HIV and Dying:
The Challenges of Caring
Avi Rose, LCSW

In August 1985, I began doing HIV work, starting as a social worker at AIDS Project Los Angeles. In May 1994, Bruce Priebe, my partner of 10 years, died of AIDS. I write this article from both a professional and intensely personal perspective, with the hope that it will be helpful to those readers who are or will be personal caregivers for people with HIV disease, as well as to those who are in a position to lend professional support and wise counsel as caregivers to the caregivers.

Having known hundreds of people who have lived and died with AIDS, I have seen individuals and families at their best and their worst. I have been warmed by witnessing the whole-hearted support of large caregiving networks of family and friends and have been sickened by watching people suffer abandonment, rejection, and isolation. I have experienced first-hand what it is like to travel the whole journey with the person I loved most in the world: from testing positive through exhilarating optimism and activism, crises and hospitalizations, dying and death, and now the ongoing process of grieving.

In this article, I focus on the period shortly before death: what is especially difficult for caregivers at that point and what is most helpful? While caregivers find themselves in widely varying situations with a whole range of financial, emotional, and other resources, I believe that when a loved one is dying, we all have a tremendous amount in common.

As death approaches, there tend to be more caregivers involved, some professional and some personal. While some points may apply broadly to this wide circle of caregiving, this article focuses primarily on the concerns of the closest personal caregivers: partner or spouse, parents, siblings, or intimately close friends. In this inner-most circle of caregivers, it is critical that all who are “family” are seen and respected as such. Family members who are not necessarily accorded legal status, such as gay or unmarried partners, need to take legal steps—for example, creating wills and durable powers of attorney—to underline the primacy of their relationship. When they have not taken such steps, it is especially important for health and mental health professionals to unequivocally acknowledge and honor people’s primary relationships.

Acknowledging the Approach of Death

It is not always clear when someone is dying. Sometimes, even if a loved one has been in a serious and steady decline with wasting, disorientation, and a cascade of other symptoms and infections, it can be hard for the closest caregivers to see, or to admit, what is going on. If this is the case, it can make a tremendous difference for physicians, therapists, or friends to speak the truth, acknowledging the approach of death gently but clearly. The language and the degree of bluntness will be different for different people, but the point is, don’t wait to say what needs to be said.

The last stages of illness usually occur after a long period of debilitation or, as was true for Bruce, after a long period of unpredictable ups and downs. As we approached the end of Bruce’s life, I was already exhausted, physically and emotionally. It was not easy to switch gears and summon whatever reserves still existed inside of me, but I knew it was absolutely necessary to do so. I knew that whatever I did during those last days
would be with me for the rest of my life. I put aside whatever could possibly be put aside and favored instead what was enduring. What really matters as death approaches is being fully present with an open, if breaking, heart.

Taking Care of Yourself

Taking care of yourself is an essential tenet of caregiving. By the time death is imminent, many of us have already learned this lesson, but in the fray of those last days, it is important to remind yourself and to be reminded by others. Remember to eat and sleep. Get some exercise. Ask for help. Express the full range of your feelings. Be clear about priorities. Cut down on non-essential activity. Don’t expect yourself to be perfect.

With my own partner, I did not know until the last three days of his life that his death was imminent, but we both understood for a month or so that it was approaching. Two weeks before Bruce died, a visit by his mother and sisters offered me the opportunity to get away for a few days of desperately needed respite. I went to a beautiful and peaceful environment to take care of myself—and felt totally miserable and unrelaxed. I called home three times a day to check in. I was supposed to be taking care of myself, but at that point, it was much harder to be away than to be at home taking care of Bruce. I realized that there are no pat techniques for support; the old prescription for “getting away” was not right for me at that time. Instead, being honest with myself about my needs and feelings was crucial. It is important to take time out, but that needs to be balanced with an appreciation of the need to be close by.

Mobilizing the Support of Others

Caregiving is best done with the support of others. Although some have managed to mobilize last-minute support networks, the end is not a good time to make new personal connections or to start a support group. Under the best circumstances, a caregiver has built a solid foundation of support, and if so, this is the time to rely upon it. In the absence of such a foundation, professional caregivers—home care nurses, hospice social workers, case managers—assume an even more important role than they otherwise would.

