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# Distancing the Past: New Forms of Discomfort with AIDS in the U.S

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## **Distancing the Recent Past: New Forms of Discomfort with AIDS in the U.S.**

John C. Hawley, Santa Clara University

In his Introduction to this collection, Gustavo Subero makes reference to the AIDS Quilt, a reference made especially significant since the year 2012 marked its 25<sup>th</sup> anniversary. The whole quilt had been last displayed in 1996; in the summer of 2012, 8,000 panels were rotated each day in the National Mall in Washington, DC. The quilt, composed of thousands of 3' x 6' panels (intentionally the size of a human grave), currently consists of over 48,000 panels honoring more than 94,000 individuals who have died of AIDS. In the early days of the quilt, in the 1980s and 1990s, the quilt grew at a rate of 11,000 panels a year; these days there are about 500 panels added each year. The executive director of the NAMES Project Foundation overseeing the quilt, Julie Rhoad, nowadays has sections displayed in various locales around the country, and tailors the choice of panels to fit particular communities (e.g., those commemorating Jewish individuals might be gathered and displayed in a synagogue, etc.), and Rhoad is intent that Americans “never leave a population uncared for” (Ulaby June 27, 2012: page [there's no page #, since it's an electronic source]). She recently noted that the newest panels are returning to the custom of commemorating individuals only by first name; these most recent additions, she says, are often for African American victims of AIDS. Though some like bell hooks argue that “black homophobia” is a myth resulting from the mistake of stereotyping African Americans as speaking with one voice (hooks), Rhoad asserts that this lack of a surname for some recent quilt panels is, suggestive of the stigma that still remains in that community against those with the disease, and repeating the stigma that attached to all early victims in the 1980s and that was similarly symbolized by the lack of surnames in the earliest panels. Thus, one might think that

the very idea of a quilt would be a perfect metaphor for the community of AIDS sufferers, yet for a number of reasons that is not actually the case. If they were laid out side by side the quilt's thousands of panels would stretch for more than 50 miles—though those commemorating African Americans who have died of the syndrome would make up only one half of one mile of those 50.

This suggests in a pictorial way one of several imbalances in the description, reporting, and imagining of the epidemic that have shaped the understanding of HIV and AIDS in the United States. According to the Centers for Disease Control and Prevention, in 2009, African Americans comprised 14% of the US population but accounted for 44% of all new HIV infections (“the estimated rate of new HIV infection for black men was more than six and a half times as high as that of white men, and two and a half times as high as that of Latino men or black women” [<http://www.cdc.gov/hiv/topics/aa/>])—yet the most common perception among the U.S. populace is that HIV is a white man's disease. This is a direct result of the skewed representation of the syndrome and its associated illnesses in the United States. Jacqueline Foertsch, for example, laments that we have seen “so far, mostly white, middle-class AIDS novels, plays and poetry” (1999: 57). If it ever was a white-man's disease, these most recent statistics suggest that things are changing in the United States. How that is happening is partially the subject of this essay.

## I. The Great Recoil: Subalterns, Aliens, Monsters, the Damned

For those who were sexually active at the time and are still alive, the growing fear of the early 80s in the United States is impossible to forget. Those who frequented the gay bath houses awoke one morning to a small article that belied its prophetic importance: this was the *New York*

*Times*'s memorable first article on the syndrome, written by their science columnist, Lawrence Altman. Published on July 3, 1981, and entitled "Rare Cancer Seen in 41 Homosexuals," his brief column-length entry was somewhat hidden on page 20, as if the event being described was a curiosity that some might take note of as roughly comparable to an outbreak of influenza in Thailand—but gays, at any rate, sat up and took notice, and began the worrying that would all-too-soon be confirmed for them on a growing and terrifying scale.

Even those most concerned did not know where to turn for more information about what was happening. *Newsweek*'s cover story of April 18, 1983, "was optimistically subtitled 'The Search for a Cure,' even though most of the experts working on the disease were still not certain what caused it, much less how to go about looking for a cure" (Kinsella 1989: 94). The article corrected earlier mistakes about how it was transmitted, and gave a thorough description of the various groups who had been contracting the syndrome. Nonetheless, misinformation, or a general lack of information, continued to confuse Americans. "Sex in the Age of AIDS" was *Newsweek*'s cover March 14, 1988, and it confidently spread incorrect information on the ease with which the virus was being transmitted (e.g., on toilet seats). At this time of unreliable information it is not surprising that the rest of the country tried its hardest to completely ignore the new health problem, principally compartmentalizing the threat as mercifully ghettoized within a group in society that was, well—the less said about them, the better.

This would eventually change, but it would take some screaming from those most affected. As has often been the case, the art community was focused on this issue well before the rest of society: by 1992 "500 professional artists in the United States put AIDS at the center of their work" (Reed 2011, 208).

Suggestions of a homosexual ‘sensitivity’ attuned to Aesthetic sensitivity, camp whimsy, or subtle codes were supplanted by images of homosexuals as forceful political advocates using collectively produced and mass-distributed imagery to advocate on their own behalf. (Reed 2011, 208).

Randy Shilts, the best early chronicler of the progression of the syndrome and American society’s head-in-the-sand resistance to acknowledging the growing threat, notes that it took the sudden eruption of gayness itself, like a ripping off of clown masks at some domestic birthday celebration, to awaken the country to what had been going on in their very midst for some years. “By October 2, 1985,” writes Shilts,

the morning Rock Hudson died, the word was familiar to almost every household in the Western world. AIDS. . . . Indeed, on the day the world learned that Rock Hudson was stricken, some 12,000 Americans were already dead or dying of AIDS and hundreds of thousands more were infected with the virus that caused the disease. But few had paid any attention to this; nobody, it seemed, had cared about them” (1987: xxi).

