

Grieving in an Apocalypse:

The AIDS Crisis and the Dawn of Patient-Directed Healthcare

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Introduction¹

It comes like a slowly dawning horror. At first, you are equipped with a hundred different amulets to keep it far away. Then someone you know goes into the hospital, and suddenly you are at high noon in full battle gear. They have neglected to tell you that you will be issued no weapons of any sort. So you cobble together a weapon out of anything that lies at hand like a prisoner honing a spoon into a stiletto. You fight tough, you fight dirty, but you cannot fight dirtier than it.

—Paul Monette, *Borrowed Time*²

It is difficult to understand, or even articulate, the shame that individual AIDS patients and their families suffered during the darkest years of the crisis. For much of the public, the perception was that people contracted AIDS because they took part in immoral behaviors. Whenever I was able to summon the courage to disclose to someone that my own father was a Person With AIDS³, inevitably, the next question would be “How did he get it?” The practiced answer that I usually gave was “Why does it matter?” but the implication was that it would have been a terrible shame if it was from a blood transfusion, but it was justice if he had been in a gay relationship or an IV drug user. Susan Sontag has explained this by writing, “AIDS is understood ... as a disease incurred by people both as individuals and as members of a ‘risk group’ – that neutral-sounding, bureaucratic category which also revives the archaic idea of a tainted community that illness has judged.”⁴

¹ I would like to thank the following people for their support in writing this paper: Dr. Andrea Maestrejuan, Dr. Shelby Balik, Dr. Meg Frisbee, MUPPETS, the anonymous reviewers who provided feedback, Keturah Barchers, Dr. Melissa Root, Angela Rivera, and my wife, Elizabeth Brinkman, for her unwavering encouragement, support, and love, not only during the writing of this paper, but throughout my entire college education. It goes without saying that this project would not have been possible without my father, Garry, and my mother, Julie. They’ve been with me the entire time, from 1989, when they realized that I, as a twelve year old, was too smart and far too curious to simply accept a new pill bottle in the medicine cabinet without question (spoiler – it was AZT).

² Paul Monette, *Borrowed Time* (New York: Harcourt Brace Jovanovich, 1988), 2.

³ Hereafter referred to as “PWAs.”

⁴ Susan Sontag, *Illness as Metaphor and AIDS and Its Metaphors* (New York: Doubleday, 1990), 134.

Consider the following joke, which I remember hearing in the playground at my grade school at recess:

Q: What does “gay” stand for?

A: Got AIDS yet?

Or perhaps this one, often told by Wall Street stockbrokers in the 1980s:

Q: What’s the worst thing about getting AIDS?

A: Having to convince your parents that you’re Haitian.

The four main groups at risk for contracting AIDS were sometimes referred to as the “4-H Club:” homosexuals, heroin addicts, hemophiliacs, and Haitians.⁵ The implication of the second joke, which flourished before HIV was found in the national blood supply, was that being a Haitian was the only reason for having AIDS that wasn’t morally objectionable, and since the joke tellers were usually white men of privilege, no one would ever mistake them for a Haitian.

Jokes like these highlight the abject shame that PWAs and their families (if they were lucky enough to have families) suffered. This only added to the misery they faced, since doctors had no idea how to help sufferers. Most patients suffering from a disease can get treatment for it. Generally, symptoms can be treated, and the impact of diseases can be mitigated, if not cured. At the beginning of the AIDS epidemic, all that was known about it was that diseases which were easily fought off by the body’s own immune system were taking hold in gay men in urban centers like New York, San Francisco, and Los Angeles. HIV, the virus that causes AIDS, would not be discovered until 1983. At the beginning of the crisis, no one knew what caused this “gay

⁵ Dennis Hall, “No Laughing Matter: Values, Perception, and the Demise of AIDS Jokes,” *Journal of American Culture* 16, no. 2 (June, 1993): 25, <https://doi.org/10.1111/j.1542-734X.1993.00025.x>, Mirko Grmek, *History of AIDS: Emergence and Origin of a Modern Pandemic* (Princeton, NJ: Princeton Univ. Press, 1990), 31.

cancer,”⁶ where it came from, or how people got it. In the face of a lack of medical knowledge, PWAs found that their only choice was to create a community among themselves where they could share ideas for treatment of symptoms among each other, support each other, and take charge of their own treatment, working closely with doctors in directing their own care.

Part I: Denial/Bargaining (1981-1983)

The novel *The Plague* begins with a doctor leaving his office when he feels “something soft under his foot,” a “dead rat lying in the middle of the landing.” The doctor kicks it aside, thinking nothing more of it.⁷ For the gay men of San Francisco, their rat was a tiny article deep in the *Bay Area Reporter (BAR)* that many may have just skipped over on the way to more interesting sections of the paper, like the local sports section one page later, or the numerous personal ads in the back. “Whatever the cause,” the blurb intoned, “health officials are baffled by an unusual increase in Kaposi’s Sarcoma (KS), a type of cancer, within the past 30 months.”⁸ This was in response to an article that appeared two weeks earlier in the *New York Times*.

