The Therapist and the Dying Client
Jeremy S. Gaies, PsyD and Michael D. Knox, PhD

Psychotherapy with the dying is especially challenging when clients are young adults as are many people with HIV disease. Despite its difficulties, however, such counseling frequently offers both patients and providers opportunities for growth and for learning to live more fully.

HIV-related psychotherapy does not require special expertise. However, modifications in therapeutic approach are appropriate to meet the challenges posed by the life-threatening aspects of HIV disease. This article defines therapeutic concerns for HIV-infected people facing death, adjustments therapists must make to meet these concerns, and psychological issues for therapists treating people with HIV disease.

Psychological Issues of the Patient
HIV disease shares several characteristics with other life-threatening illnesses, most notably the progression toward death, the multiple physical, emotional, functional, and economic losses, and the process of psychological adjustment. Much attention to psychological responses to terminal illness has focused on stage theories, especially that proposed by Kübler-Ross. While recent theorists have questioned the conception of these responses as fixed, Kübler-Ross's five stages—denial, anger, bargaining, depression, and acceptance—are of great clinical significance when viewed as positive functions of the psyche coping with the emotional demands of the illness. Denial, for example, serves a critical protective function in allowing an individual to survive the stress of catastrophic information. Allowed to progress without impediment, denial will typically and gradually fade toward realistic assimilation of complete information.

There are also striking differences between HIV disease and other terminal diseases. Among these are the intense stigma and blame associated with AIDS, the infectiousness (in particular, the sexual transmissibility of HIV), the epidemic nature of infection, the youth of patients, the roller coaster course of illness, and the process of psychological adjustment. Much attention to psychological responses to terminal illness has focused on stage theories, especially that proposed by Kübler-Ross. While recent theorists have questioned the conception of these responses as fixed, Kübler-Ross's five stages—denial, anger, bargaining, depression, and acceptance—are of great clinical significance when viewed as positive functions of the psyche coping with the emotional demands of the illness. Denial, for example, serves a critical protective function in allowing an individual to survive the stress of catastrophic information. Allowed to progress without impediment, denial will typically and gradually fade toward realistic assimilation of complete information.

These characteristics of HIV disease suggest psychological issues that may be grouped into three constellations. One constellation is loss, including losses of function, health, independence, financial security, standard of living, social support, sexual freedom, mental functioning, and normal life span. A second is stress, including that associated with uncertainty of information, uncertainty of prognosis, discrimination, stigma, guilt, and anger. Much of this stress is related to rational and irrational fears of rejection, abandonment, pain, disability, loss of mental control, and transmitting HIV. A third constellation focuses on issues related to terminal disease such as fear of death and dying, and existential and spiritual aspects of life and death. A client's emotional response to these concepts will affect his or her response to the later stages of disease: a person who perceives death as a peaceful escape from mortal existence will respond differently than a patient who sees death as painful, punishing, or empty nonexistence.

Within these constellations, issues may vary in importance for different individuals and in intensity over the duration of the illness. For one person, the most significant concern will be the loss of financial resources, for another it may be the experience of physical pain or the desire to plan the funeral. Issues will change over the course of disease, as will the content of specific concerns, for example, sexual relationships or mental functioning. Appreciation of the variability and range of responses and needs among clients with HIV disease is one of the most essential aspects of the psychotherapist's preparation for providing quality care. It is particularly important for therapists to note two aspects of HIV-related care. First, patients tend to seek therapy, even at late stages, to handle immediate needs rather than chronic concerns. Second, by the time they have reached terminal stages, many patients with HIV disease have resolved philosophical issues related to mortality and are confronting practical concerns related to dying.

Therapeutic Objectives
Although the focus of psychotherapy will vary over time, objectives always include fostering realistic hope, reducing stress, and helping the client to attain a measure of control. In the later stages of illness, for example, therapy may provide an opportunity for terminal care decision making, and funeral and memorial planning. Making decisions and taking charge of the final details may enhance client autonomy at a time when other aspects of life seem out of control.