But they cared about Rock Hudson—less so, perhaps, after his sexuality became more widely known, but he was, nonetheless, not the “typical” gay: he was not mincing; he *looked* like a real man. If *he* was one of them, then how were we supposed to steer clear of that kind of person? Suddenly, after thousands had died miserable deaths, Americans *en masse* felt not compassion—but threat.

James Kinsella and Randy Shilts have argued that non-homosexual Americans had been lulled into a false sense of immunity by such prestigious institutions as the *New York Times*—not by what it had written about the syndrome, but rather by the fact that it had not reacted to it *at all*. And, as the newspaper of record, if they did not think it worth getting upset about, then it

appeared that life could continue as always, for the normal citizen. As Kinsella records, “‘At first AIDS was a gay story,’ said a senior [*New York Times*] editor, describing the news evolution of the epidemic at the *Times*: ‘And then it became a scientific story. And finally, it was a story about government.’ Only in that last phase did AIDS become an important ongoing story that reports throughout the newspaper were covering. Finally, the epidemic had become a *Times* story” (1989: 85). That was the Spring of 1984. By contrast, the *Times* had run thirteen articles on the Philadelphia outbreak of Legionnaire’s disease in *one week*, and three of them were on the front page—but “the first two years of the AIDS crisis prompted no front-page story in the *Times* on the epidemic” (1989: 66). Larry Kramer, a founder in 1982 of the Gay Men’s Health Crisis and later founder of the more militant ACT UP, wrote his play *The Normal Heart* (1985) to protest this lack of attention; the popular play “chronicles the unwillingness of government officials and much of the gay community to take AIDS seriously” (McCabe: 17).

On May 25, 1983, the assistant secretary for health and human services announced that AIDS was now a major health concern in the United States, prompting the *New York Times* to publish its first front-page story on the syndrome. Indeed, “in the summer and fall of 1983 American media’s coverage of the epidemic leaped almost 600 percent over the previous six-month period” (Kinsella: 73), prompted by the false news that the disease could be transmitted through casual contact. In that first decade in the epidemic, there were three peaks in AIDS reportage:

In 1983, fear of widespread and rampant infection was triggered by rumors that AIDS could be spread by simple household contact. In 1985, actor Rock Hudson’s death spurred a wave of interest because it appeared as though the disease was affecting even all-American types. And in early 1987, the discussion around containing the threat with

widespread testing for the AIDS virus caused another explosion in news coverage.

(Kinsella: 4)

Yet the public was surely getting mixed messages in the remarkable silence on the issue that continued in the highest reaches of the government. By 1986, “in public, the president had uttered the word ‘AIDS’ only once” (Kinsella: 3).

Less responsible journalists used the miasma to stir up trouble, typified by the *New York Post*, which ran a front page on October 12, 1987, stating: “‘AIDS Monster’: Cops: He may have given deadly virus to dozens of L[ong] I[sland] child victims” (Kinsella: 153). As the muffled hysteria spread, stoked by coverage such as the *Post*’s, Susan Sontag published a follow-up to her acclaimed study of the misrepresentation of cancer in American society, *Illness as Metaphor* (1978), in which she had criticized the “blame the victim” approach to coverage of that ongoing health scare. Ten years later, she saw in AIDS and its representation in the American press a new manifestation of what she had attacked in her earlier book, a manifestation that was all the more insidious because it broadcast a more compelling moral message of condemnation against those suffering from AIDS. As she writes,

The unsafe behavior that produces AIDS is judged to be more than just weakness. It is indulgence, delinquency—addictions to chemicals that are illegal and to sex regarded as deviant. [...] AIDS is understood as a disease not only of sexual excess but of perversity. [...] Getting the disease through a sexual practice is thought to be more willful, therefore deserves more blame [...] From the beginning the construction of the illness had depended on notions that separated one group of people from another—the sick from the well, people with ARC from people with AIDS, them and us—while implying the imminent dissolution of these distinctions. (26, 31)

This is, perhaps, at least not surprising coming from certain quarters in the early imagination of those who had contracted the virus. But it continued, and in 1997 Tim Lawrence concludes that, in portrayals of those with AIDS, what is underscored in much of the representation until, perhaps, the end of the twentieth century, is that,

debilitated, sick, and almost dead, people with AIDS are desperate in the face of their inevitable death. Such representations play into deep and reactionary cultural narratives. AIDS has become a convenient symbol for moral majoritarians who want to hammer home their sense of contemporary moral decay: the virus is a retribution for past and current sins, a deserved and necessary ending caused by the 'sexual revolution.' The disease has come to stand for the danger of sex outside the heterosexual family—in particular of gay sex, with the distinction between gay men and AIDS regularly erased, replaced by the equation Homosexuality = AIDS = Death. Doom, powerlessness, and hopelessness are central themes: there is little chance of the diseased person having a productive life; the overdetermined body images of the person with AIDS are evidence of inner depravity. (Lawrence 1997: 243; see, also, E. Albert)

As Sontag had observed, "The most terrifying illnesses are those perceived not just as lethal but as dehumanizing, literally so [...]. the signs of a progressive mutation, decomposition" (1988: 38, 41). Much like the "thingification" by the French colonizers that Aime Cesaire had condemned as the precondition for the enslavement of those in the Caribbean, those determined to distance themselves from gay men in the 80s and 90s in the United States had first to underscore that this was something that gay men had brought upon themselves, something that gave evidence of, and also brought about, their dehumanization: AIDS sufferers were to be condemned and ostracized, rather than welcomed into the broader civil society. Many gay

activists objected to the unrelenting visual portrayal of those with HIV and AIDS as passive emaciated victims, horrifying corpses that hadn't yet died.<sup>1</sup>

