AIDS and the Meaning of Natural Disaster

Allan Bérubé

When I look at the AIDS epidemic without turning away, I find myself asking questions about the meaning of my lover Brian's death, my own survival, the HIV infection of most of my close male friends and the deaths of many other good friends. The questions I ask are the most profound I know: "Why was it Brian who got AIDS and died?" "Why not me?" "Why is AIDS attacking so many of us?" "Why now?" I want to salvage some good, some meaning, some hope from the wreckage of this storm.

People offer explanations and reassurances to try to rescue me from my helplessness, fear and loss. "Keep busy," they say. "Cheer up!" "Get angry." "Don't mourn, organize!" Individual denial—which some hospice workers call terror management—is one important way to cope with multiple loss. But ethical boundaries are crossed whenever people try to save rather than support those of us who, against all odds, try to face painful truths. They trivialize and even deny the tragedy of so many deaths when they call AIDS a "learning experience," a "golden opportunity," a "gift" or a "blessing in disguise."

As a surviving partner, it hurts each time someone denies the tragedy of Brian's death and the depth of my own sadness by explaining that there are good reasons or compensations for AIDS. Reassurances that this epidemic has its benefits—whether political, moral or spiritual—deny us survivors our inconsolable loss.

HIV itself has no inherent meaning, benefits or purpose. It is nothing more or less than an infection that is killing human beings, a natural event that exists because it exists. Yet this epidemic that so devastates our lives still makes us wonder why. When Brian and I responded to the presence of HIV in his body, we realized that, while the virus had the power to kill without intent, we had the power to create or destroy its meaning in our lives. Unfortunately, in many gay communities, AIDS often means too much.

Reasons for AIDS

There are two different kinds of responses to the "why" questions we ask about AIDS. One response offers answers; the other accepts uncertainties and dwells in the place between questions and answers. When people respond with answers, they are likely to explain why AIDS happens at particular times to particular people and what AIDS teaches us. They can cause harm with definitive answers that keep people from finding their own meanings, blame people for their illnesses, or fill the silences in which people can face their fears and grieve. When people respond to the tragedy of AIDS without answers, they are likely to challenge moral explanations and open up the possibility of wondering, listening and being silent together. But without answers, people can feel helpless and without direction.

Each of these responses has ethical implications. The stories we tell each other about why particular people do or do not get AIDS have tremendous power. They touch real lives with real consequences and have the potential for framing some of the most profound experiences in a person's life. Even our most casual comments or reassurances—"You should have loved yourself better" or "There must be a reason why your son is suffering"—can be fragments of a moral framework that, if we could see the whole, we might not condone. It is important for us, as individuals and as communities, to examine our assumptions and begin openly discussing the ethics of how we ask and answer questions that assign meaning to other people's misfortunes.

The answers we are offered cut across the boundaries of politics, religion and sexual orientation: AIDS is the inevitable outcome of the sexual revolution; AIDS—the "gay plague," the "gay cancer," the "gay disease"—was created by the "gay lifestyle;" AIDS exists to open us up to the spiritual aspects of our lives; AIDS exists because God is punishing homosexuals, drug users, prostitutes and the sexually active for their sins. The implication of all these explanations is that people get AIDS because they live bad, incomplete or unbalanced lives.

To make matters worse, people who use AIDS to teach us lessons use people with AIDS as their lesson books. They place on people with AIDS the unfair burden of being scapegoats, moral examples or the original "patients zero." Others of us, sometimes without realizing it, use people with AIDS to inspire: we expect people with AIDS to serve us as models of courage, as our spiritual teachers or moral guides, people who have the answers, or, in the words of Elisabeth Kübler-Ross, "catalysts" who set in motion "wonderful world changes." People living with AIDS have enough business to take care of without being burdened involuntarily with the task of inspiring us or teaching the rest of us how to live or die.