By confronting with dying clients the fragility of life and the value of each day, therapists begin to confront the vulnerability of their own lives and to acquire a deeper appreciation of living.

Because the emotional intensity of terminal HIV disease threatens the objectivity of practitioners, therapists are encouraged to use a structured assessment framework. The framework should be comprehensive, to ensure that issues regarding dying are not missed, and objective, to ensure that the framework is not biased toward one view of death. Among the factors assessed in a comprehensive framework are personality profile prior to illness, coping skills and styles, hope, realistic awareness of the severity of the illness, cultural and religious background, social support, self-esteem, suicide risk and other self-destructive behaviors, compliance with care, and mental functioning. To develop a comprehensive assessment, counselors should be sure they have a thorough understanding of the key issues for people with HIV disease.

Unlike most people with terminal illnesses, a high percentage of people with HIV disease experience neuropsychological impairment. Clients frequently raise concerns about loss of mental functioning. Neuropsychological assessment is often warranted to identify cognitive strengths and weaknesses and to differentiate organically-based from depression-related cognitive impairment. To avoid complications related to mental incompetency, therapists should encourage clients to deal with continued on page 2
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legal, financial and health care planning and documents, such as wills, durable powers of attorney for finances and health care, and medical directives or “living wills.” With more significant impairment, the therapy process itself must change, with increasing adjustment toward supportive therapy and psychosocial case management.

Adjustments in Process
Therapists must learn to be flexible when counseling people with HIV disease in the late stages of illness. Symptoms of terminal illness, which often make regularly scheduled weekly appointments in the therapist’s office difficult, may require home visits, hospital visits, and telephone sessions. Therapy may need to be interrupted at times depending on the patient’s physical condition. Lack of time precludes long-term approaches, and patients frequently require greater encouragement and direction to achieve necessary tasks of closure and planning in the limited time available.

Treatment flexibility also means being open to supplementary, alternative, and modified techniques, such as art or other creative therapies, family therapy including members of a gay client’s friendship network, and the use of touch. Limited physical contact is often appropriate when clients are struggling with issues of rejection, physical disfigurement, and irrational concerns regarding infectiousness. Briefly holding a client’s hand or allowing a hug at the end of a session is sometimes appropriate, while strict avoidance of physical contact can confirm a client’s fears that there is a reason to reject or be afraid of him or her. Adaptable therapists may also have to assume the responsibilities of mental health case managers or advocates. This decision must be based on the specific needs of patients. In general, as patients begin to lose independence, the tasks of case management increase. These tasks may include monitoring health care, ensuring social service involvement, helping to gain access to entitlement programs, and activating and supporting family and friends to care for the patient.

Because people with HIV disease tend to become financially insolvent during the course of the illness, there is often a need at later stages to lower rates of payment and to offer free treatment when health insurance is unavailable. Since therapists, especially those in private practice, are dependent on client fees, it may be advisable to set reasonable limits on the number of people with HIV disease in treatment at any one time. If appropriate, biweekly sessions might allow continued therapy while reducing the financial burden on both the client and counselor. Whatever procedure is chosen, it is imperative that therapists raise this issue with clients at regular intervals and, at all costs, avoid any situation that may be experienced by the client as abandonment.

The Therapist’s Psychological Issues
Conducting psychotherapy in general can be emotionally taxing for therapists. The additional challenges of treating clients who have a stigmatized disease and are the same age or younger than the therapist can be significant. For gay therapists, many of whom have lost loved ones to HIV disease, and for seropositive practitioners, the issue of identification is even greater. Maintaining a true sense of presence with the client while maintaining separation from the client’s life is critical to the psychotherapeutic relationship. Therapists can best attain the strength to be present and the objectivity to be separate by developing and enriching their own personal lives.

This balance may be threatened as the client becomes more physically ill and nears death, and the therapist experiences some degree of anticipatory grief. Anticipatory grief is a normal reaction, even for a therapist serving in a professional capacity. It is the intensity of the grief and the adaptive response to it that should be considered. The most effective response for therapists may be to acknowledge that they have feelings about the lives and deaths of their clients. It is also essential that the therapists understand that the process of dying and the psychological response to dying (both the client’s and the therapist’s) are natural and should be supported rather than manipulated, avoided, or suppressed.