Suddenly, of course, gays were “appearing” all over the United States, and some in the most surprising places. Sontag notes that “to get AIDS is precisely to be revealed, in the majority of cases so far, as a member of a certain ‘risk group,’ a community of pariahs. The illness flushes out an identity that might have remained hidden from neighbors, job-mates, family, friends” (25). This continued to change the “face” of the homosexual in the United States, and thereby throughout the world: “we’re here, we’re queer, get used to it” eventually, though not in the beginning, became a watchword of defiance from these former pariahs. As with any shunned group, such massive rejection by the larger segment of society prompted a counter-offensive: a self-identification with the ghetto, now seen as a source of political power. To be revealed, willy-nilly, “confirms an identity and, among the risk group in the United States most severely affected in the beginning, homosexual men, has been a creator of community as well as an experience that isolates the ill and exposes them to harassment and persecution” (Sontag 1988: 25). There had already been, of course, the comparatively long-established

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<sup>1</sup> See Simon Watney’s “Read my lips: AIDS, art & activism” in his *Imagine Hope* (2000: 89-105). Christopher Reed records that:

At a 1988 MoMA exhibition of Nicholas Nixon’s (b. 1947) photographs of people with AIDS, activists from the group ACT UP (AIDS Coalition to Unleash Power) sat in the gallery with photographs of energetic people captioned as ‘living with’—not dying of—AIDS. The activists talked to viewers about their criticism of the art on display and handed out fliers that concluded with the demand ‘STOP LOOKING AT US; START LISTENING TO US.’ (Reed 2011, 209)

ghettoes—the Castro region in San Francisco, Greenwich Village in New York, Boystown in Chicago, etc.—but people were getting AIDS in Iowa, in Alabama, in Colorado. . . what in hell was going on?

In the face of apparent indifference on the part of government and the majority of Americans, gays in the major cities began to mobilize in self-defense. At the ACT UP rally in Albany, New York, on May 7, 1988, Vito Russo sent out a call to arms for the gay community to pull together. “I’m here to speak out today as a PWA,” he told his audience, “who is not dying *from*—but for the last three years quite successfully living *with*—AIDS” (Russo1990: 408). Unlike wartime, when a common enemy united a people in a shared experience, this “war” has divided Americans, Russo warns. Unlike us, he reminds the crowd, the “real people in this country,” those who are not “fags and junkies,” (408) do not have to spend days and months trying to acquire experimental drugs for exorbitant prices.

And they don’t sit in television studios surrounded by technicians who wear rubber gloves and refuse to put a body mike on them because it isn’t happening to them so they don’t give a shit. . . . They don’t spend their waking hours going from one hospital to another, watching the people they love die slowly of neglect and bigotry. . . . They haven’t been to two funerals a week for the last three, four, or five years.” (409)

Thus, Russo explicitly urges those who are actually enduring the onslaught to band together and fight for governmental recognition of their health needs. “And after we kick the shit out of this disease,” he concludes, “I intend to be alive to kick the shit out of this system so that this will never happen again” (410).

This was an underscoring of the power, the agency, that AIDS-sufferers could still manifest in taking at least some control—as a community if not as individuals—in the face of

what, at the time, was an unstoppable and horrible fate. Such independence from the heterosexual community in the United States was a double-edged sword—on the one hand, as with the black power movement, frightening the mainstream Americans who were already avoiding gays; on the other hand, actually getting some results from the elected officials in some parts of the country. Russo's and Kramer's anger in ACT UP did, indeed, offer a counter-narrative to that repeatedly inscribed by pictures of those with late-stage disease. Gaunt gay men with Kaposi sarcoma, mere skin and bones, had been flashed across magazines and television newscasts, but powerful men with the virus, whether gay or straight, had not yet become the kind of symbol that Magic Johnson became in 1991. As Tim Lawrence observes, writing only slightly after the success of the protease cocktail of medications began to be seen,

they are rarely portrayed as being active, fit to work, and able to have safe sex. As such, the subjectivity of the person with AIDS disappears, while the body with AIDS remains visible. Furthermore, the focus on the individual means that the public dimension of the crisis, especially the failure of governments to provide adequate money for medical research and information campaigns, has seldom been articulated. Individualization becomes a strategy of depoliticization. (Lawrence 1997: 243).

At the same time, while the syndrome itself was becoming better understood, there remained “the persistent representation of the person with AIDS as white, gay, middle class, and promiscuous” (244). This was the situation in 1994 when Timothy Murphy, reflecting on the ethics proper for what appeared to be a status quo for some considerable time into the future, writes that

Barring an unexpected breakthrough in research for a treatment or vaccine, HIV disease will be a permanent part of the catalog of human suffering. AIDS will certainly not be

defeated by ‘get tough’ measures whose attraction will diminish with passing years, rising costs, and the foreseeable inability of dramatic headlines to energize a public inured to the epidemic. It thus becomes important that the energy of anti-AIDS measures be sustained, that it cross generations. (1994:185)

Near the end of the twentieth century, Murphy suggests, the gay man is seeking “freedom to be HIV-positive, freedom from atavistic moral conceits that AIDS is a mark of difference signaling death, ruin, and social decay” (1994: 187).