Bruce and I called on our family and friends for support from very early on, first gathering people together for that
specific purpose nearly two years before he died. At that time, we already needed intermittent help with meals, transportation to medical and other appointments, legal and financial issues, responding to piles of medical bills, and general problem-solving. For the most part, we took care of matters ourselves. But simply knowing that additional assistance was available if we really needed it helped us feel less pressured and beleaguered.

To the degree that there is a support network of family members and friends, there are many practical tasks they can take on as death approaches, either by doing them directly or by mobilizing others to do them. These include preparing meals, screening phone calls and keeping concerned people updated, taking care of children, arranging transportation and housing for out-of-town family members and friends, handling situations with family members who need extra attention or are causing problems, going to the pharmacy, taking care of pets, or taking a primary caregiver out for a meal or a walk. Friends are usually grateful and relieved to be given meaningful tasks. It is ideal to have one or two main task-organizers who can do a survey of the necessary tasks and who know the skills, personalities, and schedules of other folks.

In the midst of all this support, primary caregivers need to maintain some sense of competence. As death approaches, there are an increasing number of things over which we have no control. Or, to put it differently, the nature of what we can meaningfully affect keeps shifting. Caregivers cannot be rescued from feeling helpless in the quest to keep a loved one alive, but others can assist them in feeling that what they can do is helpful and meaningful. It is, in fact, tremendously meaningful to feed someone a meal, to keep track of medications, to help the dying person feel more comfortable by changing pillows or giving a foot massage. Doing simple, seemingly mundane things can take on profound meaning as death approaches. It was among the most powerful experiences for me simply to sit quietly or lay down holding Bruce, sometimes talking quietly to him, sometimes just breathing together in silence.

Empowering the Dying Person

While caregivers may take on a great deal of responsibility during the dying process, they must remain clear about fully respecting the autonomy and decision-making capacity of the person with HIV disease as long as it is possible, which is sometimes until the very last moment. Caregivers may need to encourage their loved ones to express their needs and desires as they arise and continue to change.

Of course, this can be severely complicated by the presence of neurological impairment and dementia. Caregivers need to be honest and sensitive in assessing someone's degree of confusion, and may need help from the professional caregivers in doing so.

Well in advance of late-stage illness, preparing legal documents such as wills, durable powers of attorney for finance and health care, and nominations of guardianship as well as making funeral arrangements are not signs of fatalism, but acts of empowerment ensuring that what the seropositive person wants will in fact happen. This is particularly important if he or she becomes mentally incompetent or in situations where different parts of a family are at odds with each other. Caregivers can help their loved ones define and memorialize their desires early in the course of illness, but as death approaches, there can be no further delay. Even an informal handwritten statement of the person's intentions, signed by the dying person and witnessed by two others, is better than nothing at all.

Abiding by the dying person's decisions can be severely complicated by the presence of neurological impairment and dementia. Caregivers need to be honest and sensitive in assessing someone's degree of confusion and may need help from the professional caregivers in doing so. Bruce became intermittently confused as he got closer to death. Real and imagined conversations, dreams, memories, and television increasingly seemed to blend in with each other. However, when a major decision required his attention, he was nearly always able to focus. I needed to tune in carefully to what he expressed and saw as important, still respecting his wishes in the midst of his confusion.

Family Dynamics

Family conflicts at the time of someone's dying or immediately following a death are the most bitter and disheartening conflicts I have witnessed. Disagreements may occur within biologi-
cal families, or between a person’s family of origin and chosen family. It is important to distinguish between conflicts that arise out of misdirected grief, which can lead to deeper emotional expression and understanding, and long-standing rivalries and rejections, which may defy any attempt at amelioration. With misdirected grief, a professional caregiver can play a critical role in helping people feel their pain and grieve, rather than acting out their pain in ways that are destructive to themselves and others. With rivalries, individuals can sometimes be held in check so that the damage they do is diverted or at least minimized.

There is no magical solution for avoiding the ugliness that can come when one part of a family shows outright disrespect for another part. Some situations are beyond mediation, and it may be critical for a caregiver or caregiving professional to lay down strict rules of conduct, and when these fail, to exclude people. You might need to tell a close friend that he cannot visit the hospital if he has been using drugs or a sister that she cannot come to the house if she can’t treat her gay brother’s partner with respect.

