Hope is a loaded word among AIDS caregivers. We sincerely want to encourage hope in people with HIV disease and yet we often feel ambivalent about proferring it. Why the hesitancy?

One source of our discomfort is the fear of encouraging false hope. Two prime rules in supportive counseling for any health care worker are, "Never lie," and "Never promise what you can't deliver." One does not say to a terminally ill patient, "You're going to be fine," or "You've got lots of years left in you." Our fear of being drawn into making such ultimately damaging statements often inhibits us from saying anything hopeful to HIV-infected patients.

Beyond this source of discomfort is the dilemma of supporting patients as the stages of HIV disease lead them to shift both the levels and loci of their hope. One's hope can come to rest at varying depths, and it can be located in different places in one's life and soul. It is often confusing to know how to support a client through these changes.

Finally, a third source of unease is responding to a client's need for eschatological hope. The word eschatological derives from the Greek word eschaton, meaning end-times. It alludes to what happens to us after death. This topic makes most professional caregivers, and even most chaplains, uncomfortable.

Sometimes the caregiver is an atheist for whom notions like life after death, reincarnation, heaven, or spirit-worlds seem very much like cultivated schizoid thinking. At other times, the caregiver's own eschatology is so different from the client's that he or she feels incompetent to be supportive. Once a patient's locus of hope moves toward the eschatological realm, caregivers are at a loss to know how to be helpful.

This article discusses the nature and dilemma of providing hope in the context of HIV disease and in the context of contrasting spiritual beliefs. Using self psychology as a theoretical matrix for conceptualizing the progression of hope in people with HIV disease, it tries to answer the question: what could help make it easier to foster hope in our clients?

False Hope

Let's get two bogies out of the way. Charlatans selling unproven, quasi-medical interventions and "spiritual" approaches locating the whole source of cure in a person's soul foist false hope upon those living with HIV disease at a time when they are desperate and most likely to be exploited. None of us wants to be associated with such manipulation. Others unwittingly cause spiritual dis-ease in people with HIV infection by using too-quick appeals to shop-worn religious beliefs.

At frightening moments, clients with HIV disease may lunge for such pat religious epithets from their pasts like "God is watching over me," or "I'm going to heaven." Relatives and religious workers will sometimes support this spiritual dash to help to deny not only the client's, but also their own sense of impending loss or fear of death. Invariably, however, the uncomfortable feelings remain. The look of fear in patients' eyes even as they mouth such spiritual aphorisms belie their effectiveness.

Stages of Hope

Imparting false hope to people with HIV disease constitutes an unwholesome intrusion into their lives, and comes from outside the client and the disease. But some of the difficulties encountered in supporting hope in infected clients stem...
Editorial: The First Person
Robert Marks, Editor

Most FOCUS articles do not justify being written in the first person, an approach that shifts the emphasis from the content of the article to the author’s relationship to that content. In the past, we have run first-person articles only when the author himself or herself is a part of the story. We have asked two inmates to talk about dealing with HIV disease in prison, a person with HIV disease to talk about what it’s like to be a research subject, and an informal caregiver to talk about how he responded to caring for his dying lover.

When we were planning this month’s issue, I assumed that the articles would be written in the third person. They were to be straightforward discussions: how can spirituality be integrated into HIV-related counseling, and to what extent is pastoral counseling, in addition to psychotherapy, useful in dealing with these issues? But talking with John Fortunato led me to realize that spirituality is neither straightforward nor impersonal, and when we write about spirituality, it is neither easy nor desirable to remain aloof from the content of the piece.

Suspending Disbelief
That is what this issue of FOCUS is really about: spirituality infuses the therapeutic relationship in the same way that it infuses our culture, and spiritual beliefs affect both the client’s approach and the counselor’s response. Counselors respond to their clients not by ignoring personal spiritual beliefs, but by acknowledging and then suspending them.

