

The Emergence of AIDS: Bodies in Revolt

As the incidence of AIDS rises exponentially, the increasing public panic indicates a need to examine the social construction of meanings attached to this disease. A phenomenological analysis of the public's panic response to AIDS shows the influence of pre-existing attitudes toward contagious disease within our cultural stock of knowledge. Specifically, analysis suggests that experience of the AIDS-infected body is structured by a set of phenomenological categories that presuppose both the fear of the body-out-of-control and the fear of death. These two fears lie at the root of the social panic over AIDS. A social phenomenological analysis provides a description of how AIDS is experienced in the social world and how the construction of the fear of AIDS casts the epidemic as a modern plague. A reflective response to the AIDS epidemic can show that the difference in meaning between epidemics and plagues is significant for human freedom. Instead of regarding AIDS as a plague, we can wage an authentic revolt against fears and panic, so that we can begin to see how our health forms a primary basis for our interconnectedness with each other and hence forms the basis for human reality.

AIDS: The Social Body in Disease

As common bearers of a single culture we share a "stock of knowledge" that includes—according to Alfred Schutz, the founder of social phenomenology—assumptions about time, space, the laws of logic, cultural customs, and our own and others' existence. One common assumption that Schutz did not identify is that which I call a "social body." The social body emerges as a central phe-

nomenological concept in an AIDS culture. The social body is not included in the concepts "human species" or "member of the human race." It is not an abstraction from daily life. Rather, it is embedded in our experiences and permeates our awareness of social life. The social body refers to our felt awareness at the pre-reflective level that the welfare of our own bodies is co-given with the welfare of others' bodies. The social body gives me my awareness of myself only insofar as I am connected with others both in a collective stream of consciousness and as a body among bodies. *The social body is the lens through which I can differentiate my private body.*

Except in times of plague and epidemic, the social body is a healthy body; we assume that other healthy people both precede and survive us. To the degree that we share health with our contemporaries, we can journey along with others, quietly noting the passing of our lives. It is often the lapse of our own health that brings us not only to a sense of our bodies, but also to the awareness of our death as an immediate possibility. Our bodies are not to be feared as long as health prevails. When our health fails, death, once dim and far away, plunges into our consciousness through the experience of the frailty of our own bodies. Our awareness of death heightens our experience of our bodies as contingent grounds for our livelihood.

Fear of the mortality of our bodies is often experienced in bodily nausea. Jean-Paul Sartre described body fear as body nausea even when we are healthy:

A dull and inescapable nausea perpetually reveals my body to my consciousness. Sometimes we look for the pleasant or for physical pain to free ourselves from this nausea; but as soon as the pain and pleasure are *existed by consciousness*, they in turn manifest its facticity and its contingency; and it is on the ground of this nausea that they are revealed. . . . It is on the ground of this nausea that all concrete and empirical nauseas (nausea caused by spoiled meat, fresh blood, excrement, etc.) are produced and make us vomit.¹

If our experience of our healthy bodies is the foundation for all encounters with nausea, reminding us of our death, then our

fears can only be heightened by the unhealthy body in our midst, and most of all the body that suddenly turns ill and cannot be returned to health—the body with AIDS.

AIDS reveals the social body in disease.² AIDS is present in the “life-world,” which Schutz described as “that province of reality which the wide awake . . . adult simply takes for granted in the attitude of common sense.”³ AIDS is far more than a retrovirus, a number of terminally ill people, a death count, or a medical mystery. Whether we think of it or not, AIDS is part of our social experience. AIDS has been built into the layers of the life-world, altering our awareness of the social body from one of health to one of fatal disease.

AIDS produces a severe dismemberment of the social body. Not only might we see the body of someone else with AIDS as out of control and near death, but as AIDS continues to spread throughout the country, we begin to fear the entire social body as being out of control and rampant with disease and death. The fear of AIDS becomes manifest in public panic over the fear of the body—the ground of our own mortality. To analyze the social body in disease we must examine how the appearance of AIDS moves into commonsense consciousness, creating fear and panic in daily social life.

