Regenerating Gay Men's

REVIVING

Sexuality and Culture

the TRIBE

in the Ongoing Epidemic

Eric Rofes

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Eric Rofes is a doctoral student in Social and Cultural Studies at the University of California Berkeley's Graduate School of Education. A longtime activist, he is the founder of the Boston Lesbian and Gay Political Alliance and served as Executive Director of the Los Angeles Gay and Lesbian Community Services Center and San Francisco's Shanti Project. He was part of the *Gay Community News* collective and has been the author and editor of seven books.

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Quotes introducing individual chapters originate from the following sources:

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Bill T. Jones, quoted at AIDS Project Los Angeles' Commitment to Live VII, January 27, 1994. See Karen Ocamb, "APLA's 'Commitment to Live' Entertains as it Raises AIDS $$$," *Bay Area Reporter*, February 17, 1994, 24.

Albert Camus, from "Summer," in *Lyrical and Critical Essays* (New York: Alfred A. Knopf, 1969), translated by Ellen Conroy Kennedy; Philip Thody (Ed.), 169.

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Eric Rofes
San Francisco

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Introduction: Life Interrupted

> People were unprepared for the atomic bomb on many psychological dimensions: the immediate relaxation induced by the all-clear signal, the feeling of being in some way specially protected, the general sense of invulnerability which all people in some measure possess even (or especially) in the face of danger, and the *total inability to conceive of the unprecedented dimensions of the weapon about to strike them.* As one man put it: "We thought something would happen, but we never imagined anything like the atomic bomb."
>
> –Robert J. Lifton,
> *Death in Life:*
> *Survivors of Hiroshima*

> At first I was afraid, I was petrified.
>
> –Gloria Gaynor, "I Will Survive"

Imagine a world without homosexual men. Consider the landscape of life in America without our participation and talents. Conjure a mental image of our nation, our cities, our neighborhoods devoid of the activity of gay men and the influence of gay male culture.

These possibilities darted through many gay men's minds in 1981 and some of us are imagining them again today. As we grapple with an ever-changing terrain on which we struggle to erect edifices of hope, we find ourselves facing the same painful conundrums we had hoped to resolve a decade ago. If AIDS is a sexually transmitted disease, why don't gay men always practice safe sex? If billions of dollars fund medical research each year in America, why

isn't a cure for HIV infection just around the corner? What forms of life can gay men anticipate over the next few decades?

When initial reports of gay cancer confronted us a dozen years ago, many of us were shocked into considering the worst. We huddled over after-dinner coffee quietly tossing out gruesome guesses of how many would fall in the epidemic. Would it be one out of six or one out of three? Glazed-over eyes flashed about the room, each of us pondering who among us would be walking the earth in ten years. Serious discussions ensued about whether the gay male population was doomed for extinction.

After a period of time, we stopped articulating these fears. Our focus shifted from shock into action. We spread the word about sexual transmission, and began formal prevention campaigns. We rolled up our sleeves and set up community-based caregiving networks. We began learning about the health care system and federal research bureaucracy and suddenly knew more about our bodies and our immune systems than we'd ever imagined.[1]

By 1985, despite the tidal wave of death which was beginning to overwhelm us, we found solace in two oft-repeated beliefs: (1) A treatment which would save our lives would be found soon; (2) Gay men in urban centers had implemented safe sex practices and halted sexual transmission in our population. These beliefs became the theoretical and spiritual foundation of our collective lives in the health crisis. They were sources of hope and we constructed elaborate campaigns of optimism upon them, as well as public relations campaigns repeatedly reminding the world that gay men had responded "responsibly" to a burgeoning epidemic.