## II. A Growing Keen: Compassion, Loss, Nostalgia

In the meantime, thousands of gay men were dying. Russo’s anger is clear, but even more obvious is the growing sense of irretrievable loss that was spreading throughout the gay community—which, thereby, was becoming even more obviously that: a community set apart from the larger group that was not as clearly traumatized. As evidenced in the AIDS quilt, many companions and friends sought ways to memorialize their loved ones.<sup>2</sup> Many novels, many memoirs, sought to keep alive the essence of the young men who had died prematurely. Many writers who had celebrated their new sexual freedom in the 70s and 80s, and who had watched friends suddenly die, looked with melancholy at what had been lost. Felice Picano’s 1995 novel, *Like People in History*, follows its characters through three decades, concluding with a determination to live, despite the losses:

I stood in the freezing darkness and desolation, and that radiator chugged and rattled and spouted, and its whistle hissed out steam so noisily and with such intensity of purpose that I slowly—amazing myself—became certain it really *did* have a purpose: to carry on

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<sup>2</sup> See Simon Watney’s “Acts of Memory” in his *Imagine Hope* (2000: 163-168).

as long as it had the power to do so, and while it remained active, to do what it did best—even if that meant attempting to warm up the entire immense, vitrescent, frigid, indifferent night. (512)

A great number of gay readers appreciate the novel's fictionalized history of the crucial decades from 1960 to 1990 when so many milestones changed American perceptions of gay and lesbian life in the United States—an era of personal liberation and intense support within the gay community that many look back upon with nostalgia.<sup>3</sup>

Paul Monette's loving tribute to his lover, *Borrowed Time: An AIDS Memoir* (1988), records the small turns taken in the last months and days in a loved one's life, almost shouting to the world that this person mattered, despite his relative anonymity and comparative youth. Monette identifies the apparent randomness with which the virus struck members of the gay community in the early days, as if it were playing with individuals who tried to take precautions against an enemy that was not well understood. He and his lover were very careful in their sex lives, starting in 1982, yet Roger was diagnosed as positive in 1985. Monette's frightened observation records the realization by many that they had begun taking precautions a bit too late:

A lot of us were already ticking and didn't even know. The magic circle my generation is trying to stay within the borders of is only as real as the random past. Perhaps the young can live in the magic circle, but only if those of us who are ticking will tell our story.

Otherwise it goes on being *us* and *them* forever, built like a wall higher and higher, till you no longer think to wonder if you are walling it out or in. (5-6)

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<sup>3</sup> One blogger records that “it has helped me dust off the glitter on the faded red sequined hot pants of my own gay identity.” Daniel G. at

[http://www.goodreads.com/book/show/449189.Like\\_People\\_In\\_History](http://www.goodreads.com/book/show/449189.Like_People_In_History)

We see in Monette's metaphor a prescient sense of the split within the gay community between those who were positive, and those who remained free of the virus—suggesting, perhaps, a split in generations, as well: the young, with more warning, now careful to avoid the older and contaminated in their midst, and thereby nurturing a deceptive sense of invulnerability.

Monette records the sense of helpless ignorance that haunted those with the earliest diagnoses. "It's not till you first hear it attached to someone you love," he writes, that you realize how little you know about it. My mind went utterly blank. The carefully constructed wall collapsed as if a 7.5 quake had rumbled under it. At that point I didn't even know the difference between KS and the opportunistic infections. I kept picturing that swollen gland in his groin, thinking: What's *that* got to do with AIDS? And a parallel track in my mind began careening with another thought: the swollen glands in my own groin, always dismissed by my straight doctor as herpes-related and 'not a significant sign'. (7-8)

Many pages later, he's awakened by a phone call informing him of Roger's death, and his memoir ends much as did Picano's novel, and as do so many of the novels and memoirs of the late 80s and mid-90s: "I swam back to bed for the end of the night, trying to stay under the Dalmane. Putting off as long as I could the desolate waking to life alone—this calamity that is all mine, that will not end till I do" (342); Monette died of AIDS-related complications in 1995. This fear of being alone for the rest of one's life, this lesson of the dangers of surrendering to loving another gay man in the age of an epidemic that appears to be strangely targeted on the same community that you have tried hard to build, this yearning for a happier time of innocence, runs through all these accounts.

Poets also sought to capture in words some semblance of the AIDS experience and the appalling toll it was taking in the gay community. Thom Gunn was preeminent in this group, especially in his 1992 collection, *The Man with Night Sweats* (1992), in which he “assembles an elegiac response to AIDS reminiscent of the AIDS Memorial Quilt, a ‘patched body’ that represents both grief and hope and stands as a successful form of nonseparatist political action” (McNeil2012: 36). Playwrights and eventually screenwriters also produced works to commemorate the loss, and most honored among this group was Tony Kushner’s *Angels in America* (1993). This Pulitzer-winning pair of plays accomplishes several important feats: it encourages its audience to accept the presence of the epidemic in their midst as long-term, and it incorporates AIDS-sufferers into full citizenship as Americans. In this second goal Kushner’s play distinguishes itself from Larry Kramer’s *The Normal Heart* (1985), which Terry McCabe describes as “the last great play that posited gay life as a subculture within, but separate from, American life” (17). Kushner’s play not only sees the gay subculture as having been increasingly incorporated into mainstream American society, but also makes bold to see its suffering as emblematic of American citizenship in the late twentieth century. Claudia Barnett argues that Kushner’s plays suggest that

AIDS is not only death but a precondition for life, as Prior [the central character] learns on his prophetic journey. He *sees* because he has AIDS; he survives because he sees; and, in the end, he shares his vision with humanity [...] This middle space [of comparative hope] is [...] modern drama’s positive pole of Purgatory, a space of possibilities [contrasting with] the negative extreme of Samuel Beckett’s drama. (Barnett2010: 472)

This is a mundane version of the divine *afflatus*, one supposes. For Barnett, “Kushner’s Purgatory [...] [is] a murky space of promise and loss—a journey to Heaven and back, a walk on damp leaves, a body ridden with disease—from which some emerge blessed [...] [and] the blessing is Purgatory” (473). It is as good a metaphor for the condition of HIV-sufferers as any, perhaps: living somewhere between heaven and hell, a metaphor that allows one to avoid complete despair. “Purgatory,” Barnett writes, paraphrasing Stephen Greenblatt, “is a story that allows the dead to live on and be remembered” (2010: 492).