The Commonsense Awareness of AIDS

Disease enters the social world on two primary levels: as a *biological event* that infects our bodies and as a *social event* to which a variety of meanings is attached by the choices we make in response to disease. The realization that one has AIDS is the awareness of being infected with a biological and social disease. As the retrovirus infects the physical body of a person, the social virus of AIDS stigmatization enters the net of relationships in which the person lives and works. AIDS becomes a social event, the constellation of values associated with it highlighting major cultural biases against unconventional sexual behavior and illegal drug use.

Thus, large groups of people become potential patients and are regarded socially as “diseased” simply by being identified as members of high-risk groups: gay or bisexual men, IV drug

users, hemophiliacs, sex partners of people with AIDS.

Since AIDS is a highly stigmatized and fatal disease, people at high risk begin watching their bodies for the appearance of the lesions of Kaposi's sarcoma (KS), weight loss, swollen lymph nodes, and insomnia as possible indicators of AIDS. With terror we can find ourselves with AIDS: "I never heard about it [AIDS]," one man says, "until I saw a special on it on 20/20. . . . The special I saw had a man with lesions on it. Mine looked kind of like that, so I went to one of the clinics and they referred me to my doctor. I went to my doctor, and he told me I had AIDS."⁴ Another person describes a similar process of self-diagnosis common in an epidemic: "I had a series of unexplained blackouts, and eventually when I started hearing what the symptoms of AIDS were, I felt that, you know, I might fit in that category."⁵

People with AIDS describe a sense of disbelief and fear at learning of their diagnosis. "I was told I had cancer, that it was in my blood—systemic—and couldn't be cut out. I was told I probably wouldn't live very long," recalls one person with AIDS.⁶ "I remember a slight sense of disbelief," writes another, "like this wasn't really happening to me."⁷

Many people with AIDS commit their date of diagnosis to memory much like a death sentence. In fact, in 1986 only 6 percent of all AIDS cases have survived more than three years after diagnosis.⁸ Others with, or at high risk for, AIDS commit suicide. Some people attempt to reduce the stigma of having the "dreaded disease" by creating a veil of secrecy and telling only a few close friends. Those who choose not to hide their illness are often treated with suspicion by their co-workers, neighbors, and friends. Some people with AIDS are quickly fired from their jobs. Those with AIDS and KS lesions sometimes stay completely out of public view, going out only occasionally to attend a movie, and even then entering only after the theater lights are out to avoid being seen.

Gay men experience the daily connection between death and sex because thousands of gay men are dying of AIDS, while others see people they have had sex with dying and wonder if AIDS has already been sexually transmitted to them or if future sexual encounters could kill them or their lovers. Young people

with or at risk for AIDS experience nearness to death outside of the normal aging cycle. A person with AIDS remarks, "At the age of twenty-eight, I woke up every morning to face the very real possibility of my own death."⁹

Friends, lovers, and relatives of people with AIDS watch near at hand the physical and social effects of the disease on those they love. AIDS causes the appearance of old age; the body degeneration of the elderly appears in formerly healthy gay men aged 20 to 50. One woman writes of her son with AIDS:

Hardest of all was watching a young, healthy man turn into a gaunt, old one, fumbling and shuffling, uncertain and confused. I watched his hair, eyelashes and eyebrows grow sparse and dull. I watched him get so thin that it was too painful to sit on a chair. . . . I lived with his dementia and held him down during his seizures. I never got used to the cane, the wheelchair, the portable commode, and the adult diapers.¹⁰

The fear of the AIDS-infectious body is found among members of high- and low-risk groups alike. One man noted that worst of all for his old high school friend, a hemophiliac dying of AIDS, was his remorse that he was dying of the "gay disease," that this was the legacy he was leaving to his young son. The friend remarked, "I wanted to hug him. This was the last time I would see him, but several of us were all suited up in gowns and masks and they had me afraid to even touch him."¹¹ One person with AIDS refers to AIDS patients as being "treated like lepers, who are treated as if they are morally if not literally contagious."¹²

Some gay men shrink from the kiss of greeting, a common practice before AIDS. Others who formerly were quite open about being gay have become quiet about it to diminish AIDS fears in others. One gay man remarks, "I have always been out. But I am about to be ordained. If my parish knew I was gay, they would not drink from the same communion cup for fear of catching AIDS."¹³ People at low risk re-evaluate their sexual practices in light of AIDS, often afraid of changing relationships for fear that they may increase their exposure to AIDS with a new part-

ner. People buying newspapers, shopping, passing by on city streets begin to notice AIDS media coverage. Some believe that AIDS is just another bad disease, like cancer. Others fear they have already caught it, by chance, or by some rare incident in their past, and become the "worried well," filling AIDS hotlines and doctors' offices, trying to assuage their fears.

