Caregivers of people with end-stage AIDS face beguiling challenges in working with the young, disabled, and dying as they try to help these individuals learn to live and die well. The average person with AIDS is between 28 and 40 years old, usually not the time when people have come to terms with their own mortality. Often just beginning to establish themselves, young men and women with HIV disease must incorporate a new and dramatic reality into their maturing sense of self. They must reconcile who they are and where they are going with the likelihood that they will have less time than they had anticipated to grow and “leave their mark on the world.”

In no other setting is this conflict so starkly posed as in the hospice, a place where people come to die: a place where resolution may occur leading to what providers often characterize as a “good death” or where it may not occur, leaving family, friends, and particularly caregivers with a sense of failure. In her studies of death and dying, Elisabeth Kübler-Ross describes death as “the final stage of growth.” This is the concept upon which hospice philosophy is based: death can be experienced as a meaningful stage of life.

Within this framework, it is the role of the hospice counselor to assist dying clients in moving toward “inner peace” and “self-possession”—the ultimate goal of “dying well.” In a residential hospice each member of the community can, in his or her own way, help to nurture these emotional adjustments in him or herself and in others.

The Corpus Christi Residence (CCR) in Pittsburgh, Pennsylvania is just such a place, a community-based residence for people facing the physical challenges of end-stage HIV disease. Individuals are admitted to CCR with an AIDS diagnosis and related physical and neurologic disabilities or both, disabilities that can no longer be accommodated at home. The residence offers medical, nutritional, social, psychological, spiritual and hospice services to people with AIDS, their families and significant others. It also offers the opportunity to abstain from aggressive medical measures, instead placing residents under the care of hospice professionals until their death.

Psychosocial Challenges

Counselors and other caregivers of people with AIDS rarely find their clients at the point of easily accepting impending death. Instead, they find them with the same defenses of most people—denial, anger, and depression—and at times, lacking the proper level of knowledge necessary for end-of-life decision-making and planning. The very nature of HIV disease can strengthen defenses that interfere with an acceptance of death. The progression of HIV disease over 10 or more years allows denial and anger to evolve as healthy coping strategies: denial becomes a means of living productively, and anger becomes a force for mounting the weaponry with which to wage the medical struggle. By the time a person experiences the physical decline of AIDS, these strategies may have become established beyond their usefulness and to such a degree that letting go of them may lead to an irrational fear of being left defenseless.

People with AIDS often look to their parents and families—both biological and chosen—to support them. Unfortunately, these individuals are sometimes unwilling
People with HIV disease are always living with HIV disease. It's hard to tell when an individual might start to die of it, and even harder to tell when the people around that individual should acknowledge that dying has entered the relationship.

At a certain point, we must all let go of living well and begin to consider a concept that Barbara Hines and Stephan Peura discuss, “dying well.” This can be a very attractive concept for both client and counselor: many of us associate the dying process with all the worst things, from pain to mental deterioration. But what does it mean to die well, and how can counseling near the end of life promote this outcome? How can people who are living truly understand what it means to the body and mind to let go of life?

Balancing Ignorance and Insight

Most counseling is client-centered, but perhaps hospice counseling is the most client-centered of all. The client must guide the counselor through his or her reality in order for counseling to be effective and for the counselor to play a useful role in helping the client die well—whether that means coming to terms with changes in functioning, saying good-bye to family and friends, or finding relief from pain. To do this, I suspect that counselors need to balance the ignorance of their clients’ reality with the knowledge of their clients’ personality, habits, hopes and dreams, former selves, and even inclinations to avoid or deny. As a client deteriorates, a counselor may become a client’s memory, offering a perspective of the past just as only the client can envision his or her future.

If dying well means putting visions of the past and the future together to attain clarity about the present, then this may be a model for hospice care. Dying well is a dangerous concept because it invites value judgment; as long as the values are the client’s, however, the goal of dying well can weave a safety net that may protect people who are dying from an uncontrollable fall into what may appear to be an unplumbable abyss.

or unable to provide support, or are themselves unable to accept the death of a loved one. The result is a lack of social support, leading to feelings of abandonment at a time when the circumstances most demand nurturing by friends and family.