Indeed, “Since *Angels [in America]*, playwrights no longer write gay-people-as-victims scripts” (McCabe2003: 17). Nonetheless, if there were those like Kushner attempting to clear a space for some possible hope for the future, one emotion that also informed all these memoirs, the novels, plays and poems written by those of the earlier generation, was a recognition and simmering resentment that the ghettoized world of camaraderie and sexual experimentation was quickly transmogrifying into something hollow, bland and pedestrian, if not reactionary.

Edmund White (2001), in his introduction to a collection of brief memoirs of artists recently dead from AIDS-related diseases and written by other artists who were their friends, typifies the nostalgia:

Most of these memoirs [...] are about a specific time, one that Benjamin Taylor calls ‘the sunlit late seventies’ [...] I suppose we should never forget that the one social milieu that was open to the homosexual in the period before Stonewall was the bohemian—and this acceptance defined much of subsequent gay artistic history. The whole idea of making art—of setting up shop in workaday America and declaring oneself an artist—was as unthinkable to most Americans of the epoch as was sexual dissidence (4)

This world died out with AIDS. In the late eighties magazines liked to publish full spreads of photos picturing all the talent wiped out by the disease, but what these photos didn't suggest was that a way of life had been destroyed. The experimentalism, the erotic sophistication, the prejudice against materialism, the elusive humor, the ambition to measure up to international and timeless standards, above all, the belief that art should be serious and difficult—all this rich, ambiguous mixture of values and ideas evaporated. (9)

Understandably, the great majority of these memoirs are written by men. One effect of the route that the epidemic was taking in its manifestation principally in men, though, was the increasing leadership roles that lesbians were assuming in maintaining the overall gay/lesbian community. This was noted with gratitude by gay men, yet some critics, in looking back over these years, lament that literature by men still does not honestly reflect these demographic leadership changes, and instead “gay authors’ continued efforts to downplay or ignore women’s important roles as supporters, healers, activists, and fellow-sufferers dissolve the radical potential of the AIDS text into the misogynist tradition that typifies the heterosexualized Western canon” (Foertsch 1999: 57).

The memoirs multiply as the years advance, and often at various removes from the individuals being commemorated: written by observers less emotionally connected to the dead, or by heterosexual caregivers whose medical specialization necessitated a constant and repeated contact with AIDS-related deaths. Abraham Verghese is one of these doctors, someone who found himself in 1985 early in his career working in a small town in eastern Tennessee and unexpectedly overseeing Johnson City’s first case of AIDS. The response among his co-workers is, by now, a familiar one that has generally dissipated:

Word spread like wildfire through the hospital. All those involved in his care in the ER and ICU agonized over their exposure. The intern remembered his palms pressed against the clammy breast as he performed closed-chest massage. Claire remembered starting the intravenous line and having blood trickle out and touch her ungloved skin. The respiratory therapist recalled the fine spray that landed on his face as he suctioned the tracheal tube. The emergency room physician recalled the sweat and the wet underwear his fingers encountered as he sought out the femoral artery. Even those who had not touched the young man—the pharmacist, the orderlies, the transport personnel—were alarmed. (1994: 10)

Not surprisingly, “the hometown boy was now regarded as an alien, the father an object of pity” (11). The death of the young man was not the end of the hospital’s panicked dilemma, since the contagion was still a novelty, even four or five years into the epidemic. Thus, the question of quarantine becomes an issue, exemplifying the insults against which Vito Russo railed.

The respirator was unhooked and rolled back to the respiratory therapy department. A heated debate ensued as to what to do with it. There were, of course, published and simple recommendations for disinfecting it. But that was not the point. The machine that had sustained the young man had come to symbolize AIDS in Johnson City. Some favored burying the respirator, deep-sixing it in the swampy land at the back of the hospital. Others were for incinerating it. As a compromise, the machine was opened up, its innards gutted and most replaceable parts changed. It was then gas disinfected several times. Even so, it was a long time before it was put back into circulation. (12)

This complex emotional response to AIDS suddenly manifesting itself in one’s own familiar surroundings, away, one had thought, from the gay ghettos that one could happily avoid and

never discuss, typified the early years of the epidemic. In towns tucked away in rural America Christian charity warred with atavistic self-preservation. Gays had always seemed alien and wrong-headed; now there was reason to more openly say so.

### III. Rebirth: Inscrutable Territory, and Amnesia

In more recent times, a sense of stark loss among those with HIV and their communities has been replaced by an ironic sense of humor, as if life itself has now become somewhat less serious, less meaningful, because one is never again fully alive and happy. Consider, for example, Alistair McCartney's *The End of the World Book* (2008), which is written as an apparently casual set of definitions, as in the following:

**Porn, Pre-Condom.** Just like you, I love watching pre-condom porn. My favorite film is probably *He Seems to be Reaching for Something*, directed by Praxiteles, the greatest Greek gay porn director of the 300s BC. In this film, some of the Gods (today we call them cholos,) wander around, cruising through the maze of antiquity, while others just stand around, waiting to be picked up, with one hip thrust out into space in the pose that was dubbed the S-curve of Praxiteles, the S standing for sex. All of them have a look of dreamy, ice-creamy contemplation on their faces; life's good in the sex-curve. They all appear very relaxed, probably because they are Gods, not to mention the fact that AIDS is such an impossibly long way away. (197)

The wry joking accompanies a callow hankering for some earlier time of freedom and experimentation that McCartney, born in 1971, has heard about from an older generation of gays.