The fear that our bodies may be struck with AIDS and become part of the AIDS death count gradually builds into panic. As the panic increases, the possibilities for people with or at high risk for AIDS are severely limited by the worried well. Gay men have not only to deal with the high death rate among lovers and friends but also the spiraling social stigmatization linking AIDS directly to being gay. A gay author writes, "With the onset of AIDS, familiar faces—the man in the bookshop, the mailman, casual acquaintances—begin to disappear and funerals become an increasingly frequent part of our lives."¹⁴

As panic splits the social body between the sick and the healthy, AIDS becomes a plague in commonsense consciousness. Talk of quarantining people with AIDS or even all persons at high risk, filters through the social world. Some gay establishments are closed down, presumably as a preventive health measure. Hemophiliacs begin experiencing suspicion at the workplace. Some children with AIDS are banned from school. One gay man learning of a friend who came down with pneumocystis pneumonia, a symptom of AIDS, recalls, "Another friend rushed up weeping with a copy of *New York Magazine* and said, this is what he's got. The article was entitled 'The Gay Plague,' and it was so hysterical that pretty soon we were hysterical ourselves."¹⁵ A reviewer of a recent gay film comments, "This is the post-gay liberation world of New York, in the plague years of the 80's."¹⁶

Is AIDS "The Modern Plague?"

There has never been an illness like it in modern times. AIDS stands today as the most serious and threatening medical and social phenomenon—the single greatest public health menace—of the age.

—*The Boston Globe*

The metaphor of AIDS as plague has quietly slipped into commonsense ways of thinking about the disease. The media in particular have spread the myth of AIDS as plague, the "gay plague," with headlines such as "Gay Plague Baffling Medical Detectives" and "Gay Plague Has Arrived in Canada."¹⁷ Even a public policy conference was entitled, "AIDS: A Modern Plague?"¹⁸ Undoubtedly, AIDS is "the greatest public health crisis in the twentieth century" and perhaps even "the most virulent epidemic known to man."¹⁹ Nonetheless, it is vital to the freedom of us all that this epidemic not be seen as a plague-like phenomenon, for such a metaphorical shift only heightens the oppressive stigmatization of people with or at risk for AIDS.

Unlike the word *epidemic*, *plague* creates a mystique of moral blame around the plague stricken. The figurative meanings of plague refer to a scourge, an evil, an act of divine anger, divine punishment. Plague can mean disease serving a moral purpose, namely, to cleanse the world of undesirables, such as the ten plagues of Egypt. Since the AIDS-afflicted are already judged to be socially undesirable, the plague metaphor for AIDS can only increase negative judgments about people with AIDS and suggest that AIDS is an instance of divine punishment. If AIDS is seen as plague, a further ostracism of all high-risk persons will result. It is possible that everything associated with a high-risk person could be seen as "infected," leading to a severing of the social body between the clean and the allegedly impure.

The host of plague-related words that have been used in the past, such as *plague bill*, *plague house*, *plague pit*, *plague mark*, *plague water*, *plague cake*, *plaguer*, *plaguey*, evidence how easily superstitions can reach into and transform daily social life.

AIDS, like plague, does appear by surprise, is incurable, and does bring disease and death. But AIDS need not disrupt the social order, our set of beliefs about life, or our relationships to each other. AIDS is, after all, a sexually transmitted disease as well as a disease spread by contaminated needles or blood products. Current medical research reports that AIDS is not spread by casual contact. Hence, whereas it may have been appropriate to fear interacting with people during the bubonic plague, no medical evidence exists to support the fear that we can "catch" AIDS from each other, short of engaging in unsafe sexual prac-

tices or sharing infected blood or needles. Most of us can, to a large extent, protect ourselves from AIDS. Very sound and effective precautions can be taken against AIDS that are not based on fear or superstition and that need not be oppressive, namely, education and accessibility to safe sex materials, legalization of the distribution of sterile needles to drug users, and routine screening of blood donations. Yet despite sound precautions, many people persist in believing that it may be possible to catch AIDS from casual contact, and have an irrational distrust of any medical claims about AIDS. They project their own fears onto a retrovirus they perceive as entirely uncontrollable.