While some tell us that the virus chooses people to teach us moral or spiritual lessons, others tell us that those infected with HIV choose this disease. Every few weeks I'm exasperated to hear yet another person explain that people with AIDS have created their illness, either literally or spiritually. A gay spiritual counselor writing in the Sentinel, one of San Francisco's gay newspapers, believes that we all choose our illnesses and deaths. "Potentially fatal situations," he explains, "such as car wrecks, cancer operations, rape, food poisoning, suicide and even AIDS...are all ways in which we express our death urge." Louise Hay, in You Can Heal Yourself, explains that many gay men have "created a destructive lifestyle" that is "monstrous" and, as a result, have created a "monstrous disease." Elisabeth Kübler-Ross, in AIDS: The Ultimate Challenge, wonders if "our AIDS patients, children and adults alike, chose to contribute their short life spans on planet Earth to help us open our lives...and to finally see the light."

AIDS does not choose people and people don't choose AIDS. I see this most clearly when I think of AIDS as just one of many meaningless though devastating natural disasters. Ever since Brian was diagnosed, I have compared AIDS to a tornado to remind myself and my friends how the puzzling randomness of disasters can make us ask questions that don't have answers.

Risks

A tornado unexpectedly touches down on a small midwestern town. Some people find safety in a shelter or basement, while

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Natural Diaster...

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others driving in cars or without shelters are caught in the storm. Many people die. Families wonder why their homes were hit; surviving spouses question why their lives were spared. Why did the tornado hit this particular town at this particular hour and kill these particular people? How were they different from the survivors? Did they unconsciously want to die? Was it just bad luck or fate or God's will? Some survivors' questions project onto the tornado a personality and a will. Did it strike with a purpose? Did the tornado intend to teach the townspeople a lesson? What were they supposed to learn? Was it that the dead might not have had to die if they had lived differently? Was it merely that death can strike anyone at any time without warning? Or was it that no one should ever live where strong winds blow?

No matter how careful we are, living in today's world means living in the path of unpredictable winds over which we have little control but which can threaten our lives. We are aware of the risks of living in cities built on earthquake faults or in the paths of tornadoes, of flying in jets, of walking on city streets at night, of making love. We take precautions, yet some of us still die. We want explanations for their deaths as much as we want to postpone our own. But the goals of leading a risk-free life, of creating a cocoon of total safety, or of being certain that one's death will not be random, are unattainable. Every day we take ordinary risks with no guarantee that we will survive.

Taking risks does not mean that we want the worst outcome to happen. Even those few who knowingly took the greatest risks, or made mistakes, or were not able to make the best decisions because of alcohol or drugs and therefore increased their chances of infection, were not choosing AIDS. We all are ultimately responsible for our actions, but sometimes events that are beyond our control radically change the consequences of everyday activities. The tragedy of AIDS is not that so many people live such desperate lives that they choose to die of AIDS. It is that so many people are dying for no reason other than that they took the kinds of risks we all take in our efforts to lead meaningful lives. Taking risks and losing is not the same as choosing to die.

Choice and responsibility are important issues for many facing this epidemic. But the act of telling those with AIDS that they chose their disease—a notion that one does not have to accept in order to take responsibility for one's health and well-being—can have damaging effects. People who are sick, especially when treatments don't stop the course of their illness, unnecessarily ask themselves, "What is wrong with me? Why did I want to get sick and die? How are my attitudes creating a fertile ground for AIDS? Why can't I choose life?" And if we are convinced that most people with AIDS really choose to get this virus, then it can be argued that they are to blame for their illness and they, not society, must pay the price.

All people with AIDS, regardless of the risks they did or did not take, deserve our respect and our care. They have a right to determine for themselves how to respond to this disease without anyone assuming that they chose AIDS to rescue them from their bad lifestyles or to complete their lives. The burning moral issue in this epidemic is not how to judge who did or did not choose their illness so that we can separate the "innocent" from the "guilty." It is rather how we all choose to respond to people who are living with AIDS and HIV.

Gratitude

Another troubling response that gives excessive meaning to AIDS is gratitude. This feeling is based on the perception that AIDS is happening now because our individual or collective pasts were immature, sinful, sick or spiritually impoverished. AIDS is assigned meaning because it forces us to grow up, it is our salvation from sin, it cures us from a deeper psychological illness or it rescues us from spiritual death.