Therapists may benefit from practicing techniques for minimizing burnout. Burnout prevention includes setting reasonable goals for therapy and for the therapist, learning to be patient, maintaining a diversity of activities outside of therapy, and finding support in one’s personal and professional life. Some form of therapist support group, including a networking or educational group with a social component, may be helpful. Employing a co-therapist for group work can be an excellent way of maintaining both support and objectivity. Other burnout prevention skills include using humor, practicing relaxation, exploring one’s own feelings regarding mortality and life meaning, identifying achievable goals that add a sense of purpose to work, and focusing attention every day on personal fulfillment.

Coping with the death of a patient can be a new and threatening experience, and there is little societal support for therapists working through grief about the death of a client. The most important way to cope with this loss is for therapists to be sure that they say goodbye to clients. Saying goodbye may mean actually speaking to a client before the client’s death, lighting a memorial candle, setting aside a few moments for private thoughts, or attending the client’s funeral.

Finding Inspiration
Providing psychotherapy to people facing the challenges of a life-threatening illness can be inspiring work, offering therapists, as well as clients, the opportunity to grow and live more fully. By sharing a client’s experience of confronting the fragility of life and learning to cherish each day, for better or for worse, therapists begin to confront the vulnerability of their own lives and to acquire a deeper appreciation of living. Therapists also witness the psychological power of courage, hope, and faith. These responses awaken therapists to the great potential of human beings to adapt to life changes, an awareness that serves the therapist as an individual as well as a professional.

Jeremy S. Gaies, PsyD is Clinical Assistant Professor of Community Mental Health at the University of South Florida's (USF) Florida Mental Health Institute, and Staff Psychologist with American Biodyne, Inc. Michael D. Knox, PhD is Professor, Chairman of the Department of Community Mental Health, and Director of the USF Center for HIV Education and Research.

References

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San Francisco, CA 94143-0884
Making Terminal Care Decisions

Jeanne Parker Martin, RN, MPH

People with HIV disease should consider their options for terminal care early in the disease process to avoid the pressures of medical complications, such as AIDS dementia complex, and psychosocial concerns, such as diminishing financial resources. It is generally accepted that a patient is "terminally ill" when disease prognosis is six months or less, so the notion of terminal care should not be limited in conception to the last few weeks of life. If considered early enough, people with HIV disease may have several options about where they die and under what conditions, including in hospitals, at home, and in group residential facilities.

Factors to Consider

Where does the individual want to die? The place where someone dies may be determined by factors out of a patient's control. A good first step is to identify, through direct questioning, whether a patient has a preference about where he or she dies. Caregivers may find that patients will be relieved, instead of dismayed, by a direct approach to terminal care issues.

Does the patient want aggressive curative therapy or palliative hospice care during the final months of life? Patients in the terminal phases of illness may choose to seek curative therapy that will extend life, even when practitioners predict that these therapies will have little effect, or patients may choose only palliative care, aimed at reducing discomfort but not at fighting disease progression. Patients seeking a curative therapy may have fewer options about where to die because treatment may require special equipment and care. On the other hand, palliative therapy, which forms the basis of the hospice philosophy of care, can be provided in the patient’s home, as well as in hotels, group residential settings, hospitals, skilled nursing facilities, and other sites.

What type of insurance or financial resources does the patient have now and expect to have during the final six months of life? The type of insurance coverage a patient has, and whether or not it changes over the course of illness, will allow access to different care options. Private insurance policies cover medically necessary care in hospitals and, increasingly, in home care settings. Most private insurers want to provide appropriate, cost-effective care and will consider options—such as home, hospice, and residential care—even if they are not specified in their policies.

Low income or indigent patients may become eligible for Medicaid (Medi-Cal in California), which pays for acute hospital services, skilled nursing facility care, and intermittent home health care. In some states, Medicaid may pay for group residential care, extended hour attendant or nursing care, and hospice care. Older and disabled patients may be eligible for Medicare, which covers acute hospital services, short-term skilled nursing facility care, intermittent home health care, and hospice care, but does not pay for group residential care, or extended attendant or nursing care.