People acting against the prevalent medical opinion of the time collectively create hysteria, which culminates in news stories of bizarre ways AIDS may be transmitted, beyond anyone's control. People are warned that "No American is Safe"; "If you live in a neighborhood in New York City with a high level of mosquitoes, you may well be at risk [for AIDS]";²⁰ and even that "AIDS may be passed thru Laundry [sic]."²¹ Such irrational fears are unproductive and maintain the oppression of people with AIDS.

The irrational fear of AIDS in plague thinking suggests that AIDS may be, in commonsense consciousness, the disease of the nuclear age. AIDS brings to the individual, like the nuclear threat that looms over our culture, the imminent threat of total annihilation. The AIDS retrovirus can suddenly appear in one's body as if coming from nowhere, and by the time it appears, it is too late for the body to defend itself, even against otherwise nonfatal opportunistic infections. Moreover we find, paralleling the AIDS epidemic, a highly infeasible military strategy. The Strategic Defense Initiative can be seen as a reaction to AIDS. At a time when members of our culture are dying in great numbers from a retrovirus that immobilizes their own bodies' immune system, a perfect immune system is projected onto outer space in our country's military strategies—a nuclear shield so powerful that President Reagan described it, in the early period of the AIDS epidemic (1983), as ultimately enabling us to "intercept and destroy strategic ballistic missiles before they [reach] our own soil or that of our allies."²² Both the AIDS epidemic and the Strategic Defense Initiative reflect a specific fear that accompanies

the fears of death and of the body-out-of-control: the fear of total vulnerability. The largest threats to our vulnerability are AIDS and nuclear war. Despite our technology, which enables us to control many events, we are still vulnerable to disease and death.

It is possible to curb the hysteria and fear about AIDS not by denying our fear of total vulnerability but by waging an authentic resistance to AIDS at the existential level through a philosophy of revolt. A philosophy of revolt against AIDS acknowledges the social body as the vital network of our interconnections to each other and emphasizes human freedom as the highest goal for a social community.

AIDS and Revolt

From now on, it can be said that plague was the concern of all of us. Hitherto, surprised as he may have been by the strange things happening around him, each individual citizen had gone about his business as usual, so far as this was possible. And no doubt he would have continued doing so. But once the town gates were shut, every one of us realized that all, the narrator included, were, so to speak, in the same boat, and each would have to adapt himself to the new conditions of life. . . . the ache of separation from those one loves suddenly became a feeling in which all shared alike and—together with fear—the greatest affliction of the long period of exile that lay ahead.²³

A philosophy of existential revolt is found in Albert Camus's novel *The Plague*, in which a town infested with bubonic plague is used to depict a social community with a social illness: fascism. Camus portrays an existential philosophy of revolt by stressing that, at the core of the human condition, both freedom and goodness link us in vital connection to each other. He suggests a dichotomy in the social world between those who choose to be pestilences and those who are the victims of pestilence, and calls for a path of healing and peace that enables us to mount an authentic revolt against all forms of oppression and even to revolt against death itself.

Camus claims that we are free to shape the values of the social world. We are responsible for our own destinies and for the level of

social oppression, or social infection, in the social body: "What's natural is the microbe. All the rest—health, integrity, purity (if you like)—is a product of the human will, a vigilance that must never falter."²⁴ Camus is aware that the creation of oppressive values, such as the stigmatizing of people with or at high risk for AIDS, is always possible because we are the makers and sustainers of human values. Yet his novel refuses an attitude of wariness toward human beings and suggests instead a rugged hopefulness in the goodness of others. At the same time that he warns we are free to choose tyranny ("the plague bacillus never dies or disappears for good, . . . it can lie dormant for years, . . ."²⁵) the narrator of the novel affirms that the lesson of plague is insight into human goodness. Dr. Rieux writes: "What we learn in time of pestilence: that there are more things to admire in men than to despise."²⁶