In the residential hospice setting, staff face daily the need to respond to the dynamic nature of HIV disease in a community made up of residents, families, partners, volunteers, and other staff that is by definition extremely changeable. Reactions to the loss of functioning, the death of another resident, or the resignation of a staff member must be addressed by balancing the needs of residents with the functioning of the community as a whole.

Hospice staff must expect grief, denial, isolation, and depression to surface. In response, providers identify and arrange for appropriate interventions, approaches that do not differ from those that might be applied outside the hospice. What can be baffling is the unwillingness or inability of residents to utilize resources that caregivers feel will comfort and support them. From the caregiver’s perspective, opportunities to “live well,” deal with issues, and die with dignity may be met with refusal. As a result, destructive behaviors or avoidance may follow some clients to the grave. For other residents, cognitive changes may progress too rapidly for them to take advantage of services that might lead to a more comfortable and resolved death. Counselors must expect that each client will differ in his or her conception of “living and dying well” and the proper way to meet death. The journey toward inner peace and self-possession can be guided by hospice staff but must be directed by clients, their values and beliefs about life, spirituality, and how they wish to confront dying. By setting their beliefs aside, counselors can help clients explore their own ideas of life, hope, productivity, and death. To do this, counselors may have to confront extreme personal emotions about death and beliefs that they have only one, time-limited chance to “succeed” with their dying clients. Three case studies describe the hospice approach.

A Place to Confront Death

Alice came to CCR from the hospital when her parents could no longer care for her at home. Although a 40-year-old African-American male, Alice, a postoperative transsexual, had been living as a woman for many years. Her history included prostitution and many years of substance abuse. At the time of admission, however, Alice was in recovery and...
Provide hospice residents with emotional support, particularly since the decline and death of other residents may challenge the protective denial many HIV-infected people have developed in order to live in the shadow of a life-threatening disease.

References

had maintained sobriety for close to two years.

Upon admission, Alice was unaware of her specific illness. In fact, her parents requested that the staff refrain from using the word “AIDS.” Alice was frightened of her condition and had turned all decision-making power over to her parents. Alice’s father had survived a serious medical illness, and now Alice relied upon his “powers of survival” to help her survive HIV disease. A CCR staff member, hoping to help alleviate Alice’s fears, inadvertently mentioned AIDS during a discussion of treatment alternatives. In the meeting that followed, Alice expressed rage at being “condemned” with a terminal diagnosis by staff, and her parents accused the CCR administrator of betraying them. For them, Alice did not have “AIDS,” and mentioning the condition put Alice in danger and would certainly lead to her diminished health.

In response, the administrator emphasized that Alice did have AIDS, but that he would instruct the staff not to talk to Alice about this. He encouraged Alice to speak with her physician and get clear information about her condition. Soon after, Alice apologized for her extreme reaction. She explained that she now knew from her physician that she had AIDS, and she was ready to accept and deal with it.

Alice’s parents believed her acceptance of AIDS was a death sentence and their distrust of the staff remained strong. In the end, Alice relied on her parents’ denial to provide her with hope and to guide her choices for care. The staff was unable to convince Alice’s parents to accept her terminal condition and agree to hospice care. Instead, Alice was transferred from CCR to a nursing home for the elderly, where she died a short time later.

The staff experienced Alice’s discharge as a failure. To them, Alice had denied herself hospice services which could have helped her “die well.” But another perspective is possible. By identifying Alice’s level of knowledge about HIV disease, the staff provided information so that she might become active and informed in her care, and allowed Alice to understand and accept her AIDS diagnosis. Alice’s choice to accept her parents’ decision to fight her death allowed Alice to continue to receive their full support and involvement in her life up to the end. Although it meant leaving hospice care, for Alice this may have amounted to “living and dying well.”

A Place to Heal

Bill was admitted to CCR near death. At 5 feet 11 inches tall, he weighed only 118 pounds and was unable to eat due to severe esophageal ulcers. A 50-year-old African-American man, Bill had worked in an automotive assembly plant for 25 years while actively addicted to alcohol and injection drugs. A relapse after two years of sobriety had contributed to his medical emergency.