“Sing out on the 4th!” proclaimed the nearly full-page advertisement for Independence Savings Bank on page A20 of the Friday, July 3, 1981 edition of the *New York Times*. The patriotic bombast of the advertisement, no doubt spurred by the release of the American hostages from Iran and the collective optimism over Ronald Reagan’s inauguration just seven months earlier, threatened to squeeze the actual article off the page, a solitary, narrow column down the

⁶ Because the first cases were among homosexuals, and the evidence for the disease was Kaposi’s Sarcoma, a rare skin cancer, it often was called the “gay cancer.” If the infection that presented was PCP (pneumocystis carinii pneumonia), it was called the “gay plague.” Eventually, it was determined that the diseases were related, so all opportunistic infections received the acronym GRID (Gay Related Immune Deficiency). Once it spread to Haitians and to IV drug users, it needed a new name. In 1982, the acronym AIDS (Acquired Immune Deficiency Syndrome) was adopted.

⁷ Albert Camus, *The Plague*, trans. Stuart Gilbert (New York: Vintage International, 1991), 7.

⁸ “Health Shorts From Center No. 1 – Gay Men and KS,” *Bay Area Reporter*, July 16, 1981, 34.

entire length of the left side of the broadsheet: “Rare Cancer Seen in 41 Homosexuals.” This article was the first mention of the disease that eventually would become AIDS in any newspaper. The “rare cancer” was Kaposi’s Sarcoma (KS), a form of skin cancer that presents as purplish blotches on the skin that resemble bruises. Prior to this, most cases of KS in the United States occurred in men above the age of 50, but the new cases had a mean age of 39. A tinge of homophobia can also be detected in the article’s lurid discussion of the sexual habits of those affected, which no doubt did more to stoke the general public’s anxieties about homosexuality than it did about skin cancer: “most cases...involved homosexual men who have had...as many as 10 sexual encounters each night up to four times a week.” The article also mentioned that many patients “reported they had used drugs such as amyl nitrate...to heighten sexual pleasure.” Shortly after this, the author of the article noted that this “cancer is not believed to be contagious, but conditions that might precipitate it...might account for an outbreak among a single group.”⁹ Exactly what those conditions were would be a matter of some debate for years to come.

The first mention of KS in an obituary in the *BAR* was on August 12, 1982, over a year after the article in the *New York Times*. Michael Maletta, an event host in the gay community, “succumbed to Kaposi’s Sarcoma” on August 4, “at the age of thirty-nine.”¹⁰ However, there is one earlier obituary that stands out. On Christmas Eve of 1981, there is a small obituary for one Wayne Francis Smolen, a local filmmaker, who died on December 3 at the age of twenty-eight “after a long period of illness.” “A long period of illness” has often been interpreted in obituaries as a euphemism for cancer, but considering the age of Mr. Smolen and the time period this occurred, it may be that he died of HIV related causes.¹¹ So early on in the crisis, there would not

⁹ Lawrence K. Altman, “Rare Cancer Seen in 41 Homosexuals,” *New York Times*, July 3, 1981.

¹⁰ Joel Laski, “Castro Service for Michael Maletta,” *Bay Area Reporter*, August 12, 1982, 5.

¹¹ Susan Sontag, *Illness as Metaphor and AIDS and Its Metaphors*, 103. A search of the Names Project Database did not turn up Mr. Smolen. Mr. Smolen is, however, mentioned in a blog post about the San Francisco Gay Film

even have been language to describe what the disease was, but there can be no doubt that shame would have factored into any decision regarding a disclosure in a newspaper obituary, regardless of whether that publication was gay-friendly or not.

One of the first things mentioned as a possible cause of the “gay cancer” were “poppers.” Poppers, which were quite popular in the bathhouses of San Francisco, were ampoules of stimulants, either amyl or butyl nitrate, which would be broken and then inhaled during sex at the moment of orgasm, thereby increasing the pleasure of the user. One article, careful to explain that “no clear associations have emerged,” also mentioned that “the use of various ‘pleasure chemicals,’ most notably poppers and ethyl chloride, [were] being considered as possibilities.”¹² The manufacture of poppers was essentially unregulated and there had been no studies of the long-term effects of their use.¹³ For a large sector of the gay community in San Francisco, the solution was clear: if you didn’t use poppers during sexual encounters, you wouldn’t get the “gay cancer.” However, a sense that this was something more than a side effect from tainted drugs can be seen in an announcement for a November 1981 meeting of the Stonewall Gay Democratic Club, where the preeminent doctor treating Kaposi’s Sarcoma, Dr. Marcus Conant, would give a lecture on “research and treatment of *this killer which is stalking the Gay community*.”¹⁴

Aside from this one phrase, the *BAR* tended to keep a relatively moderate tone when discussing the “Gay Cancer.” In a January 1982 editorial, editor Paul Lorch, mainly in response to criticism that the paper wasn’t doing enough, wrote that the paper “reported whatever there

Festival, where he is described as an “obscure gay filmmaker.” See “575 Castro St.” <http://575castrostreet.blogspot.com/>.