The gay community's mass reaction to the epidemic has approximated Elisabeth Kübler-Ross's stages of coming to terms with death, described in her landmark book, *On Death and Dying,* published a decade before the advent of AIDS.[2] These phases, while described as distinct entities, are often neither discrete nor sequential and frequently overlap. This is also true of our community's response to AIDS. While some individuals responded immediately to the first reports of GRID (Gay-Related Immune Deficiency) and gay cancer, 1981-1984 were years of denial, shock, and fear throughout much of the gay population; 1985-1989 was a period of agitation and anger. We then shifted briefly into the third stage,

bargaining, and made conscious and unconscious pacts (with fate? ourselves? God?) to ensure our individual or collective survival: If we were HIV positive and volunteered in AIDS service organizations, we wouldn't be allowed to become sick. If we were uninfected and donated a lot of money, we would be spared the plague. As a community, we told ourselves that if we were the best little boys in the world, this nightmare would end swiftly. Like a holy prayer, we chanted over and over that HIV is a chronic and manageable illness, hoping no one else would have to die. We repeatedly proclaimed to the world that gay men had halted transmission of the virus, praying no one else would become infected.

Time magazine described similar phases in 1992:

> The first wave of gay response to AIDS was fear, mixed alternately with denial and paranoia. The second wave, the past few years, has been a therapeutic anger, an opportunity for the grief-stricken to vent their pain and for the dying to give meaning to their premature passing. The third and current wave of gay response to AIDS is once again dominated by fear, this time based on a sense of grim inevitability.[3]

In 1993 two events jolted us collectively into Kübler-Ross's stage four–depression. Our creeping recognition that we had not found treatment solutions broke into public consciousness. At the International AIDS Conference in Berlin, the treatment that claimed much of the AIDS establishment's largess of hope–AZT–was repeatedly and publicly undermined. At the same time, multi-city epidemiological evidence and anecdotal reporting began to confirm what many had suspected: new infections among gay and bisexual men were again on the upswing; significant numbers of men were engaging in anal intercourse without a condom.[4] Thus the dual foundation of our collective hope–no new infections and the imminent development of a cure–eroded from under our feet, and a thick veil of depression, which for years had hovered just overhead, dropped over the community.

Some have observed a diminution of public interest in AIDS. San Francisco gay writer Bruce Mirken captured the sentiment of many in an essay titled "Reasons to Riot," in which he wrote:

> It's almost as if we've gotten used to this. It's as if we've come to feel that having our friends and lovers die every day is normal. It's as if we believe it inevitable that profit-obsessed drug companies and scientific turf battles will continue to distort the research agenda and the things that could save lives in the short term–like needle exchange and education programs that actually give young people honest information–will never happen on a large enough scale to do any good.
>
> It's as if we've given up.[5]

In a posthumously published cover story in *The New York Times Magazine,* Jeffrey Schmalz wrote:

> Once AIDS was a hot topic in America–promising treatments on the horizon, intense media interest, a political battlefield. Now, 12 years after it was first recognized as a new disease, AIDS has become normalized, part of the landscape .... The world is moving on, uncaring, frustrated and bored, leaving by the roadside those of us who are infected and who can't help but wonder: Whatever happened to AIDS?[6]

But has AIDS been normalized? Or is something else going on? Certainly a shift in thinking about the epidemic has occurred. Rather than being a temporary incident necessitating temporary responses, AIDS has become seen as a characteristic feature of contemporary urban life. Accepting that no magic bullet is in sight that will cure the infected or prevent further cases is different from seeing AIDS as the "normal" or "usual" state of being.

Something complex and difficult to quantify is transpiring that is especially evident in the gay community. Schmalz wrote, "Now even the gay movement has pushed AIDS to the sidelines." He cites the 1993 March on Washington as indicative of this shift:

> Six years earlier, in 1987, a similar gay march had one overriding theme: AIDS. If there was a dominant theme last April, it was homosexuals in the military. To be sure, AIDS was an element of the march, but *just* an element. Speaker after speaker ignored it. (p. 60)

Schmalz highlights remarks by Torie Osborn, former executive director of the National Gay and Lesbian Task Force, who states,

"There is a deep yearning to broaden the agenda beyond AIDS. There's a natural need for human beings who are in deep grieving to reach for a future beyond their grieving" (p. 60).