Gastric feedings supplied Bill with nourishment and despite his poor prognosis, he began to respond to medications. He gained weight and slowly began to eat. As Bill recovered, his energy level increased. Within three months, he gained 30 pounds and established a life outside CCR. Bill stayed at CCR and remained active in community, social, and recreational events. Aware of his potential for another relapse, Bill continued substance abuse counseling. Direct conversations about having AIDS, however, were challenging for Bill; he was able to admit that he was an addict, but stopped short of acknowledging HIV infection.

At first the staff tried to encourage Bill to attend support groups to help him address and accept his HIV disease, but Bill was resistant and denied the extent of his illness. Bill believed this strategy would keep him healthy. The staff felt that Bill would better respond to his health issues by accepting his disease.

Responding to both Bill’s inclinations and their own concerns, CCR staff encouraged Bill to become active in planning a local agency’s AIDS healing weekend. In helping to plan and attending the event, Bill met and came to know other individuals with AIDS in a positive environment. Participating in this way has helped Bill to become involved, on his own terms, in his diagnosis and healing. In the end, staff were successful in providing a therapeutic experience for Bill while taking into account his approach to his illness.
A Place for Community

Toby, a 45-year-old White man, was difficult from the start. He was admitted to CCR in advanced stages of AIDS and HIV-associated dementia. His demeanor was either grumpy or withdrawn. While staff were able to address his difficult behaviors, Toby's decompensation increased, and he was required to eat alone due to shocking behaviors, including spitting and urinating on the table at meals.

At community meetings, staff encouraged angry residents to separate the awful behaviors from the dying man, and to confront their own fears about dementia which arose in response to Toby's decline. Gradually, residents agreed to assist and monitor Toby in their own ways, taking turns sitting with him at meals, holding his hand at bedside when he became immobile. In the end, several once-irritated residents were able to wish Toby goodbye and missed him after he died. Toby's dementia became an opportunity for the staff to educate the entire community, helping residents accept difficult behaviors through education about dementia, and by encouraging a “there-but-for-the-grace-of-God-go-I” outlook.

Responding in the Hospice Environment

As these cases suggest, hospice is a place for the most severely ill to get support and comfort in a community setting. The first responsibility of hospice staff is to provide information about HIV disease, the hospice community, and end-of-life issues and planning.

Secondly, hospice staff should provide residents with emotional support to deal with HIV disease and death, particularly because the decline and death of others may challenge the protective denial many HIV-infected people develop in order to live in the shadow of a life-threatening disease. Counselors can assist by helping residents develop and maintain support systems made up of biological families, families of choice, the hospice community, and staff. In a setting where death is so present, spirituality and ritual may comprise a particularly valuable source of hope and emotional support. Residents and staff are encouraged to study and practice spiritual customs, and the expression of sorrow can be a comfort to the entire community and ensure residents that their deaths will not go unnoticed or unacknowledged.

Finally, until the end of life, productivity can provide meaning. Staff who come to know residents, their likes and dislikes, can assist them in finding and participating in the activities he or she finds productive and satisfying within his or her current physical and mental abilities.

Conclusion

Counselors and other caregivers of people dying of AIDS are faced with many challenges including dementia, denial, depression, anger, fear, and a reluctance or inability to accept death. In residential settings, further challenges arise as the community is affected by each death. The goal of hospice is to establish an environment that allows growth, communication, and achievement despite physical and emotional decline. The hospice setting is particularly powerful because it enables each individual to experience the full spectrum of life with all of it emotions while facing the reality of death.

Clearinghouse: Caring for Dying Clients

References


Hospice care seems a natural paradigm for treating HIV disease, a condition that shortens the lives of most people who are HIV-infected. Hospice care relies on a variety of approaches to heal the mind and the soul, if not the body. But while hospice care has been well-developed in the United States and the United Kingdom, it has in many ways overlooked a crucial tool in responding to the mental health needs of dying residents: psychiatry.

The first modern hospice was opened in the United Kingdom in 1967. In recent years, a variety of HIV-specific hospices have been developed in many countries, and people with HIV disease have been incorporated into more traditional hospices. Yet psychiatrists have been only occasionally represented on hospice staffs, and then only in a limited way. In the new world of managed care—which seeks to define very clearly the role of each professional participating in health care—psychiatry is vulnerable to being misunderstood and excluded.