¹² Robert Bolan, “New Bugs...No Alarm,” *Bay Area Reporter*, August 13, 1981, 16.

¹³ Poppers seemed to be a convenient scapegoat among the public, if not entirely accepted by the medical community. See “Stonewall Topics,” *BAR*, November 5, 1981, 3. The popper myth had some precedent. After the Spanish olive oil scare in the summer of 1981 and the Tylenol murders in Chicago in October of 1982, the idea that poppers could be contaminated gained even more credibility among the public.

¹⁴ “Gay Cancer to be Topic at Stonewall,” *BAR*, October 29, 1981. Italics mine.

was to report,” and that “until the facts are in, the paper will not stampede.”¹⁵ Of course, the moderate tone did not extend to the letters to the editor, which ranged from dismissive (“When we find out what is causing gay cancer, will it matter? What if it, too, were caused by alcohol or cigarettes?”),¹⁶ to self-flagellating (“the lifestyle we have created for ourselves is as lethal to us as the Moral Majority”),¹⁷ to completely off the wall. In the same issue, right next to Lorch’s editorial, was a letter to the editor which suggested that “victims of Kaposi [sic] Sarcoma...pursue inquiry as to the beneficial aspects of eating a few delicious purchasable mushrooms each day,” and wondered if it “wouldn’t be nice if out of the gardens of homophobes a cure for gay cancer did grow.”¹⁸ The letter writer’s ideas about the prejudices of mushroom farmers are beside the point. The implication seems to be that this was not just a fight against a disease, but a fight against those who would cast shame upon sufferers.

While the bargaining was clear in the San Francisco gay community, denial, too, can be seen elsewhere during the first 18 months of the outbreak. In the seminal history of the AIDS crisis *And the Band Played On*, Randy Shilts identifies a flight attendant named Gaetan Dugas who was diagnosed with KS in 1980 as his candidate for patient zero, the person who brought AIDS to North America. Extremely promiscuous, Dugas believed he “had 250 sexual contacts a year,” and estimated that he had been with 2,500 partners in the previous 10 years.¹⁹ The CDC interviewed Dugas during their attempts to understand “gay cancer” in 1982. When doctors suggested to Dugas that he may be infecting others, he said, “someone gave this thing to

¹⁵ Paul Lorch, “The Year of the Plain Brown Bottle,” *BAR*, January 14, 1982, 6-7.

¹⁶ Dick Robert, “Other Poisons,” letter to the editor, *BAR*, January 20, 1983, 6.

¹⁷ Arthur Evans, “Lethal Lifestyle,” letter to the editor, *BAR*, September 2, 1982, 7.

¹⁸ Jason Serinus, “Home Remedies,” letter to the editor, *BAR*, January 14, 1982, 7.

¹⁹ Randy Shilts, *And The Band Played On: Politics, People, and the AIDS Epidemic* (New York: St. Martin’s Griffin), 1988, 83.

me...I'm not going to give up sex."²⁰ Shilts admits that whether or not Dugas was patient zero in North America is "ultimately unanswerable." What is clear, however, is that Dugas "had been what every man wanted from gay life; by the time he died [in 1984], he had become what every man feared."²¹

As winter turned to spring in early 1983, nothing was happening. In New York, Mayor Koch was avoiding the issue. In San Francisco, Randy Shilts at the *Chronicle* was writing stories about AIDS whenever possible, but no actual progress, either medically or in the court of public opinion, was being made against the disease. The White House Press Secretary, Larry Speakes, often made snide homophobic jokes and comments during his press briefings whenever a journalist would ask a question regarding AIDS.²² However, a story in the *BAR* from a few months earlier, in December 1982, shows that people suffering from this unknown disease were beginning to realize that it was up to them to find their own treatment. Just 9 days before Christmas, a 29-year-old gay man named Richard Harbaugh took his own life in Golden Gate Park one day after having his KS (Kaposi's Sarcoma) diagnosis confirmed. In the note pinned to his clothing, he wrote, "I can no longer stand the pain...my gut is never still.... I am weak and no one to touch, to hold, to cry on. Oh my loneliness [sic]. The void. I sigh." He was not found until the following day. "Even his final wish – *that his body be donated to science* (italics mine) – was thwarted: rigor mortis had set in, making the corpse useless."²³ Richard Harbaugh's suicide makes it clear that those who were experiencing the horror of the mysterious disease were

²⁰ Shilts, *And The Band Played On*, 138.

²¹ Shilts, *And The Band Played On*, 439.