The historical response to AIDS by the gay, lesbian, and bisexual communities has been complicated since the start of the epidemic; they have *never* embraced a single-issue agenda with a focus on AIDS–even in the heyday years of AIDS activism. Individuals whose sole political focus is AIDS might feel that the gay community is leaving them behind, but something else is occurring here, different even from a reshuffling of political priorities. Osborn's statement about the need for vision and hope amidst deep grieving provides a clue to what is really going on, but not in her intended way.

The experience of deep grieving does *not* allow for "reaching towards the future." On the contrary, individuals who are in the midst of bereavement experience a heightened sense of focus on the past and profound barriers to looking forward. Only when mourning approaches completion does the human spirit begin to dwell again in the present and reestablish a connection with the future. Deep loss intrudes on life at every turn; "normalizing" cannot occur under these circumstance because suffering people are obsessively revisited by their loss. Yet activism in the gay community has seen a resurgence of energy and resources since 1992. Increasing demands for vision, long-range planning, and concrete achievements have been issued. How is it possible for the community to be "reaching for the future" if such activity is oppositional to a state of deep grieving?

The answer to this question is speculative but my thesis is that many of us have entered a stage of the epidemic where we have reached the limitation of our ability to mourn. This is a concept some of us would have challenged as impossible just a few years ago. When I talk with other gay men who have been greatly affected by the epidemic–some of us HIV positive and some of us HIV negative–and when I look honestly into myself, I find evidence that normal cycles of grief are not occurring. Close friends and lovers die and we feel nothing. Masses of gay men vow to avoid attending memorial services whenever possible. The sight of formerly handsome faces now narrowed and scarred with lesions no longer evokes an emotional response.

Studies of survivors of the Holocaust noted a parallel disruption in the ability to mourn:

> There seems to be an absolute limit to how much an individual is able to give up through grieving. The limitation is a double one–first there is only so much a person can grieve over *at one time*. . . . Secondly, there is an absolute or lifetime limit to what a given person can absorb in terms of either loss or accepting negative qualities of one's self. There are both qualitative and quantitative factors in the limitations on what can be dealt with through mourning. The quantity or quality of losses may be beyond one's capacity to integrate, e.g., when in the case of the Holocaust one's entire people and civilization perished.[7]

The mass psychic numbing occurring in large pockets of the gay community might easily be mistaken for disinterest or a return to other matters because the affect is similar. We accept such an assessment at our own peril. Rather than normalizing the epidemic and accepting its impact in our day-to-day lives, some of us who inhabited the gay community before the arrival of AIDS have been traumatized by it. Frozen feelings are quite different from psychological adjustment; they indicate neither engagement nor adaptation. The dissociation we experience as a lack of feeling, numbness, or ennui is familiar to many clinicians as a common response to mass catastrophes such as earthquakes, trainwrecks, or extreme historical events. Referred to as the "disaster syndrome," this pattern of behavior is a "psychologically determined response that defends the individual against being overwhelmed by traumatic experience. The person appears dazed, stunned, apathetic, and passive."[8]

When visions of cultural extinction again intrude upon the thoughts of many gay men, we are experiencing deepening psychological impact caused by relentless, progressive devastation of our identity and community. Rather than passively becoming bored and losing interest in AIDS, our shell-shocked conditions are caused by deep bruises on our psyches that become more severe as they continue to be unidentified and untreated.