Fortunato explains how psychotherapists can suspend disbelief or disagreement and help clients to use their own spiritual resources to resolve complex issues. Thaddeus Bennett and Mark Henrickson discuss how pastoral counselors can approach these issues more directly by inviting God into the therapeutic relationship.

What the authors do not say, however, is that traditional psychotherapy has resisted the spirit and focused almost exclusively on the psychological examination of personality, self, emotion, and intellect. The fact that the tenets of psychotherapy allow little room for clients to seek answers beyond themselves—that is, in the spiritual realm—adds to the obstacles to spiritual exploration.

As many practitioners have learned, HIV disease poses dilemmas that cannot be confined by the boundaries of psychotherapy. Death and dying, the afterlife, the power of faith to heal, the way we relate to others, the expression of our sexuality, and the relationship between our spiritual and physical well-being: the questions come in quick succession, and their resolution is rarely solely within ourselves.

Most notably, the domain over which hope can operate does not remain constant during the course of HIV disease. That is, the locus of hope changes as HIV disease progresses. When clients first find out they are seropositive, caregivers often feel pressured to give false hope—hope of a cure or of indefinite management of the infection and avoidance of death. Wanting to help, but not wanting to lie, we often give mixed messages of hope. On the one hand, we tend to avoid the issue of ultimate hope and talk instead about now and about protocols and procedures. On the other hand, in trying to respond to clients’ despair, we tend to allude to clinical data about survival rates and people’s ability to have “lots of good years” after infection.

As the health of people with HIV disease begins to deteriorate, we tend to focus more and more on the present and the near-term future. Clients at this stage often stop alluding to the distant future, and so do we. During the terminal stages of the disease, clients often focus on dying and talk little, if at all, about hope. In response, practitioners concentrate on pain management, life review, and helping clients achieve as good a death as possible.

There is something very right about this progression. But something about hope in AIDS care is missing here. What is right is the tacit acknowledgment that, as patients with progressive illnesses approach death, their worlds become smaller. In self-psychological terms, their pool of external supportive selfobject functions dries up. These selfobjects might include one’s job, hobbies, recreational activities, the sense of having wholeness of body, or the ability to relate meaningfully with others, whether sexually, politically, affectionally, or intellectually. Inevitably, people with HIV disease—like other people with progressive illnesses—must incrementally give up hope of deriving self-affirmation through some and eventually most of these life functions. As their worlds shrink, it seems absolutely appropriate that caregivers help them shift their focus and concentrate on the smaller worlds that have now become their reality.
I often find it helpful to liken spiritual conversation to hypnotic induction, an “entrancing” dialogue to help clients achieve spiritual peace.

Eschatological Hope

What lacks in this progression is any cogent method of dealing with eschatological hope and the discomfort it raises for AIDS caregivers. However, this uneasiness can be overcome. Moreover, in good conscience, we really must help HIV-infected people work through the question of what happens to them when they die.

In his book, Sister Death, Episcopal Bishop O’Kelly Whitaker notes that dying people have four major concerns: first, that they die with someone at their side who cares about them; second, that they suffer as little pain as possible; third, that they die with dignity and not grotesquely; and fourth, that they have some answer to this precise question, “What happens to me when I die?”

For HIV-infected people, the first three concerns can be satisfied by providing good psychosocial support and medical care, and in many communities, good systems of care have already been developed. The final need—an answer to the question of what happens after death—is much less reliably addressed.

It is the shift from a “this-worldly” locus of hope to an “other-worldly” locus of hope that seems to cause the most disconcerting caregiving bump. To smooth that transition, caregivers need two things: a conceptual model that follows the development of hope over the course of HIV disease, and a way of understanding eschatological hope that minimizes their own discomfort. The conceptual model would help assess clients’ current levels and loci of hope, describe their belief systems, evaluate their abilities to be introspective, appraise the solidity of their senses of self, and describe their most-used selfobjects. Such a framework would help caregivers provide appropriate and supportive care at each stage of a client’s hope.