²² Lopez, German, "The Reagan Administration's Unbelievable Response to the HIV/AIDS Epidemic," Vox.com, last updated Dec 1, 2016, <https://www.vox.com/2015/12/1/9828348/ronald-reagan-hiv-aids>. There is a short video at that page with recordings from Speakes's briefings. They have not aged well.

²³ Lorch, Paul, "KS Diagnosis, Takes Life," Bay Area Reporter, December 23, 1982, 16.

adamant that those experiences should mean something to the broader community, or at least make some sort of difference to the living, even in death.

Part II: Anger/Depression (1983 – 1987)

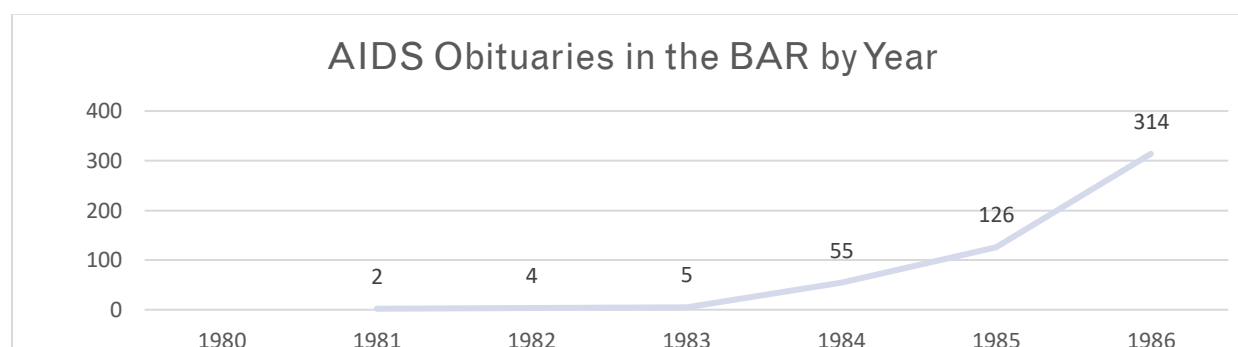
The *BAR*'s moderate editorial tone would stop, however, upon the publication in the *New York Native* of Larry Kramer's "1,112 And Counting" in March of 1983. Paul Lorch, the editor of the *BAR*, re-printed it in his own newspaper, and it became the clarion call for more to be done by local and State governments, as well as the Federal Government. "If this article doesn't scare the shit out of you," the article began, "we're in real trouble."²⁴ In a way, it served as something of a Declaration of Independence from doctors, from politicians, and from the media, particularly *The Advocate*, one of the country's largest gay publications, which had "yet to acknowledge that there [was] anything going on." If no one was helping them, Kramer believed, then the gay community needed to do it themselves. Kramer reserved particular animus towards "closeted gays," writing "As more and more of my friends die, I have less and less sympathy for men who are afraid their mommies will find out or afraid their bosses will find out or afraid their fellow doctors or professional associates will find out." Kramer was sick of the shame that kept so many silent, and knew that they had to "fight to live." He ended his article with "I know that unless I fight with every ounce of my energy I will hate myself. I hope, I pray, I implore you to feel the same," before making "a list of twenty dead men [he] knew."²⁵ The gay community was facing

²⁴ Larry Kramer, "1,112 and Counting," originally published in the *New York Native*, March 14, 1983.

²⁵ Kramer, "1,112 and Counting."

an existential threat, and the shame inherent in both the disease and in homosexuality threatened to kill them faster than the disease itself.

How dire of a threat AIDS actually was can be seen in the number of obituaries published in the *BAR*. The GLBT Historical Society maintains an online database of all obituaries published in that newspaper for its entire run. The database is searchable by name and by date, so it is possible to count obituaries that mentioned AIDS either explicitly or tangentially. Because of the shame that PWAs faced, obituaries often alluded to the disease in roundabout ways, the most familiar of which is “a long illness.” Someone who died might request that a donation be made to the Shanti Project, a non-profit organization that focused its mission on PWAs, or to Ward 5B, which was the AIDS ward at San Francisco General Hospital. From 1981 to 1986, the number of obituaries of AIDS patients appearing in the *BAR* that could be determined by either explicit mention of AIDS or the implication of the disease is as follows:²⁶



Going any further would belabor the point. By 1986, nearly one person per day was dying of AIDS in San Francisco. It would not be until August 13, 1998 that the *BAR* could proclaim that

²⁶ Numbers in the table were compiled by the author. Other ways AIDS might have been mentioned in roundabout ways included phrases like “that disease which we all know too well,” “the same affliction affecting so many in our community,” as well as “and the same scourge which took his partner 6 months before.”

for the first time since the beginning of the AIDS epidemic, “no obituaries were filed with the paper for that issue.”²⁷