Some of the psychiatrist’s responsibilities may be handled by other practitioners who are not able to provide a deeper understanding of the complex picture of organic brain dysfunction, side effects of medical or psychiatric drugs, effects of grief or of substance abuse, or the psychiatric effects of opportunistic infections or cancers. For example, hospice social workers and psychologists can assume the role of providing psychotherapy, hospice physicians are prepared by their training to prescribe psychotropic agents, except for perhaps the very newest ones, and all members of the staff—even volunteers—retain primary care interests in the people they treat. In the hospice setting, psychiatrists are most often used to take care of “disturbing,” unruly patients, and are expected to do so simply by prescribing sedative medication and not by seeking the social or psychological roots of psychological distress.

The Absence of Psychiatry

In order to study this situation and to understand more clearly the potential role of psychiatrists in HIV hospice care, I took the opportunity of a sabbatical year in 1993-1994 to visit a number of HIV hospices in the United States and the United Kingdom. While the hospices I visited were generally creative, comfortable places, they lacked the benefits of a psychiatric perspective.

I found that a well-trained psychiatrist, experienced in HIV-related and palliative care, could significantly improve the quality of life for a person in the later stages of HIV disease. A psychiatrist can understand the disparate causes of a given psychiatric problem and can evaluate and treat it holistically, that is, within the context of the complex issues I have described above. Too often a condition was simply written off as “AIDS dementia,” when a more careful and integrated analysis by a psychiatrist might have indicated a combination of causes that go deeper than this diagnosis: organic illness, substance abuse, the effects of bereavement, and the effects of HIV-related medications.
During the later stages of HIV disease, as brain dysfunction is more likely to arise and as impending death may challenge mental health, this kind of sensitive analysis is crucial to palliative care.

In the United Kingdom, the trend has always been to have inpatient bedded hospice, both traditional and HIV. The United Kingdom now has well over 200 inpatient hospices, nearly 400 home care teams, approximately 250 hospital-based support teams, and over 200 day care centers. Many of these programs treat people with HIV disease, although the mission of most of them remains the care of persons with cancer. In the United States, where there are well over 2,000 hospice programs, most are a combination of home and hospital-based support teams. There are only about 20 free-standing inpatient hospices, and very few day care centers. These hospices tend to be much less professionally focused than the British hospices, and few use psychiatrists. When asked about this, one hospice professional suggested that it was based on a wish not to “pathologize” residents’ problems.

I visited three inpatient hospices in the United Kingdom, two in London where the disease is primarily still in the gay community, and one in Edinburgh, where it is primarily among injection drug users. All of these programs offer client-centered care. For example, at London Light House, which was created by the gay community, staff make a great effort to create a “home-like” atmosphere: residents may bring pets and favorite furniture; staff encourage the active participation of lovers and family; and staff dress in street clothes. The residence also stretches the concept of hospice by including inpatients at many stages of illness, even very early when social, not medical factors, are the focus of distress.

There is no psychiatric input at any of these hospice. At London Light House, there is even skepticism about psychological treatment in general, and there are no psychotherapy groups. Instead, there are many complementary therapies aimed at mental health, including aromatherapy and massage therapy. Psychiatric medications are considered an aspect of medical care and are prescribed by physicians other than psychiatrists. Overall, while there is a tremendous sense of openness and caring, traditionally trained psychiatrists—and even psychologists and social workers—practice their craft only indirectly as consultants. Psychiatrists are not actively involved in American hospices either.

What happens when psychiatrists are not part of the active treatment team? The most significant shortcoming is that the treatment team lacks the perspective of a physician who is trained to evaluate both the physical and psychiatric pieces of the whole patient picture, enabling a more precise understanding of the effects of dementia, grief, opportunistic infections, substance abuse, the effects of HIV treatment, and the effects of psychopharmacologic agents. In hospices on both sides of the Atlantic, I believe that many of these issues were more accurately delineated because I participated in the process. Many psychiatrists in the United States are more than willing to serve as hospice consultants, whether voluntary or paid, yet they are not used because of the “guild” issues I allude to above. The time is ripe to make use of this tremendous resource.