Such humor, tentative and detached though it may be, will nonetheless strike some older readers whose friends or lovers have died terrible deaths, as premature, to say the least. As we

have noted, the 1980s and well into the 90s had been an era in which the medical community had grown almost as fearful of the syndrome as had the general public. In comparing the epidemic with earlier diseases that seemed unavoidable—and therefore became oddly attractive—Sontag describes the “syphilis-envy” of 1920’s Romania, in which artists would embrace the disease as supposedly bringing with it, just before madness, a great burst of creative intensity. “But with AIDS,” she writes, “—though dementia is also a common, late symptom—no compensatory mythology has arisen, or seems likely to arise. AIDS, like cancer, does not allow romanticizing or sentimentalizing, perhaps because its association with death is too powerful” (1988: 23-24).

Palliative care seemed the only option for doctors, regardless of the sophistication of their hospital setting. “In the absence of a magic potion to cure AIDS,” writes Verghese, “my job was to minister to the patient’s soul, his psyche, pay attention to his family and his social situation [...] My training had not really prepared me to be this kind of doctor” (1994: 271-272). It was becoming abundantly clear that all workplaces, and not just hospitals, would need to put in place policies and procedures that had been well-thought-through, as advised by Earl C. Pike, the AIDS and Training Coordinator for the Chemical Dependency Program Division of the Minnesota Department of Human Services: “I have come to recognize,” he writes in 1993, how critical the organization’s role is, and will be, in fighting this epidemic—both in terms of treating clients and employees with HIV or AIDS well, and in terms of providing education and support for behavior change to reduce the transmission of HIV [...] Although debate continues in some arenas, the vast body of knowledge, and the mass of policy that has derived from it, is constant. Administrators need not avoid policy development for fear that ‘things will change.’ (1993: xiii-xiv)

Pike's words clearly indicate that, by 1993, there was a growing understanding that the epidemic was here to stay, and was likely to get worse. The need to institutionalize protocols for dealing with AIDS patients accompanied a growing understanding that, with an escalating epidemic, caregivers themselves were experiencing severe psychological problems of despair and burn-out, and physical exhaustion. Reflecting in 1995 on his work with Shanti, a worldwide organization of volunteer caregivers working with the dying, its founder, Charles Garfield, writes that "I think it's clear by now that acknowledgment and support are vital for those people who work and sometimes live in the vortex of trauma and loss that are part of the AIDS pandemic" (283).

This approach also suggests that the human suffering that had become so evident throughout the United States had slowly worked as a solvent on the hardened prejudices of American society. Somewhat surprisingly—but only after years of terror-mongering in some quarters—American society was growing more understanding of, if not respectful of, gay men in its midst. As Gregory Herek argues in 1997, "AIDS could have created a major backlash of prejudice and hostility against gay men and lesbians, but it did not" (212), and the gay community had a hand in this. He asserts,

The [gay and lesbian] community recognized early on that AIDS could be used to eradicate the hard-won victories of the 1970s, and it organized quickly to prevent such an outcome. Gay people were supported in this effort by largely sympathetic public health and medical establishments that incorporated civil rights safeguards into their traditional responses to communicable disease [...] Although members of the political right attempted repeatedly to use AIDS as a justification for repressive measures, they failed because the public became convinced that such measures were unnecessary and ineffective. (213)

As it gradually became clear how many Americans were dying from AIDS, and as authorities extrapolated from this figure to estimate the appalling number of those infected with HIV who did not yet themselves know, changes slowly came to American attitudes towards those in their midst who had no future, except that of a horrible death. As noted above, “by creating new visibility for gay people, their relationships, and communities, the epidemic may have hastened the emergence of new public identities and roles for gay men and lesbians” (Herek 1997: 212-213). And six years after he saw his first patient, Dr. Abraham Verghese recognized the changes. “I think if [that first AIDS patient’s] voyage were to happen today,” he writes in *My Own Country* (1994), “he might find a community in Johnson City better equipped to deal with him, to accept him. I have faith in the town and its people. I remember the acts of human kindness that illumine our world” (429). This optimism, whether supported by any facts or not, can be comforting in an age of hopelessness in the face of the syndrome, which was still the case in 1994 when Verghese published his book. This changed, beginning around 1995, when the representation of sero-positivity as an inevitable death sentence seemed miraculously to fight its way towards the more hopeful representation of HIV infection as a manageable, though chronic, set of health problems that could be managed with a very careful regimen of very expensive medications. The epidemic, though by no means over, was now becoming treatable. This regularization of the prognosis for the virus evolved further in October 2012, when a home test kit became available over-the-counter, very similar to a home pregnancy test. Such a test would likely never have been produced if there were not also some hope that a positive test result would not lead to a spike in suicides. As one writer notes, “in the past, some advocates have opposed home testing on various grounds: that finding out one is infected is so stressful that it should be done only in the presence of a counselor, that the uncertainty around the test would be stressful,

and that getting a false negative could encourage someone to have unprotected sex. But since the disease is no longer an inevitable death sentence and it is clear from the epidemic's continuing spread that Americans are having unprotected sex anyway, those objections began to pale" (McNeil: 2).

The medical advances were a belated echo of the legal corrections that had been steadily transforming the role of gays in American society. In 1986, for example, the Supreme Court upheld, in *Bowers v. Hardwick*, laws against sodomy (and 66% of Americans felt that homosexual relations between consenting adults should be illegal). Just 17 years later, in *Lawrence v. Texas* (2003), the court overturned that ruling (and 60% of Americans felt that homosexual relations between consenting adults should be legal). "What made the difference between the 1986 and 2003 rulings," writes Terry McCabe, "was not some new legal theory, but society's growing acknowledgment of gay rights as civil rights, plain and simple" (McCabe: 17).