By June of 1983, the well-documented indifference of the Reagan Administration had become too much for many sufferers. At the Second National AIDS Forum, held in Denver, Colorado, a group of men and women, led by Michael Callen of New York and Bobbi Campbell of San Francisco, drafted what would become known as the “Denver Principles,” a set of “recommendations” for healthcare professionals, PWAs, and for all people, as well as a declaration of rights of PWAs. This was the first articulation that AIDS was something different. One of the recommendations for PWAs read, “Be involved at every level of decision-making and specifically serve on the boards of directors of provider organizations.” Another read, “Be included in all AIDS forums with equal credibility as other participants, to share their own experiences and knowledge.” This assertion of the right of PWAs to be involved intimately in their own treatment was without precedent in modern times. In the preamble of the Denver Principles, the committee rejected the term “victims” because it “implies defeat” and only sometimes accept the term “patients” because it “implies passivity, helplessness, and dependence on the care of others.”²⁸ To reject “defeat” is to reject the shame in that defeat. To reject “passivity, helplessness, and dependence” is to reject the shame of being passive, helpless, and dependent on others.

By the end of 1983, the AIDS crisis was in full swing. In May, a team of researchers in France isolated a retrovirus that would be identified as HIV, but gay men, IV drug users, hemophiliacs, and female partners of IV drug users were still dying at alarming rates. Paul

²⁷ Timothy Rodrigues, “No Obits,” Bay Area Reporter, August 13, 1998.

²⁸ “The Denver Principles,” 1983, People With AIDS Advisory Committee, http://www.actupny.org/documents/denver_principles.pdf.

Lorch, the editor of San Francisco's *Bay Area Reporter* summed up the feeling in his editorial, writing, "how many times – in one year – can a heart fracture? One dies but once...does one die a little bit more as one's comrades fall away?"²⁹ As he noted in the same editorial, San Francisco was about a year behind New York in its experience of AIDS.

In the absence of FDA-approved drugs that would if not outright cure the disease, at least slow its progress, PWAs often turned to home remedies and home concoctions that would approximate the effects of more expensive options. One such recipe for Peptide-T, an experimental drug that purportedly blocked HIV from entering T-cells, published in *PWA Newslines*, suggested that if patients were uneasy about injecting themselves with the diluted solution, it could be mixed in another ratio, then put in an "Afrin 12 Hour Nasal Spray inhaler, sold over the counter."³⁰

Michael Callen, one of the authors of the Denver Principles, compiled a booklet for PWAs entitled *Surviving and Thriving with AIDS: Hints for the Newly Diagnosed*. Essentially a collection of interviews, transcripts of speeches and panel discussions, and short essays containing advice written by PWAs, it was intended to "present information to People with AIDS and AIDS-Related Conditions and concerned friends."³¹ The advice essays show the varied and imaginative ways in which PWAs were attempting to combat their illnesses. One PWA wrote that because he had "nothing to lose," he started to use "AL 721" which was a "potent form of lecithin which [made]...cell membranes resistant to viral attacks." As it was

²⁹ Paul Lorch, "'83, A Hard Year to Fathom," *Bay Area Reporter*, December 29, 1983, 11.

³⁰ Garance Franke-Ruta, "Mr. Boston's Guide to Mixing Peptide T," *PWA Coalition Newslines*, September 1991, 34.

³¹ Michael Callen, *Surviving and Thriving with AIDS: Hints for the Newly Diagnosed* (New York: People With AIDS Coalition, 1987), iv. I have a hazy memory of this booklet sitting on the coffee table in our living room when I was about 12 years old.

available only in Israel at the time, he flew to there to receive the treatment.³² Another PWA suggested that one could cook up a batch of AL 721 at home by mixing PC-55, another form of lecithin available from a laboratory on Long Island, with water and butter to make a margarine-like spread that could be eaten with a “fat-free breakfast.” To avoid diarrhea, a known side effect, he suggests eating “brown rice and other solid foods.”³³ Another memorable recipe suggested mixing soya lecithin with orange juice in a blender while adding two tablespoons of corn oil. “It makes a sweet emulsion, like pudding and tastes like an Orange Julius,” he writes. “Serve cold. Yummy!”³⁴

Part III: Acceptance/Depression (1987-1996)

In the wake of Rock Hudson’s death from AIDS in 1985, funding for AIDS research increased, and drug companies became convinced that an AIDS drug might be profitable. Azidothymidine (AZT) was the first drug treatment approved by the FDA that attacked the HIV virus, rather than acting as a prophylactic for opportunistic infections or treatment for those infections that took hold. Originally developed as an anti-cancer drug in 1964 from the “sperm of herrings,” it showed promise in clinical trials, but there were plenty of concerns.³⁵ During one of those trials, many participants “showed signs of serious bone marrow suppression, and anemia occurred in the majority. One in five required multiple blood transfusions.” Researchers were so alarmed, they considered aborting the entire study.³⁶ Some, including Michael Callen and his

³² Anonymous, “My Illness (Some Thoughts about AL 721),” in *Surviving and Thriving with AIDS: Hints for the Newly Diagnosed* (Vol. 1), ed. by Michael Callen (New York: People With AIDS Coalition, 1987), 55.