Some gay men's gratitude toward AIDS, and the larger society's perception that AIDS is making gay men grow up, project a "Peter Pan" stereotype of gay men. In the old days, the story goes, gay men used to be uncaring, unthinking, irresponsible and self-destructive adolescents who were obsessed with quick sex, partying, drugs, dancing, youth and beauty—a pre-AIDS "lifestyle" that was so hopelessly compulsive that only massive deaths could change us. Some characterize this "lifestyle" as if it were an illness itself that inevitably led to AIDS and for which AIDS is a cure. AIDS has replaced bathhouses with literary bookstores, discos with country-western bars, cruising with dinner parties, casual encounters with long-term commitments, partying and promiscuity with community service and monogamy. The media have been quick to report the news that AIDS finally has forced gay men to act like adults. The lesson is that AIDS has improved our lives.

It is true that many of us have responded to this epidemic by making changes in our lives. We take responsibility for our past actions and accept the consequences without self-hate. We educate each other about safer sex and other safe practices. We ask for help and offer it. We demand the services we deserve from our governments. We learn how to live well in the present. We pay more attention to our health and explore all possible treatments. We celebrate our lives together. We face each other's deaths and come to terms with our own. We remember, grieve and hope. We respond to AIDS as we would to other life-threatening situations; we reorganize our lives and take care of each other.

But it is important to remember that when we make these changes, we are the same people we were before AIDS. Our strength and power do not originate in this disease, but grow out of who we were as individuals and men and women, as families, as friends and as communities before HIV entered some of our bodies.

If we have anyone to thank for the changes we have made, it is ourselves and each other, not AIDS. We deserve the credit. We can be proud of who we are now, and of what we are doing, without making the present seem better than it is by painting a bleak portrait of our past. The caricature of our past doesn't do justice to the depth and maturity of our lives before AIDS, including the sexual creativity that has enabled us to protect ourselves and each other by eroticizing safe sex. Nor does gratitude towards AIDS take into account the physical pain, the multiple losses, the discrimination, the anti-gay violence, the isolation and the cruel accusations that tear us apart today.

Few of us respond to this epidemic without fear and confusion, without love, without anger and without aching to know why. It is the patchwork of these responses, not the disease itself, that gives meaning to our lives as we weather this terrible storm.

Allan Bérubé is an historian, who has just completed Coming Out Under Fire, a book about gay men and lesbians and the military during World War II. An earlier version of this article was published in Out/Look, a lesbian and gay quarterly.

Request for Submissions and Comments

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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Life Review and the Threat of Death
Janice Krupnick, PhD and John Shill, MD

Over the years, knowledge about the course of HIV infection has changed the way in which it is treated and the prognoses of those who are infected. The medical conditions of many seropositive people are stable over long periods of time, and the goal of medical treatment is fast becoming maintaining the health of chronically-ill patients. As the medical picture has changed, the psychological needs of the population of infected people have also shifted. Psychological treatment used to seek only to provide emotional support; now, there is a greater opportunity to explore and resolve deeper psychological issues.

These issues arise out of the tremendous psychological stress involved in coping with a diagnosis of HIV infection, and the accompanying barrage of internal, interpersonal, and societal repercussions. Treatment requires a reexamination of an individual's sense of self and direction, and his or her perceptions of life and the world. As individuals struggle to find meaning while confronting their own mortality, they may instigate a process of life review during which they reassess the ways they have structured their lives, made decisions, and conducted relationships. This process may help answer troubling questions such as: Why me? and Why AIDS? as well as help clarify what the individual would like to change and accomplish in the time that remains. This article will explore the role of life review in the psychological treatment of people with HIV infection.

Psychological Context for Life Review

People facing life-threatening diseases respond by experiencing different phases of stress. For each person, however, the order of these phases varies. Initially, there is an outcry, the immediate response to the news, followed by denial, which is characterized by emotional numbing and avoidance of threatening ideas and actions. After this is an intensive phase of emotional response, including waves of agitation, tension, insomnia and recurrent nightmares. In coming to terms with the reality of the situation, individuals are likely to oscillate between denial and intrusion—the experience of feeling overwhelmed by painful thoughts and emotion—as they "dose" themselves with information about HIV infection. Denial of the grimmer realities keeps them from becoming overwhelmed; intrusion allows them to psychologically integrate painful truths and prepare for the future.