From an economic point of view, many companies came to recognize this newly-visible community of gay (HIV positive) men as a potential niche market, and this had the welcome side effect of validating the group as representatives of a much larger, and arguably culturally influential "tribe." Sherry Wolf writes that

The gay advertising drought of the eighties, resulting from the explosion of AIDS and a spate of gay militancy that advertisers shunned, gave way in the nineties to a dramatic rise in national brands targeting the market. One spokeswoman for Miller beer explained her company's ubiquitous ad campaigns in gay neighborhoods and bars matter-of-factly, "We market to gays and lesbians for business reasons because we want to sell out product to consumers. It doesn't get more complicated than that." (Wolf 2009: 153).

Admittedly, the stated motivation is not very complicated; in fact, it is perfectly normal, and that is perhaps the point. Gays and lesbians in the nineties had become a legitimate, visible, vocal, and courted market in the United States. They had not been, heretofore.

The emerging, if sometimes begrudging, acceptance of homosexuality in American society wrought unexpected changes in attitude among this “target” population of new customers. The evolution of an effective “cocktail” of pills coincided with an odd combination of, on the one hand, what Edmund White describes as “a new queer Puritanism—the appearance of many gays who want to marry, to adopt, to blend in, and to become virtually suburban” (2001: 9) and, on the other hand, the rise of “barebacking,” anal copulation without the use of a condom.

The changing consciousness is well-encapsulated in two entries in Alistair McCarthy’s novel: first, *Extinction*:

Sometimes when I look in the mirror on the medicine cabinet in our bathroom, I am reminded of the time my mother took me to the Museum of Natural History. We saw a tiny fossil of a small, strange, winged creature. The pattern of its wings was so delicate. It was as if the ancient bird was hurtling toward us, flying through the slate-gray rock. As I looked, my face pressed up to the glass case, some joy in me snapped.

Thought took us to the brink of extinction, but on further reflection, we have decided to come back. (78)

Second, *Masque of the Red Death, The*. In the entry with this title McCarthy compares Poe’s story to a porn movie well-known in the gay community, *The Other Side of Aspen*, in which gay skiers welcome a masked stranger to their lodge, without fear, which is the opposite of what Poe’s characters do—Poe’s characters more understandably flee death.

However, whereas the guests in Poe's story are horrified by this ghoulish masked stranger, who is Death himself, and attempt to turn away—an attempt that of course in the end proves to be futile—the guests in *The Other Side*, perhaps knowing that there is no longer any point in hiding and that any attempt to do so would be ineffectual, welcome the masked stranger, who is Death himself, into the fray. (158)

This is an interesting commentary on the 1983 movie, produced in the years when death did seem to be seriously stalking the gay community and last, desperate orgies at a snow lodge might have special appeal. What McCarthy might have considered, however, are the subsequent films in that series. *The Other Side* part VI, for example, was released in 2011—and the participants are visibly careful to use condoms. One twenty-year veteran pornography director, Chi Chi LaRue, has decided never to film bareback scenes, and includes a warning against such activity in each of his films. Many other directors have clearly come to other conclusions, and are trumpeting the erotic potential of unprotected anal intercourse. The point McCarthy makes about the carpe diem atmosphere in which the first film in the series was made, in any case, makes great sense. What does not make as much sense, is the quickly expanding market in “bareback” pornography in the gay community and, of more concern for those tracking increasing rates of STD and HIV transmission, the apparently increasingly popular engagement by younger gay men in barebacking itself.<sup>4</sup> This is accompanied by a truly bizarre activity known as bug-chasing, in which an individual actively seeks out HIV-positive men who are willing to bareback and pass the virus along; this is called “gift-giving” (Cooper 2003: page [this is a web resource,

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<sup>4</sup> A clear and concise introduction to this rapidly changing topic is offered on the ‘bareback’ entry on Wikipedia [http://en.wikipedia.org/wiki/Bareback\\_%28sex%29](http://en.wikipedia.org/wiki/Bareback_%28sex%29) accessed 12 July 2012.

so has no page]). Such activity seems very much of a piece with the amnesia that we will discuss in what follows.

Queer theorists nowadays, as well as some older gay men, criticize a growing comfort among gays with settling in as normal American citizens: “There is a transition under way,” writes one, “in how queer subjects are relating to nation-states, particularly the United States, from being figures of death (i.e., the AIDS epidemic) to becoming tied to ideas of life and productivity (i.e., gay marriage and families)” (Puar: 2007: xii). Some, principally from the Stonewall generation, lament what is being lost in the process of incorporation and domestication. “In the arts an edginess, a quirkiness, even a violence has given way to stylistic blandness,” writes Edmund White:

Gay fiction has now become a wading pool for minor talents to dabble in; the novels often sound transcribed from the film scripts they long to become: novel as novelization. Publishers, who recognize that few gay novels can be expected to sell more than twenty thousand (or even ten thousand) copies, are now content to throw dull genre fiction out into the world and let it sink—or paddle—unaided. Gay bookshops are closing down (from seventy-five two years ago to fifty now [2001]), and most of the serious gay literary publications (with the exception of the *James White Review* and the *Gay and Lesbian Review*) have stopped publishing. A tackiness, a sort of steroid-injected sex-shop conformism, has replaced the old transgressiveness of gay art. (2001: 10)<sup>5</sup>

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<sup>5</sup> Viewed from a broader perspective, though, Christopher Reed argues that:

By the turn of the millennium—a century after Wilde made the aesthetically sensitive, persecuted homosexual a paradigm for the modern artist and a quarter century after Warhol made camp a paradigm for postmodernism—the connotations of ‘gay art’ equally