In both my professional and personal experience, I have seen far more good family support than ugly rejection. Bruce’s parents and sister were with us when he died and stayed for most of the following week, attending a memorial service presided over by a rabbi. A week later I flew to the Midwest to be with them for their hometown memorial service in a rural Baptist church. The differences in our cultures were evident in these rituals and in so many other ways, as it was when Bruce was alive. Fortunately, I did not have significant differences with Bruce’s family of origin about homosexuality, beliefs about afterlife, or money and possessions. The open expression of emotion and verbal nature of Bruce’s and my circle of friends was different from what Bruce’s parents and sisters were accustomed to, but they deeply appreciated all the love and support that was extended to them. It helped them return home to grieve more openly and fully with their own community than they otherwise might have been able to do. Among all of us, there was (and still is) enough love, familiarity, and respect to transcend and actually value our differences.

Conclusion
For a long time, I have felt baffled by the phrase “death and dying.” Why is it put in that order when dying obviously comes first? I have learned through my years of talking with so many people as they have looked toward the end of their lives that it is, in fact, easier to reconcile with death than with dying. Death is final; dying is uncertain. Death happens in a moment, dying can go on for weeks or even months. Dying can be painful and messy, and nothing—not even death—is more frightening. Perhaps we put death first in our accustomed phrase, because, ironically, it is easier to comprehend.

It is no accident, then, that many of us feel lost in the dying process. However, I know from my own experience that in the midst of the most intense pain I have ever felt, it was possible to be fully present, to feel the whole surprising range of my emotions, and to stay clear about how to care for myself and for Bruce. Knowing that the last days of Bruce’s life were filled with the best and most loving care possible will make a profound difference to me for the rest of my life.

Clearinghouse: Death and Dying

References


The Dying Process
Stephen E. Follansbee, MD

Those people with progressive symptoms of HIV disease usually travel a long road toward disability and death. For many, an HIV diagnosis itself and each little physical insult that follows is part of the process of dying. But physiological dying is a very specific and active process that occurs only towards the end of life when the body’s systems begin to fail. This is an important psychological insight because it affirms that for most of their illness, people with HIV disease are, in fact, living.

Categories of Dying

It is useful to think of dying as encompassing four “categories,” two of which are primarily psychological and two of which are primarily physical.1 In response to the initial HIV diagnosis, an individual may begin the psychic process of accepting death. Sociologic dying, the second category, involves the withdrawal from people and activities. Biological dying involves the loss of those characteristics that constitute being “human,” for example, personality. Finally, physiologic dying represents the failure of the body’s organs, the state that most of us recognize as death. The “terminal phase” of dying involves all four of these processes, although the psychological aspects may begin months or years before the physical processes noticeably progress.

Everyone experiences all these categories, although people differ in their attention to any one of them. The process of dying for a person with HIV disease is influenced by other factors, including stigma, fear of contagion, memories of the deaths of others, and the sense that death equals “failure.” Many people will not focus on psychic or sociologic aspects until they face the biologic and physiologic stages of dying; others will never be able to distinguish the psychic from the physical aspects. It is also important to note that the psychic and social aspects of dying may also present physically, for example, as apathy or anorexia.

Confusion may arise when patients and providers use the term “dying” to describe different categories: the patient focuses on the psychic or social aspects of the process while the provider focuses on the biologic or physiological aspects. For people with HIV disease, dying often begins when he or she receives a positive antibody test result. But providers may not recognize the dying process for several years until immunological deterioration is advanced. This discrepancy may lead to misunderstanding or conflict. By introducing the categories of dying, providers can help patients recognize the difference between living with HIV disease and dying from it.

The Process of Dying

While it is not possible to describe in advance the physiologic process of death for every individual, most people experience a progression as various organ systems begin to shut down. The kidneys lose their blood flow early as blood pressure drops, and this process is hastened by dehydration. The skin also loses blood flow and will become cool or mottled in a “livido” or cob-web pattern. Gastrointestinal function deteriorates so that oral intake of food or liquids becomes less desirable to do” or cob-web pattern. Gastrointestinal function deteriorates so that oral intake of food or liquids becomes less desirable to

See also references cited in articles in this issue.

References


Contacts

Paul Brenner, Jacob Perlow Hospice, Beth Israel Medical Center, First Avenue at 16th Street, New York, NY 10003, 212-420-4570.