³³ Steven Gavin, “AL 721 Substitute (Home Formula),” in *Surviving and Thriving with AIDS*, 57.

³⁴ “HIV Man,” “More Thoughts about AL721,” in *Surviving and Thriving with AIDS*, 58.

³⁵ David France, *How to Survive A Plague: The Inside Story of How Citizens and Science Tamed AIDS* (New York: Alfred A. Knopf, 2016, 178-179.

³⁶ David France, *How to Survive a Plague*, 238.

doctor, Joseph Sonnabend, were critical of the design of the studies, particularly the Phase II study.

Phase II followed a standard double-blind protocol with a placebo. AZT would be given to only half of the participants. If fewer people died while taking AZT than those taking the placebo, the efficacy of the drug would be proven. However, in order to be eligible to participate in the trial, patients were required to discontinue all other medication, including any prophylaxis medication for PCP (pneumonia).³⁷ Testimony in congressional hearings that summer called them “death trials,” since denial of prophylaxis medication would almost certainly cause “preventable deaths.”³⁸

Callen would later write of the study that researchers conducting the study “lost track” of 25% of the participants who received AZT during the trial. “It is not possible to support the claim that AZT extends life when you don’t know whether nearly a quarter of the people in your sample are dead or alive,” he wrote.³⁹ One journalist, writing of the AZT trial in 1989, noted that the study “became unblinded on all sides” because the side effects of AZT were so severe that it was obvious who was taking the drug and who was receiving a placebo. Patients later admitted that they would have the medication analyzed to determine if they were receiving AZT, and others would share the drug with others receiving the placebo “out of solidarity with each other.”⁴⁰ For individual patients to corrupt a clinical trial in this way speaks to the perception among many patients that doctors and researchers were aloof and uncaring about the average

³⁷ David France, *How to Survive a Plague*, 215.

³⁸ *Ibid.*

³⁹ Michael Callen, *Surviving AIDS* (New York: Harper Collins, 1990), 206. Callen refused to take AZT, famously calling it “Drano in pill form.”

⁴⁰ Celia Farber, “Sins of Admission: The AZT Scandal,” originally published in *Spin*, November 1989. Archived online at <http://www.virusmyth.com/aids/hiv/cfsins.htm>. Quoted in Michael Callen, *Surviving AIDS*, 207.

PWA. For many PWAs, there was still a feeling that they, the patients, knew better than the doctors what was going on with AIDS.

AZT was approved by the FDA in early 1987. Once AZT was on the market, the maker of the drug, Burroughs Wellcome, said it would cost patients \$10,000 a year.⁴¹ Some independently owned pharmacies recognized that the high cost of drugs used to combat HIV made them inaccessible. One pharmacy in Greenwich Village offered PWAs prescription drugs “at cost.” The owners wrote, “as members of a community, we want to do our part in helping to cope with the AIDS epidemic.”⁴² Clearly, there was some sense, at least at the community level, that some measure of compassion towards the suffering of PWAs was necessary. Other PWAs who were interested in alternative drug therapies would organize “buyer’s clubs,” where drugs not approved by the FDA would be bought in foreign markets and then smuggled into the US. Members would then pay monthly for the right to receive those drugs. Among the drugs common in the buyer’s clubs were Compound Q, DDC, Alpha Interferon, and Peptide T.⁴³

Another newsletter, for members of the Vancouver PWA Coalition, often reprinted short articles from *Surviving and Thriving With AIDS*, but definitely filtered them through a Canadian lens. As early as August of 1987, some members in Vancouver planned to write a Canadian version that would help PWAs “cope with the disease in British Columbia.”⁴⁴ Much like

⁴¹ France, *How To Survive A Plague*, 253.

⁴² “Prescription Drugs Available at Cost for PWAs,” in *Surviving and Thriving with AIDS*, 60.

⁴³ Hannah Dorf, “Managing Your own Survival: Buyers Clubs in the AIDS Epidemic,” May 17, 2018, *Health and Medicine in American History*, Grinnell College.

<https://lewisar.sites.grinnell.edu/HistoryofMedicine/spring2018/managing-your-own-survival-buyers-clubs-in-the-aids-epidemic/>. The story of the buyer’s clubs was brought to the screen in the 2013 film *Dallas Buyers Club*. Another excellent attempt to separate fact from fiction in the film can be found in Dylan Matthews’s excellent *Washington Post* article “What ‘Dallas Buyers Club’ Got Wrong About the AIDS Crisis.” https://www.washingtonpost.com/news/wonk/wp/2013/12/10/what-dallas-buyers-club-got-wrong-about-the-aids-crisis/?utm_term=.a45605ca3efc.