Conclusion

To implement psychiatric care in a specific hospice, involvement might first be limited to consultation on individual cases. Then, as the usefulness of psychiatric assistance becomes clear, the psychiatrist might become more involved. This must be an active process, with the psychiatrist working not only to provide services but also to seek funding for these services and to provide evidence of long-term efficacy and economy.

In Philadelphia, we have convened a monthly meeting of 25 “Psychiatrists Concerned About AIDS.” We have met more than 20 times, educating ourselves about the discrete psychiatric issues of HIV disease as well as the political strategies for overcoming the exclusion of psychiatrists from acute and palliative care. By pooling resources and assisting one another, we are making inroads into resolving the split between psychiatry and hospice care.

References


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Comments and Submissions

We invite readers to send letters responding to articles published in FOCUS or dealing with current AIDS research and counseling issues. We also encourage readers to submit article proposals, including a summary of the idea and a detailed outline of the article. Send correspondence to:

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Recent Reports

Pain at the End of Life

Although guidelines for pain management extrapolated from cancer treatment have been helpful in the care of people with HIV disease, little is known specifically about the pain experienced by HIV-infected individuals. A small retrospective survey of terminal-stage AIDS patients suggests that pain is widespread in this population and that it is most common in the lower back and extremities.

Fifty patients—40 men and 10 women—from a residential hospice in Boston answered a series of questions about their pain experience including: location; intensity; quality; onset, variations, durations, and variability; manner of expressing pain; means that relieve pain; means that exacerbate pain; effects of pain; and plan of care to manage pain. Fifty percent of the sample had suffered a bout of *Pneumocystis carinii* pneumonia at least once; 50 percent had experienced other viral infections; 22 percent had experienced HIV-related cancers, and 20 percent had been affected by candidiasis. Applying this definition, researchers found the prevalence of pain among AIDS patients to be about 54 percent. Twenty of the 50 patients reported pain at the time of admission to the hospice, and 23 were able to describe the pain they had experienced in the course of their illness. As many as 15 of the patients were unable to rate their present level of pain on the given scale, although at least five of these patients reported experiencing pain at the time of the study.

Researchers asked subjects to rate such pain on a scale of 0 to 10. Reported levels of pain averaged 7.5. The range of “worst level of pain” was 6 to 10, with a mean of 8.6; the range of “best levels of pain” was 0 to 6, with a mean of 2.5. Subjects rated “acceptable levels of pain” as ranging from 0 to 6, with a mean of 2.1. Subjects most frequently reported pain in the lower extremities and back. Many of the subjects—36 percent—described pain as “aching”; lower numbers described it as “sharp” (16 percent) or “throbbing” (10 percent). The majority of patients reported that their pain could be relieved with medications; narcotic analgesics were four times more prevalent than non-narcotic analgesics.

Evaluating Palliative Care
Butters E, Higginson I, George R, et al. Palliative care for people with HIV/AIDS: Views of patients, carers and providers. *AIDS Care.* 1993; 5(1): 105-116. (University College London and Middlesex School of Medicine; and National Temperance Hospital, London.)

A user assessment of an HIV-related palliative care program identified problems in terms of symptom control, pain management, patient and family anxiety, and communication with health care professionals.

Subjects were participants in the Community Care Team (CCT), a program that provides physical, psychological, and spiritual support to people with HIV disease and to their informal caregivers. Services include symptom control, counseling, bereavement follow-up for families and caregivers, and education and advice on diagnosis, nursing, and terminal care needs.

CCT team members began by assessing the program themselves and identified 17 areas of service that formed the foundation of the program. Researchers then interviewed 19 patients and eight informal caregivers at home. They asked subjects to rate eight of the 17 areas, which included both physical and emotional care issues.

The CCT team rated symptom control, patient anxiety, and family anxiety as most important current problems in their services. Patients rated pain control, symptom control, and patient anxiety as the areas in most need of additional concentration, assigning marginally higher ratings to pain and symptom control than did CCT staff. Caregivers assigned high ratings to pain control, symptom control, patient anxiety, family anxiety, and communication of professionals with patient and family. Ratings of patients, caregivers, and the CCT staff were in close agreement, indicating that views of CCT’s providers reasonably reflected those of patients and caregivers.