C. Richard Chapman, PhD, Box 356540, University of Washington, Seattle, WA 98195-6540, 206-685-2083.

Avi Rose, LCSW, Tri-City Health Center, 38355 Logan Drive, Fremont, CA 94536, 510-713-6664.

Kitsy Schoen, LCSW, 5478 A College Avenue, Oakland, CA 94618, 510-528-8455.
The dignity of a peaceful death, without pain, fear, or futile therapy, can be realized only if time is spent in its preparation.

Pain is associated with dying. In fact, the literature suggests that many dying patients do not have severe or prominent pain, and those who do would respond to better pain management.2

People with HIV disease starve to death and must be forced to eat. While anorexia and wasting may be connected to HIV medications and conditions, weight loss ultimately results from the dying process.

Dehydration is painful. In fact, dehydration allows the body to slip more quickly and peacefully into metabolic coma.

Talking about death may kill patients or suggest that they give up living. Studies have shown that most patients with terminal illness know they are dying.2

Practical Management

Avoid overdiagnosing and overtreating the dying patient who has begun the physiological process of dying.3 Although medicine has traditionally taught its students to obtain more information through laboratory tests and imaging studies, it may not be necessary to establish further diagnoses if the treatment options are either non-existent or would be rejected by the patient. Medical treatment should include the withdrawal of medications and therapies that are only “sustaining” and do not contribute to the comfort of the patient. Why continue to treat HIV-related conditions during the brief terminal phase if they are unlikely to cause deterioration in a patient’s quality of life?

Medical therapy should include as much comfort as necessary, responding to pain, anxiety, nausea, and other uncomfortable symptoms.4 Management involves a few general principles. In the terminal phase, providers need to overcome fears of “overdosing” patients with pain medications. In general, as patients deteriorate, pain control may be easier, requiring smaller doses at less frequent intervals. However, the route of administration may need to change as the gastrointestinal tract and skin lose function and swallowing or skin absorption become ineffective. Alternatives include administration intravenously, subcutaneously, or under the tongue, making swallowing unnecessary.

Other comfort measures include providing moist wash rags to relieve dry mouth, even if patients cannot swallow, and avoiding the traditional turning of the patient to prevent bedsores since movement may be uncomfortable. Loved ones should be encouraged to avoid projecting their beliefs about the needs of the dying patient. They should ask the patient about food, water, and pain. If the patient is aware, his or her own perceptions should be accepted and honored. It is not appropriate to “force feed” the dying patient.

Conclusion

The spectre of death hangs over people with HIV disease throughout infection. Providers should neither postpone discussing death, nor abandon patients once the process of physiologic dying advances. The dignity of a peaceful death, without pain, fear, or futile therapy, can be realized only if time is spent in its preparation. Availability of clinicians during the dying process is necessary to provide reassurance and council about the futility of intervention. Even after death, practitioners should invite survivors to ask questions. Dealing with death does not make the epidemic less horrible, but it is crucial to the complete care of people with HIV disease.

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:

Editor, FOCUS
UCSF AIDS Health Project, Box 0884
San Francisco, CA 94143-0884
Decision-Making, Families, and Dying

Cognitive decision-making is more effective than emotional decision-making in enabling families to cope with the stress of caring for a dying loved one and in diminishing disruption, according to a summary of six research studies. Caregivers and health care professionals can help families distinguish between these two styles of decision-making, minimizing the emotional hurdles of HIV disease and enabling them to concentrate on achieving family goals.

Researchers studied 100 HIV-affected families from 30 states and a variety of socioeconomic settings. More than half of the families were White, 38 percent were Black and 10 percent were Hispanic; 46 percent were Catholic, 27 percent were Protestant, and 20 percent were Jewish. Researchers either interviewed families, observed them in their natural settings, or asked them to describe their experiences in a narrative form.

The studies documented family decision-making in the different phases of three stages of HIV disease: while the loved one was living with HIV; during the “living-dying interval” when the loved one is being cared for in a hospice, hospital, or home; and during bereavement. Cognitive decisions were ones that were rational, deliberate, and enacted over time. Emotional decisions were spontaneous and reactive. During the first stage, the families experienced the impact of learning about the diagnosis and the initial disruption in family roles. Other phases that occurred during this stage included understanding why the diagnosis happened, informing others about the diagnosis, and experiencing the emotions brought about by the intrusion of HIV disease into the family.