⁴⁴ Nicholas Gray, “Creating a Vancouver AIDS/ARC Resource Book,” *Vancouver PWA Coalition Newsletter*, August 1987, 6.

Newsline and *Surviving and Thriving with AIDS*, the Vancouver Newsletter shared alternative remedies, such as using BHT (a food preservative) as an anti-viral treatment. In the same issue, a small notice appeared regarding a “man who travels frequently between Vancouver and Switzerland” that wished to provide “care to someone with AIDS” at his home “near Zurich and Bern.” There is an essential weirdness to this “very generous offer” that cannot be overstated; flying to a country halfway around the world for free to be cared for while you slowly die seems reckless at worst and irrational at best. However, the fact that something like this would even be entertained as a valid (or sensible) option speaks to the desperation many PWAs must have felt at the lack of resources or treatment options.⁴⁵

San Francisco, in contrast to New York, had quickly recognized that AIDS was a public health crisis and funded treatment programs locally. One such program was Ward 5B at San Francisco General Hospital, a 12-bed unit dedicated to treating AIDS patients. Prior to the creation of Ward 5B, AIDS patients were often isolated in rooms far away from the nurses’ station. As a result, their rooms were filthy, the food was never hot, and nurses often neglected them.⁴⁶ This new ward was revolutionary in its approach to treatment. Patients were given the agency to decide who visited them, and “In some cases, patients make decisions concerning their medication, their treatment, and even the length of their stay.”⁴⁷ Groups like the Shanti Project, a counseling and support program for PWAs, could provide “one full-time Counseling Coordinator and three half-time counselors” to Ward 5B.⁴⁸ The isolation, though, was much harder to combat.

⁴⁵ “BHT as an Antiviral” and “Hospice in Switzerland,” *Vancouver PWA Coalition Newsletter*, November 1986, 2-3. Saying someone’s home was near Zurich and Bern is extremely vague, to say the least. Zurich and Bern are approximately 75 miles apart. It would be much like saying someone lived near Denver and Colorado Springs.

⁴⁶ Mike Hippler, “AIDS = A Personal Exploration (Part II: Learning About Ward 5B at S.F. General),” *Bay Area Reporter*, November 3, 1983.

⁴⁷ Hippler, *Ibid.*

⁴⁸ Linda Maxey, “Counseling Program at S.F.G.H.,” *Eclipse: The Shanti Project Newsletter*, Summer 1984, 7.

One patient on the ward tended to keep to himself, seeing few visitors or even other patients.

“Basically,” he said, “my lover and I are loners.”⁴⁹

For IV drug users who contracted HIV by sharing needles, the issues of isolation were no different. One such person felt that when he was in rehab in “the Midwest [at Hazelden],” no one knew how to act.... some counselors or therapists handled [him] with kid gloves” after learning he was HIV positive. He also wrote about the “ton of anger inside” him, mainly directed “toward the ignorant and bigoted people who [didn’t] understand (or [didn’t] want to)” his disease.⁵⁰ For him, his shame turned to anger once he realized that the shame came from others, rather than from within himself.

Even into the 1990s, PWAs often found more support among each other than from the medical community. “Back then in the late 80s it wasn’t spoken about much, and so we were quiet about it, until we met on Friday nites [sic] – we all felt like outcast, all confused and frustrated.”⁵¹ Those Friday night meetings were an evolution of a regularly scheduled Narcotics Anonymous (NA) meeting that met in the basement of Mercy Hospital (now Mercy Medical Center), in Rockville Centre, New York. 10 to 20 PWAs regularly attended the meeting, along with spouses (and sometimes children). NA, like its forerunner, AA, believes that addiction is a disease and promotes the twelve-step program as a means to help addicts recover from the effects of that disease. For the members of that Friday night meeting, the evolution to a focus on the disease of AIDS rather than the disease of addiction seemed natural. Perhaps the twelve steps could help them “recover” from AIDS as well. As one member of the group wrote, “with the

⁴⁹ Mike Hippler “AIDS = A Personal Exploration (Part III: Patrick Walker, Patient on Ward 5B),” *Bay Area Reporter*, November 17, 1983.

⁵⁰ Joseph DePolo, *Personal Papers*, 1987-1989, in the possession of Angela Rivera. Used with permission.

⁵¹ Lisa DePolo, *Personal Papers*, 1990-1993.

help of people I know in the program I've learned that pain is inevitable, but suffering is sort of optional."⁵² That last line sounds like something my father would have said. He was of the belief that even though the pain was real, it didn't have to hurt.

My father, a recovering IV drug user, was one of the architects of this home-grown strategy to use the twelve steps in an attempt to "recover" from AIDS. He would often lead the meetings on Friday night, and our home was always open to anyone who was in the program with him. For years, he would host three barbecues in our backyard each summer: Memorial Day, the Fourth of July, and Labor Day. What had started as a small gathering of ten or fifteen people would eventually turn into an event attended by nearly one hundred. As the sun went down, there would be an impromptu NA meeting, where everyone could share.