Loss of job-related income, costly medications, and routine expenses such as food and shelter may diminish financial resources. Assets such as cars and homes may be sold to help pay for insurance premiums or other health-related expenses, but patients should consider how such sacrifices will affect quality of life.

What human resources are available to assist as the patient's physical or mental status deteriorates? Patients who prefer home care may be able to facilitate this care, even without insurance coverage, by organizing friends and relatives to provide round-the-clock support. This type of care requires a cohesive and reliable network of volunteers, as well as one or two individuals who are available to help organize and run this network. In addition, patients and their caregivers should consider how support services from community programs can provide additional assistance.

What cultural and religious distinctions should be considered? Patients should give credence to their own cultural and religious beliefs about death and where to die. Lack of adherence to these cultural mores may make the dying process difficult and have lasting emotional consequences for survivors.

Hospital Inpatient Care

Before they die, people with HIV disease may experience multiple episodes of acute illness requiring repeated hospitalizations. Although the focus of hospital care is generally rehabilitation to prior level of functioning, some individuals require hospital care as disease progresses and conditions deteriorate. To deal with the needs of dying HIV-infected patients, hospitals may offer designated specialty units, skilled nursing facilities for patients with long-term inpatient needs, and inpatient hospice units.

Because hospitals offer care around the clock, some may feel that this is the safest environment for people whose conditions are deteriorating. They also may find a medical setting, where expert care is readily available, to be comforting and may fear that, if a patient remains at home, family members will not provide the "right" care to deal with medical emergencies, pain, or death itself.

Individuals should make terminal care decisions when mentally competent and with the help of health care professionals.

Home Care

When offered adequate physical care and emotional support by either family, friends, or professional caregivers, most individuals choose the familiar surroundings of their homes for terminal care. Whether receiving short-term, intermittent care, extended nursing care, or hospice care, home care is most often provided by a coordinated professional health care team.

This team generally consists of the patient’s attending physician, nurses, social workers, home health aides, attendants, and counselors, and addresses both physical and psychosocial needs. Specialty services, such as intravenous therapy, total parenteral nutrition, and respiratory care can be provided by most home care agencies and may be needed even during terminal phases. While family or friends may provide all or part of necessary terminal care, they usually require professional instruction, and supervision.

Group Residential Care

Some communities have developed group residential hospice facilities. These home-like facilities are cost-effective because they consolidate services, such as round-the-clock attendant and nursing care, and deliver them to patients who would otherwise have to use more expensive hospital settings. Despite this, group settings often are not covered by public or private insurance programs. Skilled nursing facilities and nursing homes, while appropriate for terminal care, provide limited access to people with HIV disease.

Conclusion

Under the best circumstances, individuals will make terminal care decisions while they are mentally competent and with the help of health care professionals. They should also assign to trusted friends or relatives decision-making rights under durable powers of attorney for health care and include these people in terminal care planning. This preparation is important, because the practical aspects of terminal care are as influential in determining a patient’s comfort with dying as is his or her spiritual approach to death.

Jeanne Parker Martin, RN, MPH, Executive Director of Hospice Programs for Visiting Nurses and Hospice of San Francisco/PPMC, writes and lectures often about HIV-related out-of-hospital care.

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Recent Reports

Death Anxiety and Religion. California School of Professional Psychology-Fresno, and Fresno Department of Mental Health (Omega: Journal of Death and Dying, Vol. 22, No. 1, 1990-91).

Findings from a survey examining death anxiety and religious beliefs contradicted an earlier study that found that cancer patients were less anxious about death than control group members. In the new study, gay men with AIDS were more anxious about death than uninfected gay men.

The current study consisted of 51 men with AIDS who had been diagnosed a mean of 9.7 months earlier and 64 men who stated that they were not HIV-infected. Participants were from the San Francisco area and were a median of 35 years old; subjects with AIDS had slightly lower levels of education. The men with AIDS had a mean Death Anxiety Scale score of 8.6 compared to 6.5 for uninfected men, and this difference was statistically significant.