Cognitive decisions by family members in this first stage of illness included doing research on the disease, choosing to give up work so as to spend more time with the person with HIV disease, and choosing to ignore their own and others’ biases about sexuality and illness. Cognitive decision-making produced hope, security, and courage for family members. Family members who reacted emotionally tended to blame the infected person and isolate themselves from society. They reported experiencing more despair and helplessness.

The second stage of illness was characterized by the following tasks: reorganizing the family in order to overcome role strain, crystallizing the memories that family members would be left with after the death, and dealing with the imminent separation from the dying person. The emotional strain of this stage rendered it the most difficult in which to make cognitive decisions, including avoiding competing with other loved ones for the infected person’s attention, spending time with the loved one doing things that he or she wished, and signing documents about end-of-life procedures. Emotional decision-makers failed to cooperate with other family members and tended to become self-absorbed. As a result, they ignored the wishes of the dying loved one and were unable to achieve family intimacy.

In the final stage of bereavement, family members have to go through the phases of mourning and realigning their social networks. Cognitive decisions for this stage included creating a mourning ritual and forming new social alliances, often with other families or people who lost someone to AIDS. Relief and relaxation were the rewards of cognitive decision-making in these stages, whereas guilt and alienation remained with those who did not take active, rational steps to overcome these hurdles. Since few people are prepared for the hurdles that present with HIV illness in the family, health care practitioners can teach families the differences—and consequences—of cognitive and emotional decision-making.

Culture and the Personal Experience of Death
Koenig BA, Gates-Williams J. Understanding cultural differences in caring for dying patients. Western Journal of Medicine. 1995; 163(3): 244-249. (Stanford University.)

The boundaries between life and death are as much culturally constructed as they are scientifically defined. But according to an essay on cultural differences, health care providers who interpret a patient’s end-of-life decisions based upon perceived cultural values should be wary of reducing people to their culture and ignoring other equally important determinants of their beliefs about death.
Group therapy can help terminally ill patients regain a vital sense of community as well as a basic sense of security. Benefits of group therapy that recur from study to study include fostering of hope, detoxifying death, enhancing social support, improving coping skills, and developing a sense of internal control in group members. Despite a lack of specific literature on open-ended groups with terminally ill patients, the necessity of dealing openly with issues of deterioration and death suggests that an ongoing group will have more benefit than a time-limited group. Facing the loss of other group members will force patients to confront their own impending death.

Research shows that unconsciously, the group setting also brings about a return to the mother-child fantasy: the “child-state” of unknowing and total trust in a needs-gratifying mother is duplicated in the member’s relationship toward the group. The group becomes a separate entity—of which the participant feels a part—that will go on even after an individual dies. In this way, participants can also de-emphasize the trauma of impending death by focusing on their own union with the group and the part of them that will go on living in the group’s collective memory.

Next Month

HIV itself threatens the mind as well as the body, and over the past few years, knowledge regarding HIV-related cognitive impairment has burgeoned. It is now clear that cognitive impairment affects between 55 percent and 65 percent of people with AIDS.

In the February issue of FOCUS, Penelope Zeifert, PhD, Mark Leary, MD, and Alicia A. Boccellari, PhD present the latest information on HIV-related cognitive impairment. The authors are all associated with the University of California San Francisco and have been involved in the pioneering work in this field. They have just completed a monograph on this topic for the AIDS Health Project.

The issue will discuss the treatment of cognitive impairment and, since there is such a range of causes, will focus attention on diagnosis. It will also summarize the variety of causes and how these causes relate to one another.
DID YOU KNOW?

You can access a FREE searchable archive of back issues of this publication online! Visit http://www.ucsf-ahp.org/HTML2/archivesearch.html.

You can also receive this and other AHP journals FREE, at the moment of publication, by becoming an e-subscriber. Visit http://ucsf-ahp.org/epubs_registration.php for more information and to register!

ABOUT UCSF AIDS HEALTH PROJECT PUBLICATIONS

The AIDS Health Project produces periodicals and books that blend research and practice to help front-line mental health and health care providers deliver the highest quality HIV-related counseling and mental health care. For more information about this program, visit http://ucsf-ahp.org/HTML2/services_providers_publications.html.