This same phenomenon may be observed in segments of the community that exhibit a contrasting demeanor. Some rail against any change in our assessment of progress against the epidemic, believing

the maintenance of hope is possible only if we steadfastly cling to our original sources of hope and assume a studied optimism: a cure is on the horizon and gay men are no longer becoming infected. We repeat these tenets over and over to ourselves, like a mantra. The vast system of AIDS service providers and activists, attempting to fulfill their critical role as the source of collective hope, urges us to "be here for the cure" and insists that "hot gay men practice safe sex 100 percent of the time." Historian Allan Bérubé identified the impact of this kind of incessant optimism early in the epidemic:

> These attempts to protect us from our pain usually go unchallenged because they are often camouflaged with good intentions. They can lie hidden within consolations; they can be disguised by a well-meaning but patronizing desire to give us short-cuts to hope.[9]

Can we acknowledge a profound depression that has settled over a large portion of the community without losing the ability to forge collective response and fight for survival? If we opened our eyes and told the truth about the horrors that we endure, would we fall over the edge of the abyss?

I believe that any hope for collective survival is rooted in the realities of our lives, however harsh and seemingly unacceptable. Our inability to continue confronting the ever-intensifying manifestations of AIDS has brought us to the point of paralysis. As long as we continue on a path where our primary strategy for survival ricochets between total shutdown and a mass pep rally cheering on denial, we ensure our doom. Tactics of moralizing, distortion, and outright mendacity must be replaced by facing the realities of contemporary gay men's lives, however complex and severe. We need to take a hard look at Elisabeth Kübler-Ross's fifth stage: acceptance. Rather than leaving us on a barren desert of despair, an acknowledgment of what we endure may lead us to a blueprint for the regeneration of social order.

Our ability to pass through the deformed landscape of contemporary gay male life without engagement or emotion draws on a skill gay men develop early in life. Many of us have kept information about key aspects of our lives tucked discretely in the closet; this is the "don't ask, don't tell" treaty which has long governed interac-

tions between American gay men and the broader society. Feminist writer Susan Griffin believes this state of emotional shutdown is a common feature of contemporary life:

> There are many ways we have of standing outside ourselves in ignorance. Those who have learned as children to become strangers to themselves do not find this a difficult task. Habit has made it natural not to feel. . . . But this ignorance is not entirely passive. For some, blindness becomes a kind of refuge, a way of life that is chosen, even with stubborn volition, and does not yield easily even to visible evidence.[10]

Living at a step removed from ourselves creates a bizarre state of consciousness. Each day three paradoxical strains weave through many gay men's lives: (1) We witness significant amounts of death and disfigurement which cause us to feel profound threats to our individual and collective survival; (2) We pretend that this is not happening; (3) We analyze, understand, and articulate our situation using metaphors and theories that minimize our circumstances.

Initial work on the psychosocial impact of AIDS during 1981-1983 arose out of the need to cope with the sudden death of individuals. Our great challenge was to support each other through the shocking early death of a close friend or lover. We were informed by various theories of grieving, each constructed around a single, discrete death. The popular discourse on death and dying suited our situation and provided a conceptual framework for understanding AIDS.

Yet by 1985, the weight of death and infirmity had increased exponentially in epicenters of the epidemic. We found ourselves at the limit of the death and dying discourse's application to our situation, and sought new knowledge in theories which attempted to explain human response to a *series* of deaths. Thus "cumulative grief" and "multiple loss" became paradigms through which we understood what was happening to us. An extension of theories of death and dying, the literature of cumulative grief focuses on permutations of the process of mourning resulting from an accumulated overload of loss.[11] Theories of cumulative grief helped explain why we shut down for short periods of time, how our psyches integrated several deaths that occurred in the same period of time, and what effects repeated loss had on the grieving process.

Once again, by 1989, the impact of the epidemic had moved to another level for many gay men and discussions of multiple loss no longer seemed to fit the circumstances. One group of researchers, studying AIDS-related bereavement among New York City gay men, summarized the complexity of their losses:

> In 1981 the annual incidence of AIDS-related bereavement was less than 2%. By 1985 the noncumulative annual incidence had reached 18%. That figure continued to increase to 23% in 1987. These rates do not reflect the fact that of those who are bereaved, over one third have lost two or more close individuals within the same year. Some men have reported as many as six close losses in 1 year . . . whereas others have been chronically bereaved of close loved ones for 3 or more consecutive years of the epidemic.[12]