Fostering Hope

There are six principles that may help caregivers foster hope among clients, make the process of dying as spiritually rich as possible, and help reduce caregiver discomfort around discussing eschatological hope. First, as their “this-worldly” networks of selfobjects shrink, patients face an increased need to reinvoke or develop anew “other-worldly” or spiritual selfobjects. In other words, as HIV disease gradually erodes the network of supportive selfobjects in the world, clients must develop more robust selfobjects within themselves. Their locus shifts. If we listen, patients will tell us what these selfobjects need to look like.

For example, one client with severe peripheral neuropathy could no longer work as a theater lighting designer, work that had been the locus of meaning and hope in his life. He began making pencil drawings of mythological fantasies, shifting his locus from external to more internal, from the stage to paper. Finally, his eyesight failed and he could no longer draw. He began talking more about life after life, using metaphors of light, shadow, color, warmth, and translucence. His locus of hope had moved largely into the realm of the eschatological.

Second, caregivers should form no opinions about their clients’ belief systems or eschatologies based on denominational affiliation. Many a Catholic has confessed to me his or her belief in reincarnation; many a Jew has affirmed a belief in heaven. When a client says, “I’m a Buddhist,” ask him or her to tell you what that means.

Third, caregivers who are atheistic, for whom any notion of continued existence after death is meaningless, can nonetheless be helpful to clients who believe in life beyond life. Perceiving a client’s eschatological beliefs as illusory is fine, as long as the caregiver understands that they are useful, functional illusions (and as long as the caregiver can respect the client’s perception of atheism as equally illusory).

I often find it helpful to liken spiritual conversation to hypnotic induction. The hypnotherapist induces the client into an hypnotic state using language and images and thoughts that the client already has. The goal is to achieve a state of deep relaxation. For example, as a client’s eyes become heavy from looking up, the hypnotist simply says, “Your eyelids are feeling heavy.” It is the empathy and tone of the hypnotherapist’s voice that helps induce the relaxation. Focusing on the eyelids is only a medium through which the hypnotherapist connects with the client; in a sense, it is inconsequential. Similarly, spiritual conversation is very much an “entrancing” dialogue. The purpose of the conversation is to help clients achieve a state of spiritual peace. Their images, metaphors, and thoughts need not be especially or even remotely mean-
ingful to you in order for you to use them to help clients achieve a deeper level of hope and spiritual peace, especially as they near the ends of their lives.

Fourth, “toxic” beliefs can usually be countered by antidotes from within the client’s own religious tradition. For example, what if a client believes he is damned—without possible redemption—based on a fundamentalist reading of Christian scriptures?

An Islamic client was once refusing pain medication during terminal stages of HIV disease. I asked him why he insisted on suffering so. He replied that Allah, a god of justice, was rightly punishing him for a wicked life. The next day, I asked him to help me understand Allah’s position. I gratuitously added that Christians believe in a god who is just, but also merciful. He became quite defensive and insisted that Allah, too, was a god of mercy, a god of great mercy. I furrowed my brow and asked, “So when is Allah going to show you mercy?” He looked flummoxed, hesitated, then blurted out, “Not yet!” The next day he took morphine.

Fifth, be prepared for radical shifts and looping. As much of the death and dying literature asserts, people do not progress in an orderly way toward acceptance of death. Hope is merely another dimension in this progression. Clients may say that they look forward to heaven one day and wail, “I’m afraid there will be nothingness!” the next. Just keep walking with them.

Finally, don’t worry about your clients “doing it wrong.” If a client begins talking about heaven early in their illness, just listen for what that means and assess what will facilitate his or her spiritual peace. If another client remains focused on this world until the last breath, that is his or her spirituality. Let it be.

What if a client cannot reach spiritual peace before death? What if he or she dies depressed or angry or anxious? First, the caregiver should not feel as though he or she has failed. Personality traits and mood disorders are deeply imbedded. Psychological resolution of serious pathology in the last year of life is just not likely.