A life review and how it is approached is central to determining a person's capacity to cope with these stresses and is influenced by an individual's character and pre-existing developmental conflicts. For example, a person who is typically a goal-oriented achiever is more likely to actively seek out and try to understand the complex nature of the infection and its bewildering therapeutic approaches, while a more dependent, anxiety-prone individual may become overwhelmed and rely on hearsay and the advice of others. For many, this threat to life occurs during young adulthood, when such a challenge is unexpected and when previous life experiences have consisted of progressive achievements. The difficulties that result are compounded by the fact that friends who might provide emotional support are often equally confused, overwhelmed, and unfamiliar with such situations.

A Case Example

The following case illustrates an unusually successful outcome for a man who enters therapy following notification of his positive HIV antibody test. While such results are not always achieved, the case shows how the threat of AIDS can be a positive inducement for psychological development. The life review process was an integral part of the therapy.

Tom is a 38-year-old white male who came into therapy complaining of anxiety, depressed mood and difficulty maintaining relationships. At five years of age, after his parents abandoned the family, Tom was separated from his older brother and sent to a series of foster homes. In several of these situations, he was physically and sexually abused. Tom responded to his feelings of depression, low self-esteem, anger and abandonment with antisocial conduct.

As a teenager, Tom resorted to alcohol use, drug use, and casual sex to quell his rage and numb his pain. At 16, he ran away to live in the city and took on short-lived jobs. In his early twenties, he married, hoping tradition would offer him stability. But the demands of responsibility brought on by the birth of a child overwhelmed him. He began to pursue a gay lifestyle, which he felt was truer to his central identity. As his social life became more disorganized and impulsive, he had a series of brief love affairs.

Tom entered therapy with great anxiety and fear about the future. Once he believed he could be understood and helped, he was able to honestly review his life with his therapist. Through this process, Tom recounted the predominant features of his most significant relationships and came to understand how he had fallen into patterns with others that imitated these earlier destructive and unloving relationships. He was also able to see how his early life experience led him to engage in activities that put him at risk of HIV infection: multiple sex partners and intravenous drug use. At the same time, Tom was able to see the positive influences that had existed in his life, for example, one foster mother who had appreciated and encouraged him.

Tom was slowly able to form an alliance of trust with his therapist that enabled him to begin to understand his compulsion to repeat earlier patterns of rejection and other self-destructive behaviors. By projecting these patterns onto his therapist and discussing them openly, Tom was able to explore these "transference" reactions. (Transference is the psychological process by which psychotherapy patients impute their therapists with characteristics of earlier significant figures.) In doing so, he was able to find new ways to understand the events of his life and to see his therapist as different from the people who hurt him. Tom was also able to ask for help without feeling degraded as a result of his needs and without pulling away from those who supported him.

Eventually, Tom was able to stabilize his life. He became involved in a relationship with a man who was supportive and rewarding rather than demanding and abusive. Despite its challenges, the relationship was free of the intense turmoil and instability that characterized his earlier life. Tom was also able to take responsibility for his medical care and investigate early treatments for HIV infection. He found a new job, embraced a healthier lifestyle, contacted his former wife, and made an effort to be more present in the life of his adolescent child.

Through the use of a life review in a psychotherapeutic setting, Tom was able to find a niche for himself in the world where previously he felt he had none. The actual threat of AIDS and the loss of his life, something he had in the past viewed so cavalierly, and the interest of the therapist spurred him to acknowledge the positive aspects of his life and helped him achieve a level of maturity and satisfaction that had previously eluded him.

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A group of terminally-ill breast cancer patients participating in support groups lived nearly twice as long as those receiving only medical care, according to a recently completed 10-year study.

The study found that 50 women participating in at least one year of weekly, 90-minute support group meetings survived an average of 36.6 months, compared to 36 women, not attending support group meetings, who survived an average of only 18.9 months. Researchers state that members of the support groups benefited because they were encouraged to take a more active role in their medical treatment. Both groups of women received similar medical treatment during the period of the study. At the beginning of the study, women in the control and intervention groups were of similar ages—an average of 55 years old—and at similar stages of disease—all with metastatic carcinoma of the breast.