By the late 1980s, it seemed inappropriate to discuss the "stress" of the epidemic, or to talk about uninfected gay men as simply the "worried well." We realized we weren't affected simply by the fact that people had died, but the manner in which they had died. This was understood also among A-bomb survivors in Hiroshima:

> Survivors were thus affected not only by the fact of people dying around them but by the way in which they died: a gruesome form of rapid bodily deterioration which seemed unrelated to more usual and "decent" forms of death.[13]

The corpses had mounted beyond our most extreme nightmares, but what was worse was the dawning realization that the human death toll was only a portion of the loss we were suffering. Our intimate relationships, erotic response, and sexual subcultures were becoming freakishly deformed by the epidemic. We were pulled in many directions, weighing dead bodies against dead dreams. As one gay man said:

> I've been feeling the loss of unprotected sex for years. It's like mourning: it's a fact of life. Maybe at this point I'm so used to loss, having lost so many friends, that losing forms of sexual expression is just another loss. It's certainly nothing

> compared to having lost friends, so I feel I don't really deserve to mourn it too much.[14]

Because the epidemic seemed initially to have a slow, personal, and private impact, we have failed to consider seriously its parallels with earthquakes and other mass community disasters. The vast social science literature of disaster has a great deal to offer our understanding of current response to AIDS. Like a trainwreck occurring in slow motion, or a tidal wave hitting over a period of a dozen years, the epidemic has confronted survivors with an overwhelming volume of death and mutilation, and undermined the fragile social order. We stand now in the path of a tornado, our worldview alternately confused, overwhelmed, and fragmented, wondering whether we are on the brink of destruction or the brink of redemption.

One man summarized the conflict in this way:

> HIV is all around me: in my life, and in my community. I talk about it, I think about it, it's everywhere. Sometimes I walk in a foggy state, not really in touch with my feelings. Sometimes I feel it will overwhelm me, and I need to get away. But I can never really get away from it. Sometimes I feel if I tilt my head it'll come pouring out my ears.[15]

Many of the surviving population of gay men of all antibody statuses who comprised community before AIDS are in a stage of coping with the epidemic fraught with intensifying contradiction. We want to survive and we want to die. We want to comfort and we want to blame. We seek answers and we do not care anymore. While a careful analysis of the situation can promise neither to stop our suffering nor to end the current acceleration of new infections, it may provide an understanding of what is happening to us and some clues to what the future will bring. We may find a foothold of relief in circumspection, but no miracle cure for the malaise.

NOTES

1. Edward King, *Safety in Numbers: Safer Sex and Gay Men* (New York: Routledge, 1993), 170-172 discusses various other periodizations of the epidemic.

2. Elisabeth Kübler-Ross, *On Death and Dying* (New York: The Macmillan Company, 1969).

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7. Henry Krystal, "Integration and Self-Healing in Post-Traumatic States: A Ten-Year Retrospective," *American Imago* 48(1):104 (Spring 1991).

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11. Tom Grothe and Leon McKusick, "Coping with Multiple Loss," *Focus: A Guide to AIDS Research and Counseling* 7(7):5-6 (June 1992). See also Ray Biller and Susan Rice, "Experiencing Multiple Loss of Persons with AIDS: Grief and Bereavement Issues," *Health and Social Work* 15(4):283-290 (1990).

12. John Martin, Laura Dean, Marc Garcia, and William Hall, "The Impact of AIDS on a Gay Community: Changes in Sexual Behavior, Substance Use, and Mental Health," *American Journal of Community Psychology* 17(3):269-293 (1989).

13. Robert J. Lifton, *Death in Life: Survivors of Hiroshima* (New York: Random House, 1967), 59.

14. "Aaron" quoted in Will I. Johnston, *HIV-Negative: How the Uninfected Are Affected by AIDS* (New York: Insight Books-Plenum Press, 1995), 179.

15. From an unpublished interview by William I. Johnston, December 1, 1993.

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