An existential philosophy of revolt resists oppressive values that stigmatize people with and at high risk for AIDS by refusing to cast judgment on people needlessly. For Camus, there are no absolute values save a hope for goodness and freedom. We each must choose our paths in life for ourselves and on our own terms. Similarly, there is no deep meaning to life itself, except for the meanings we create. There is no deep message in getting AIDS. No one deserves to have AIDS. Each of us has before us the constant task of giving our lives meaning, even though much of what happens to us may be beyond our control, or absurd. Through the character of Tarrou in *The Plague*, Camus emphasizes the tyranny of choosing to judge others when their actions commit no harm. Such judgment is to pass a death sentence on others, to bring death into the social world by limiting the freedom of others needlessly:

All I maintain is that on this earth there are pestilences and there are victims, and it's up to us, so far as possible, not to join forces with the pestilences. . . . I grant . . . a third category: that of the true healers. But it's a fact one doesn't come across many of them . . . and anyhow it must be a hard vocation. That's why I decided to take, in every predicament, the victim's side, so as to reduce the damage done. Among them I can at least try to discover how one attains to the third category; in other words, to peace.²⁷

Tarrou believes that everyone has plague, that we all risk infecting each other at the level of human freedom and possibilities. But through Tarrou, Camus suggests that we can be vigilant about the values we bring into and maintain in the social world—that we can strive to reduce the damage done in respect to the lived situation of AIDS, and that, moreover, we can attempt to be healers of the social body in the midst of an epidemic instead of spreading harm.

An existential philosophy of revolt against AIDS recognizes the ambiguity of choices amidst risk factors for our physical and social health. Whereas epidemiologists define the level of biological risk for AIDS, existentialists continually evaluate the risks for freedom we take by our social activities in regard to AIDS. It is our task to measure, with a gambler's eye, our own balance between risk and safety. Whether an individual practices safe sex or not, whether an IV drug user chooses safe needle use, whether a person with AIDS decides to accept or refuse medical care or gives in to despair or revolts, whether all of us choose to spread the plague myth about AIDS or fight against it, and to what degree, are in the end the measures of our own value. As Camus writes, each of our lives, particularly evident in epidemic, "could be only the record of what had to be done, and what assuredly would have to be done again in the never ending fight against terror and its relentless onslaughts, despite their personal afflictions, by all who, unable to be saints but refusing to bow down to pestilences, strive their utmost to be healers."²⁸

An existential revolt against AIDS, like any authentic striving for meaning, is also a revolt against death. It is absurd that we all die, if not of AIDS, then of something else. Although we cannot choose not to die, we can choose, within our own situations, the risks we will take with others, and with our health, in ways that help us live ever more deeply. In some respects, AIDS is yet another instance of our mortality. AIDS brings us to a confrontation of the absurdity of death and the desire to make life meaningful. Camus suggests that the creation of meaning always happens within the frame of life and death. Reflecting on the death of Tarrou from plague, Dr. Rieux concludes that what we really have in life is knowledge of friendship and its memories and that, sifting through all of our experiences of ourselves and oth-

ers, what we can retain is the limits of our knowledge. "Knowing meant that: a living warmth and a picture of death."²⁹ Within the framework of living warmth and an image of death, we take up our lives, choosing either revolt or despair, resistance to oppression or fear.

A phenomenological analysis of the AIDS-infectious body reveals two general responses to the biological and social threats of AIDS: a panic arising from fear of death and the body-out-of-control, and an existential revolt against the social oppression of having AIDS. The former response can only lead to irrational consequences that may jeopardize the rights of persons with or at high risk for AIDS, specifically the rights to freedom, adequate health care, and social possibilities. The latter response offers to maintain our essential freedom and stresses our interconnections with each other as members of a social body in which the value of each of us is linked to the values all of us create. It thus encourages sound social policy on AIDS issues. Such a philosophy of revolt against AIDS can define and evaluate the dilemmas of choice and risk inherent not only in epidemics of contagious disease, such as AIDS, but in the health of social life altogether.