Still the question remains, how do caregivers make peace with a client’s unpeaceful death? Each of us must answer that question out of his or her own eschatology. For myself, as a believer in a dimension of life beyond time and space where “every tear shall be wiped away,” I take comfort in eschatological resolution to these unfinished pieces of spiritual business. Others may simply take comfort in the fact that, at death, all earthly troubles cease even if nothing follows. There are no easy answers here.

**Conclusion**

The distinction between psychological and spiritual growth or healing is a Eurocentric invention. Most Eastern cultures countenance no such difference. Especially in our work with patients who are gravely ill, it may be best not to be confused by this academic separation.

One need not be depressed to understand and empathize with a depressed patient. Similarly, one need not be a Buddhist to understand the meaning of karma for a Buddhist client and to empathize with that client as he or she explores karma’s role in HIV disease. It is most important to remain flexible, to appreciate the need for eschatological exploration, and to keep as one’s focus the fostering of hope in whatever way helps clients through their illness to the ends of their lives.

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**Clearinghouse: Hope and Spirituality**

**References**


Pastoral counselors, then, should have a grounded relationship with God as they engage clients in an exploration of the role of God in their lives. To enter into a pastoral counseling relationship, however, does not imply or require clients to "believe," but simply for them to be available to explore those issues that are related to this "absolute reality."

Pastoral counselors are often ordained in a religious tradition; however, not all clergy are pastoral counselors and not all pastoral counselors are clergy. Many, but not all, clergy and lay people have specific training and certification in pastoral counseling. *Psychotherapists, unless specifically trained in pastoral counseling, should not attempt pastoral counseling, just as untrained pastoral counselors should not engage in psychotherapy. Referrals to pastoral counselors or pastoral counseling agencies can be found through hospital chaplains, local churches, social service agencies, and local AIDS service organizations.

### Encountering the Spiritual Issue

Sometimes clients raise spiritual issues in obvious ways: "Why is God doing this to me?" "What happens when you die?" "Is my son being punished because he used drugs?" "Why are so many of my patients so young?" Sometimes these issues are more subtle: clients may present with a pervasive but undefined sense of purposelessness, hurt, or anger; they may strive "to make sense of it all" 3; or they may use phrases such as "innocent victim" that suggest a judgmental attitude coming from a heartsick or angry place.

In pursuing the rarely achieved goal of a value-free approach to clients, providers trained in more traditional mental health
disciplines often scrupulously avoid raising spirituality, as though it had no bearing on clients' immediate concerns. But ignoring spiritual issues teaches clients that it is inappropriate to integrate these issues into their overall ecology of life concerns. Counselors may miss what may be a key organizing component of their clients' lives. At a minimum, secular practitioners need to ask questions like, "Does spirituality play a part in your life?" or, "Is your thinking about your disease shaped by your religious tradition?" If the answer is yes to these kinds of questions, then psychotherapists should consider a referral to a pastoral counselor.

Pastoral counselors approach clients not in a value-free way, but in a value-neutral way. They listen for and speak the language of "God-talk" while always encouraging clients to articulate their own spiritual concerns in their own vernacular. It is often helpful for clients to work with pastoral counselors within the same religious tradition—particularly if the tradition has a strong cultural identification embodied, for example, in the liturgies of Judaism or the botanicas (herbal and healing centers) of many Latino cultures. However, it is not necessary for pastoral counselors to share every view and value of their clients. Pastoral counselors, using the basic theories and techniques familiar to all counselors, create a context for discussing spiritual concerns and support clients trying to define, question, or re-evaluate what they have been taught or what they believe about their own relationship with God.