Psychosocial Needs of Hospice Residents
Baker NT, Seager RD. A comparison of the psychosocial needs of hospice patients with AIDS and those with other diagnoses. *Hospice Journal.* 1991; 7(1): 61-69. (Cedar Valley Hospice, Waterloo, Iowa; and University of Northeast Iowa.)

Hospice residents with HIV disease require more staff support than do hospice...
patients with other illnesses due to their youth and social stigmatization, according to a small survey of hospice staff.

Thirteen staff members of Cedar Valley Hospice in Waterloo, Iowa—including nurses, psychosocial team members, and other staff—responded to a seven-item questionnaire evaluating whether residents with AIDS required more time than similarly aged residents without AIDS; whether more time was actually given to these residents and, if so, why; whether young residents in general required more time; and whether it was more stressful to work with residents with AIDS and, if so, why. At the time of the survey, the hospice population included 11 residents with AIDS and 36 non-AIDS residents. All of the AIDS residents were male, 22 of the 36 non-AIDS patients were male, and all residents were 50 years old or younger.

Residents with AIDS required face-to-face staff contact twice as often as residents with other illnesses and telephone contact two-and-a-half times as often. Nursing staff estimated that visits with these residents took 15 minutes to an hour longer. Ninety-two percent of the staff agreed that the extra time required was due to the special physical and emotional needs of residents with AIDS. Although social isolation was a commonly reported problem, levels of family support for residents with AIDS did not differ significantly from other patients.

Palliative Care for People with AIDS
Kuhl DR. Ethical issues near the end of life: A physician’s perspective on caring for persons with AIDS. Journal of Palliative Care. 1994; 10(3): 117-121. (St. Paul’s Hospital, Vancouver, Canada.)

An essay on palliative care identifies several emotional issues that come to the foreground as people respond to late-stage HIV disease and describes ethical issues for physicians dealing with pain and symptom management.

Many people with AIDS experience feelings of helplessness when faced with the multiple decisions surrounding an unpredictable condition. The inability to plan the course of one’s life with any certainty contributes to a sense of powerlessness at a time when many people already feel they have lost their autonomy to their illness.

Relationships to partners, family, and friends are complicated near the end of life. People with AIDS must define which relationships are important to them. The process of creating a living will may help to clarify this by forcing clients to assess current relationships in their lives and state explicitly what roles they wish these people to play throughout the course of their illness.

Palliative care should seek to enable individuals to exercise control. In doing so, practitioners should respect above all a client’s “personhood”—his or her ability to assume active roles, maintain routines, plan for the future. Practitioners should ask clients how they see themselves, what they would like, where they would like to receive care, and how they can best be helped in achieving personal goals.

Respect for dignity, autonomy, and individuality means helping clients exercise the right to make informed decisions about their own care.

Suffering, lack of control, and loss of dignity may raise ultimate questions of the right to die. Sometimes suicide is a desirable course of action for patients whose physical pain seems uncontrollable or whose emotional pain at losing control of their lives to their illness seems unbearable. Providers need to be prepared to confront these issues in order to help clients resolve them.

Next Month

Among providers and clients alike, there is an intuitive sense that depression is a reasonable and common response to being HIV-infected. But according to a review of the literature by Judith G. Rabkin, PhD and Robert H. Remien, PhD, this assumption is unfounded. In the August issue of FOCUS, Rabkin and Remien, both professors at Columbia University, find that depression is not correlated with disease stage, T-helper cell count, or HIV-related medication use. They also clarify when and among whom HIV-related depression is likely to arise and treatment approaches.

Also in the August issue, Bruce Victor, MD, Director of the Clinical Psychopharmacology department at California-Pacific Medical Center in San Francisco, discusses the reciprocal relationship between depression and sexual dysfunction. He describes the inextricable link between depression and sexual dysfunction, and how antidepressant use may both respond to sexual dysfunction by reducing depression and exacerbate dysfunction through biochemical interactions.
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