spread of the AIDS infection, the authors recommend that "public health intervention practices should continue to target prevention of HIV transmission through sexual contact, the sharing of contaminated needles, and perinatal exposure."

AIDS: A Significant Risk Factor for Suicide. A study published in the *Journal of the American Medical Association* (March 4, 1988) reported that there is a higher rate of suicide among New York City residents diagnosed with AIDS than in patients with chronic or life-threatening diseases among members of the general population. According to this study, the profile of the typical individual with AIDS who commits suicide is that of an unmarried, white, gay man aged 37 years, who has known his diagnosis for less than six months. Men aged 20-59 years with a diagnosis of AIDS are 36 times as likely to commit suicide than men in the general population.

The high number of AIDS-related suicides may be attributed to a combination of several factors: psychosocial stressors, such as the loss of a lover or friend due to AIDS, social stigma, the withdrawal of family support, and decreased occupational abilities; and possible biological mechanisms. Interestingly, a high proportion of suicides occurred in hospital settings, as patients leaped to their deaths suddenly and impulsively. The

researchers suggest that this might indicate a possible biological mechanism within the central nervous system, which is known to be affected in people with AIDS.

The authors believe that the results of their study are an underestimation of the actual number of AIDS-related suicides, suggesting that a) suicides occur where AIDS or HIV status is not known, and b) some suicides may be attributed to other causes (such as drug overdoses). Health care professionals should be aware of the suicide risk for their AIDS clients, and if they suspect depression or suicidal thoughts, they should counsel or make a referral, appropriately.

Because of the increased risk of suicide, the recently advocated idea of widespread HIV-antibody screening is of particular concern, according to the researchers; appropriate counseling regarding the significance of test results and the ramifications of the disease need to be available to recipients of test results.

Cervical Cells Found Directly Infected with HIV. Researchers reported in the March 1988 issue of the *Annals of Internal Medicine* that HIV has been isolated in cells lining the cervix, and suggest that this finding may explain how the disease is transmitted to newborns and through heterosexual contact. Cervical tissue samples were collected from four female HIV-seropositive heroin users and specific cell types within these samples (endothelial cells and monocyte-macrophages) were found to be directly infected with HIV. Similar cell types have been found to be infected in nervous tissue.

This study suggests that HIV may enter cervical secretions from HIV-infected cells within cervical tissue and may explain how the virus is transmitted from an infected female to her sexual partner. Cells within the cervix may also play a role in the acquisition of HIV from an infected male partner. These findings also support the idea that newborns may become infected during vaginal delivery by an HIV-infected mother. The researchers also reported that an increased risk of HIV infection may be present in women with pre-existing inflammation of the genital tract.

Next Month

Almost from the very start of the AIDS epidemic there have been promising treatments upon which physicians, patients, and loved ones have placed their hopes and expectations. Although the popular media continuously remind us that AIDS has "no known cure" and is "100% fatal," those closer to the epidemic realize that the true picture is not quite so simple. In the May issue of **FOCUS**, **William J. Woods**, PhD will present counseling guidelines for those health care providers whose clients and patients are trying to decide whether to take experimental anti-AIDS drugs. Woods is the Project Manager for Project Inform, a national information clearinghouse for experimental treatments for people concerned about AIDS. He is also a Research Fellow with the UCSF Center for AIDS Prevention Studies.

Also in the May issue, **John Krowka**, PhD will discuss the meaning of helper T-cells and their significance in understanding the status of the human immune system. He will also look at the usefulness of periodic helper T-cell counts in the monitoring of HIV infection. Krowka is the Assistant Research Immunologist at the UCSF Laboratory of Medicine.

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The amount of research information now appearing in the medical and lay press staggers most AIDS health care and service providers. The goal of **FOCUS** is to place the data and medical reports in a context that is meaningful and useful to its readers.

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