Healing versus Curing

Though traditionally considered only at the end of a life, pastoral counseling and care can be used to heal at any stage of life. The philosopher of science Rene Dubos wrote in 1978, "To heal does not necessarily imply to cure. It can simply mean helping people to achieve a way of life compatible with their individual aspirations—to restore their freedom to make choices even in the presence of continuing disease." Here is where we suggest pastoral counseling differs from the medical model of psychotherapy. The medical concept of "curing" is established by definition: we say cancer has been cured if we do not see the return of symptoms within X number of years. In most spiritual traditions, however, "healing" means simply "to restore to wholeness," and generally involves the songs, prayers, and incantations of an entire community of support. As Robert Sardello wrote, "Let us be clear: healing does not necessarily bring the individual release from disease; healing is not to be confused with cure of symptoms."5

Conclusions

We have suggested that in the age of HIV disease, clients often raise spiritual issues; that pastoral counselors bring a unique perspective to working with these issues; that the goal of "healing" in pastoral counseling is different from that of "cure" in more medical models; and that the task of pastoral counselors is to invite God and God's love into the relationship with the client. Only with deep respect both for God and the individual should this task be undertaken.

References


Authors

The Rev. Thaddeus A. Bennett, MDiv is a priest in the Episcopal Diocese of Los Angeles. He was the founder and Executive Director of the AIDS Ministries Program of Connecticut and the founder and President of the National Episcopal AIDS Coalition.

The Rev. Mark Henrichson, MDiv, MSW is a doctoral student in Social Welfare at the University of California, Los Angeles, and holds a National Institute of Mental Health AIDS Research Training Fellowship. He was the director of the AIDS/HIV Program for the Hartford, Connecticut Health Department and had a private practice counseling people with HIV disease.
Personal and Social Factors Influence Hope

A group of gay men reported generally high levels of hope, irrespective of their HIV infection status, according to results of the first phase of a longitudinal study of factors that influence hope. Social relationships that were emotionally and materially supportive had the greatest effect on the maintenance of hope.

Researchers queried 208 gay men about personal and social variables, psychological functioning, HIV serostatus, and symptoms in relation to levels of hope. Of these men, 124 were seropositive and 84 seronegative. Subjects were primarily White (87 percent), had a median and average age of 38 years, and were well-educated (62 percent college graduates) and financially well-off (median income $30,000-$35,000). At statistically significant levels, men who reported higher levels of positive social support and who perceived themselves as having an inner sense of control and a commitment to their lives were more hopeful.

Hopelessness was associated with clinically diagnosed depression, as measured by the Hamilton Depression Scale, but was more strongly related to self-reported depression among a larger group of subjects. Researchers found no association between HIV status or number of symptoms and levels of hope.

The Essential Need for Spirituality and Hope

Despite having to face a terminal illness, sometimes in isolation without societal support, a group of people with HIV disease were spiritually well and hopeful. The study found that existential well-being (a sense of purpose in and satisfaction with life) played a greater role in achieving hope and spiritual well-being than did religious well-being (a sense of well-being in relation to God).

A review of the sparse research on the subject found that hope is an essential component in sustaining life and positively affects treatment outcomes. It also revealed that both chronically and terminally ill people appear to have a greater spiritual perspective and to have made the most changes to achieve this perspective.

Following the review, investigators administered two questionnaires that measured hopelessness and spiritual well-being to 65 men, recruited at an outpatient HIV clinic. Spiritual well-being included both existential and religious dimensions. Of the subjects, 31 were seropositive, and the others were diagnosed with AIDS or ARC. Fifty-six percent were gay men, 18 percent were bisexual; the mean age of respondents was 35 years.

All study respondents scored high on measures of hopefulness, overall positive levels of spiritual well-being, and these two attitudes were significantly correlated to one another. People with AIDS were more hopeful than people with ARC. Overall hopefulness may have been related to the fact that subjects were being treated at a large, highly regarded research center with state-of-the-art treatment and therapy.

Both existential and religious well-being were predictors of hope, irrespective of HIV infection status. However, existential well-being had a much closer statistical relationship. The authors suggest that this may be true because of the common estrangement of gay people from organized religion.