For men with AIDS, higher death anxiety was associated with the belief that religion had done more harm than good, with greater church attendance, and with adherence to the religion of their childhood, but not with intensity of religious conviction. In fact, subjects with AIDS who had greater strength of religious conviction displayed less death anxiety than those without such convictions. Among uninfected men, the only significant correlation between death anxiety and religion was that those who belonged to their childhood religion displayed higher death anxiety.

Subjects with AIDS attended church more frequently than uninfected individuals, were more likely to have spiritual beliefs associated with formal religion, and were twice as likely to have had the same religious affiliation since childhood. Seventy-six percent of the people with AIDS believed in life after death, compared to 92 percent of those without HIV disease. The researchers state that the small sample size and preliminary nature of the study limits its validity.


Anxiety and fear of death can be reduced by maintaining a "floating" perspective, according to a philosophical treatise on the subject. Such a perspective, in which an individual is aware that there can be no absolute knowledge of death, encourages a person not to settle on any one view but to maintain an ongoing inquiry about the nature of death.

The author defines "death" as the complete absence of life, and, therefore, as something that cannot be experienced. The floating perspective suggests a flexible and open-ended way to view death. It avoids seeking closure or control, or viewing death as leading to the attainment of an outcome, such as spiritual transcendence or after-life. Anxiety associated with such an acceptance of the conditions surrounding death can be seen as something positive, as a wellspring of creativity or a meaningful part of life. This approach becomes an ongoing personal inquiry, changing as life changes, but never dominating it.

The floating perspective contradicts many cultural approaches to death, particularly among those in the Western world. Westerners construct rigid views of death because they cannot resign themselves to a fate over which they have no control, and they seek proof of survival after death out of a fear and a belief that life is futile.


Researchers comparing hospice care to hospital and home care found significant differences in the types of patients using each option and the kinds of care they received.

The broad-based British study compared 45 cancer patients who received hospice care to 126 who received conventional methods of care. Interviewers visited the homes of patients after they died and spoke to the person who knew most about the individual's last year of life.

Hospice patients experienced fewer medical interventions of a curative or investigative nature as they approached death, and 30 percent of the hospital patients had an operation on their last admission to the hospital compared to none of the hospice patients. Hospice patients were less likely to suffer from conditions other than cancer. Patients receiving a significant amount of hospice care were as likely to die in hospitals as other patients but were more likely to know that they were dying.

Physician care for 91 percent of the hospice patients was rated as excellent, compared to 40 percent of the conventional care patients. Ninety-six percent of the hospice group rated nursing and other staff care as excellent, compared to 57 percent of the others.

AIDS Health Project Film To Be Broadcast. Absolutely Positive, produced by San Francisco filmmakers Adair & Armstrong in association with the AIDS Health Project, is a powerful introduction to the world of healthy seropositive people, individuals whose concerns have received little media attention but who make up the majority of people affected by the epidemic. Absolutely Positive will air on public television channels throughout the United States on June 18 as the premiere broadcast of the PBS documentary series P.O.V. Check your local listings for exact date and time.

Next Month

It has almost become a cliche that, without a cure for HIV disease, prevention remains the most important health intervention. Sexual behavior change, the primary prevention message, is promoted on subway platforms, in television commercials, during health education classes, and in counseling sessions. HIV transmission would be eradicated if educators were as successful in ensuring compliance with these messages as they have been in ensuring exposure to them. In the June issue of FOCUS, Deborah A. Cohen, MD, MPH, Assistant Clinical Professor of Family Medicine at the University of Southern California, reviews and evaluates the range of approaches to safer sex promotion, including environmental, individual, and group counseling strategies.

Condom use is perhaps the most prominent component of safer sex messages. Also in the June issue, Philip Kestelman, MA, MSc, formerly of the Planned Parenthood Federation in London, examines how condoms are evaluated for impermeability to HIV and discusses some misconceptions about condom use.