The support groups, which were led by a psychiatrist or social worker, and a therapist who had breast cancer in remission, emphasized open discussion about coping with cancer and chemotherapy or radiotherapy. Group leaders taught members strategies in self-hypnosis to help control pain. They did not suggest that group therapy would lengthen group members' lives. Those in the intervention group built strong personal relationships with each other, and members visited each other in the hospital.

[Editor's note: Because of similarities between HIV infection and cancer, the success of support groups for cancer patients may apply to support groups for people with HIV infection.]

**Recent Reports**

**Support Groups Extend Life Expectancy of Cancer Patients.**

Stanford University and the University of California, Berkeley (The Lancet, October 14, 1989).

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**An Excerpt**

**AIDS and Its Metaphors.** Excerpt from AIDS and Its Metaphors by Susan Sontag. Copyright (c) 1988, 1989 by Susan Sontag. Reprinted by permission of Farrar, Straus and Giroux, Inc.

In AIDS and Its Metaphors, novelist and essayist Susan Sontag examines the range of AIDS metaphors from the more obvious plague images to those focusing on sexuality, catastrophe and apocalypse. Below is a brief excerpt from the book.

Much of the well-intentioned public discourse in our time expresses a desire to be candid about one or another of the various dangers which might be leading to all-out catastrophe. And now there is one more. To the death of oceans and lakes and forests, the unchecked growth of populations in the poor parts of the world, nuclear accidents like Chernobyl, the puncturing and depletion of the ozone layer, the perennial threat of nuclear confrontation between the superpowers or nuclear attack by one of the rogue states not under superpower control—to all these, now add AIDS. In the countdown to a millennium, a rise in apocalyptic thinking may be inevitable. Still, the amplitude of the fantasies of doom that AIDS has inspired can't be explained by the calendar alone, or even by the very real danger the illness represents. There is also the need for an apocalyptic scenario that is specific to "Western" society, and perhaps even more so to the United States. (America, as someone has said, is a nation with the soul of a church—an evangelical church prone to announcing radical endings and brand-new beginnings.) The taste for worst-case scenarios reflects the need to master fear of what is felt to be uncontrollable. It also expresses an imaginative complicity with disaster. The sense of cultural distress or failure gives rise to the desire for a clean sweep, a tabula rasa. No one wants a plague, of course. But yes, it would be a chance to begin again. And beginning again—that is very modern, very American, too.

Later in the book, Sontag writes:

That even an apocalypse can be made to seem part of the ordinary horizon of expectation constitutes an unparalleled violence that is being done to our sense of reality, to our humanity. But it is highly desirable for a specific, dreaded illness to come to seem ordinary. Even the disease most fraught with meaning can become just an illness. It has happened with leprosy, though some ten million people in the world, easy to ignore since almost all live in Africa and the Indian subcontinent, have what is now called, as part of its wholesome redramatization, Hansen's disease (after the Norwegian physician who, over a century ago, discovered the bacillus). It is bound to happen with AIDS, when the illness is much better understood and, above all, treatable. For the time being, much in the way of individual experience and social policy depends on the struggle for rhetorical ownership of the illness: how it is possessed, assimilated in argument and in cliché. The age-old, seemingly inexorable process whereby diseases acquire meanings (by coming to stand for the deepest fears) and inflict stigma is always worth challenging, and it does seem to have more limited credibility in the modern world, among people willing to be modern—the process is under surveillance now. With this illness, one that elicits so much guilt and shame, the effort to detach it from these meanings, these metaphors, seems particularly liberating, even consoling. But the metaphors cannot be distanced just by abstaining from them. They have to be exposed, criticized, belabored, used up.

**This Month and Next Month**

In the the November issue of FOCUS, we stated that our December issue would include articles about nutrition and AIDS. The San Francisco earthquake (from which we have safely recovered) and other not-so-natural disasters have delayed this issue. We have replaced Dr. Beach's article with the piece by Allan Bérubé. This is the first in a periodic series of what we call "think pieces," articles that approach HIV counseling issues from a more philosophical perspective.

In the January issue of FOCUS, we will explore issues of nutrition, AIDS and immunity. The issue will examine how nutrition plays a role both in the disease process and the healing mechanism, nutritional requirements for people with HIV infection, and ways in which practitioners can help patients reach decisions about the range of alternative nutritional therapies.