Communicating About Death And Hope

Spiritual and emotional healing may occur through the dying process if clinicians and HIV-infected patients are able to communicate openly and honestly about the realities of facing a fatal disease and about the powerful HIV-related metaphors that confront both groups, according to a philosophical essay on relationships between clinicians and people with HIV disease.

Clinicians fulfill many roles as the needs of patients change. These range from parent, fighter, technician, teacher, and “covenanter” in response to patient roles of child, victim, consumer/manager, learner, and “covenanter.” Clinicians need to
ask their patients explicitly: “How do you want me to work with you?” By responding to expressed needs, the therapeutic relationship evolves, trust builds, and decision-making is truly shared.

Discussing death should occur early in treatment given the lethal nature of HIV disease, and discussions about the limitations and uncertainties of treatments can occur as the clinician-patient relationship deepens. These matters can be broached early on by bringing up Living Wills and Durable Powers of Attorney for Health Care. Clinicians should foster open communication about every aspect of HIV disease, including discussions of illegal actions such as active euthanasia.

HIV-infected patients must be able to talk with their clinicians about hope for the future. Honest discussions about the disease create a realistic hopefulness: by stating clearly and openly that they will be there to offer personal support throughout the course of the disease, clinicians offer more true hope than by assuring that death can be postponed.

In addition, by encouraging ongoing communication between patients and their circles of support, clinicians secure their patients’ involvement in living until death. By keeping the flow of communication in the support network moving, a mutuality of caring evolves. This keeps hope alive for all those involved. Fostering this kind of open and honest communication also results in preventive bioethics, an approach that proactively confronts bioethical conflicts—raised by issues such as euthanasia, limiting medical treatment, and encouraging hope—and in this way keeps them from emerging.

Religion and Death Anxiety
Franks K, Templer DI, Cappelletty GG, et al. Exploration of death anxiety as a function of religious variables in gay men with and without AIDS. Omega. 1990-91; 22(1): 43-50. (California School of Professional Psychology, Fresno County Department of Mental Health.)

Gay men with AIDS who were more involved in formal religion reported higher death anxiety, according to a study of religious variables and the response to death.

Study participants included 115 gay men from the San Francisco Bay area with a mean age of 36. Of these, 51 were diagnosed with AIDS and 64 were seronegative. The mean education level was 13.7 and 15.3 years, respectively. Study participants answered a 10-item religious inventory. Those with AIDS answered two other questions that self-rated their health status, while those without AIDS responded to two questions about knowing people with AIDS.

The mean death anxiety score (8.6) was higher for those with AIDS than without (6.5), but death anxiety for those without AIDS was greater than that reported by gay men in the pre-AIDS era. Among men with AIDS, higher death anxiety scores were associated with frequent church attendance, adhering to the religion of childhood, having no spiritual belief systems other than formal religion, and asserting that religion had done them more harm than good. Men with AIDS with “serious” health conditions also had high death anxiety levels. Having a strong religious conviction was the only religious variable associated with lower death anxiety in the men with AIDS. Among seronegatives, belonging to the same religion as in childhood was the only variable correlated with higher death anxiety scores.

Regardless of HIV infection status, adhering to childhood religion was most predictive of greater death anxiety, although having less education was also significant.

Next Month
People with mood disorders have a more difficult time responding to treatment for HIV-related psychological and physical conditions. HIV disease, itself, and its medications may lead to or exacerbate mood disorders. In the July issue of FOCUS, John Baker, MD, a UCSF AIDS Health Project psychiatrist and Associate Clinical Professor, examines the causes of and treatments for depression and mania, among the most severe mood disorders. He focuses in particular on the psychopharmacological response to these conditions.

Suicide may follow depression, but it may also be perceived as a rational choice unrelated to psychological distress. Also in the July issue, James R. Jones, MD, a UCSF resident in psychiatry, and James W. Dilley, MD, Director of the AIDS Health Project and Associate Clinical Professor of Psychiatry, present preliminary findings from a small study of HIV-infected men on the prevalence of rational suicidal thinking.
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