With the greater visibility of gays in American society, there seems to be a whiff of “you can’t go home again” in White’s lament that in contemporary fiction, film, and television “what isn’t being shown are gay men in a gay world, people as fully expressed socially as sexually” (10). And, one must admit, the old gay enclaves have now become remarkably similar to heterosexual communities, extremely commercialized places that are not very transgressive, at all (if one overlooks the proliferation of pornography shops—which, arguably, do not fill the social role that bookstores once did). White and his brethren lament the loss of gays as countercultural, as anti-institutional. One might think of the comparative seriousness of the Mormon church in *Angels in America* versus its silliness in *Book of Mormon* (Trey Parker, Robert Lopez, Matt Stone, 2011), where the message, while surely informed with heavy-handed criticism of the church’s hypocrisy, seems to be encouraging the audience at every turn to shout: “let’s have some fun, the crisis has passed.” To give the playwrights their due, there is a compelling song early in the musical that reminds the audience that the virus is decimating large percentages of the African population.

Increasingly, some critics are objecting to what they describe as a comforting amnesia, an unseemly putting-behind-us of the epidemic, as if it were over, as if there were not many thousands of Americans (let along those in the rest of the world) living with HIV. Richard Canning laments the erasure of this reality from the popular arts by a younger generation of gays that just wants to get the party started. “Again and again,” he writes, “popular narratives have returned us to the convenient, ubiquitous storyline of coming to terms with one’s marginal sexuality and ‘coming out’” (2011: 26)—in other words, to the world of adolescence.

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included the ‘in-your-face’ anger, political engagement, and sexual explicitness associated with ACT UP, Mapplethorpe, and Wojnarowicz. (Reed 2011, 228).

The wider world of HIV infection, which continues at epidemic levels and is decimating host populations, must expect no look-in, barring the rare, exceptional art house vehicle [...] Surely there is something massively forgetful about our contemporary moment and its fostering of all manner of GLBT identities in, as it were, a historical bubble—one that avoids the years 1981 to 1997, and which pretends that the world post-1997 is HIV-free.

(27)

His point is that the “drug-cocktail-dependent person [...] no longer experiences—if s/he ever did—the visceral, salutary uplift of restorative good health, but instead plows on in the imperfect, always uncertain here and now” (26), but this is rarely represented in novels, poems, or films in the United States in the twenty-first century. This gives the impression that, as gays increasingly assimilate, their motto has become: the less said, the better, as far as the bad old days of AIDS are concerned.

This concern underscores the problem that historians of the gay liberation movement have with some queer theorists, whom they accuse of papering over the messiness of the early decades, including the horrors of AIDS, as a tactic for moving on. What is objected to is “the gesture of disavowing a gay past in order to procure a queer rigor” (Castiglia/Reed 2012: 5). This was especially true in the first wave of queer theory, which Christopher Castiglia and Christopher Reed suggest “arose at a particular moment for reasons other than greater intellectual acuity and [...] at least one of those reasons was the general unremembering that took hold in the aftershock of the first years of AIDS” (5) The community was traumatized, and reacting as a trauma victim would to the assault from an unstoppable epidemic. “It was that context that not only demanded a ‘queer subject,’ solitary and outside history, but that also

detached itself from its intellectual roots in ways that made ‘gay theory’ seem an anachronistic oxymoron” (5).

The second wave of queer theorists, they contend, is more “historically grounded, socially engaged, multiethnic, and sensitive to the spatial and temporal operations of sexuality” (4), and thus has helped mitigate what the two critics call “coercive unremembering and queer counter-memory” (4), but they nonetheless want to reaffirm, in the face of some queer theorists, that “sexuality *should* matter: it should be the thrilling, dangerous, unpredictable, imaginative force it once was and no doubt still is, although more often quietly and out of public sight” (9)—thus, the new puritanism that White sees dominating today’s gay community.

Much like Edmund White, Castiglia and Reed lament what has been lost since the unifying struggles against a deadly disease:

The collective trauma of AIDS was a fact of life. Just when we most needed models of culture that would allow us to mourn our losses and strengthen ourselves to resist the conservatism that made those losses seem inevitable, just when our pleasures and the cultural spaces for enjoying them were most precarious, we began a process of temporal isolation, distancing ourselves from the supposedly excessive generational past in exchange for promises of ‘acceptance’ in mainstream institutions. The signs of these losses are everywhere: in the monopoly of ‘gay marriage’ in place of debates about sexual world-making; in the assimilation of sexual minorities and the subsequent abandonment of supposedly restrictive gay ‘ghettos’; in the insistent invisibility of AIDS or sexual liberation in popular media; in the dearth of radical, public, and collective challenges to mainstream institutions. (9)

However wounded such authors may legitimately feel themselves to be, though, this brief survey cannot conclude without a return to the observation made in its opening: there is at least one community in the United States in which AIDS has not been brought under control. For a complex set of reasons that would go beyond the scope of this essay, the various African American communities are still underrepresented in fiction, film, and gay community newspapers. Marlon Riggs's 1989 film, *Tongues Untied*, Keith Boykin's *Beyond the Down Low* (2004), and Cathy Cohen's *The Boundaries of Blackness* (1999) demonstrate the complexities of silencing and shame within black communities on this issue, but also indicate the racism within gay white America that perpetuates the marginalization of this group of gay men. The same could be said, though less uniformly, about the representation of Hispanic men infected with HIV. The amnesia that is growing among a younger white generation of gay men, the "de-generation" that Castiglia and Reed lament, literally pales in comparison to the inadequate representation of AIDS among America's racial minorities.

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