Dad abhorred suffering; upon his and my mother's move to Minneapolis in 1995, he helped the partner of a friend, wracked by AIDS in the final months of his life, find some measure of acceptance in the inevitability of his death. My father was something of a missionary, too, embodying the twelfth step: "Having had a spiritual awakening as a result of these steps, we tried to carry this message to addicts [or PWAs], and to practice these principles in all our affairs."⁵³ He would bring the twelve steps to anyone who would listen – as well as some who would not – often handing out an NA meeting list along with the clean syringe when he worked with the Twin Cities underground needle exchange.

The nature and design of individual NA meetings is known only to the members who attended those meetings; meetings would often dissolve and others would pop up in their place. The "Fellowship," as it calls itself, was slow to respond to the issue of HIV and AIDS in

⁵² Joseph DePolo, *Personal Papers*, 1987-1989.

⁵³ "12 Steps of Narcotics Anonymous," <https://12step.org/references/12-step-versions/na/>, Accessed 2 May 2019.

Narcotics Anonymous meetings. In 1989, the NA World Service Board of Trustees, in an attempt to “find a solution to the issue of special interest [i.e. HIV/AIDS] meetings,” reported that “in some regions, there are meetings for...people with AIDS [and] people who are HIV positive.”⁵⁴ Some members of NA believed that HIV and AIDS was a separate issue that should be divorced from NA’s true mission, which is to help addicts recover from their addiction to drugs. From this bulletin, it is clear that meetings such as the one on Friday night in the basement of Mercy Hospital were common, if not widespread, throughout the organization, and using the 12-step model to respond to AIDS was not unique to my father’s Friday night meeting in Rockville Centre.

Four years later, in April of 1993, the Board issued another bulletin, outlining the organization’s official position on HIV and AIDS. After noting their own aimlessness regarding HIV and AIDS, the board wrote, “while there are many issues around HIV and AIDS that may well be outside issues, the experience of recovering addicts with HIV is not.” The Board also understood that everyone could “gain from sharing and being open toward an understanding of new aspects of powerlessness and surrender.”⁵⁵ It seems doubtful that my father or anyone in the group that met on Friday nights was terribly concerned with the Board’s feelings regarding their meeting, but this makes clear that there was some understanding at higher levels that people could use the program to recover from more than just addiction to narcotics.

For families of PWAs, the difficulty of living with someone slowly dying was often unbearable, and as the end loomed, there was often a desire for it to come quicker. My mother

⁵⁴ “Special Interest Meetings,” Narcotics Anonymous World Services Bulletin #18, April 1989, <https://www.na.org/?ID=bulletin18>.

⁵⁵ “HIV and AIDS in NA,” Narcotics Anonymous World Services Bulletin #27, April 1993, <https://na.org/?ID=bulletins-bull27>.

kept a diary during the year before my father died of AIDS complications on June 21, 1996. One of her peculiarities when it came to her diaries and letters was that she always noted the exact time she began writing, in 24-hour notation. Most of the entries were written late at night. Shortly after midnight on May 16, 1996, she mentioned that my half-brother (from my father) called to say that his wife was pregnant. “Decided not to tell Garry till after Sunday. Sure makes me feel like shit but don’t want to give him any more to hold on to.”⁵⁶ A few days later, she wrote, “felt sorry I had to disappoint him about his wanting to come home but I cant let him home ever as he will not want to leave.”⁵⁷

The nursing home where my father spent his final days was located in what was, at the time, a low-income, crime-ridden neighborhood just south of downtown Minneapolis. Two years before his arrival, the name of the facility had been changed from “The Ebenezer Caroline Center” to the “City of Lakes Transitional Care Center.”⁵⁸ It was clear that the facility had been hastily set up in response to the growing number of PWAs in the Twin Cities area nearing the end of their lives. Most of the building was vacant - long dark hallways stretched out, abandoned gurneys lining the walls. Light fixtures were missing shades, exposing bare bulbs. Vacant patient rooms contained hospital beds stripped bare, the mattresses slightly askew on their frames. As my mother succinctly observed on May 21st, it was “really weird around there.”⁵⁹ For myself, I spent Tuesday afternoons with him. We would talk, play cribbage, or if he was feeling mentally

⁵⁶ Julie Botts, *Personal Diary*, Vol.1, May 16, 1996. My mother’s diaries came into my possession after her death on March 31, 2014. In her diary, she is unable to reckon with the idea that she wanted him to die. This is the closest she comes to articulating the emotions surrounding that subject. Out of respect and love for her, I will forego using [sic] for grammatical errors. I have reproduced her words exactly as they were written.

⁵⁷ Julie Botts, *Diary*, Vol. 1, May 22, 1996.

⁵⁸ “History,” Historic Abbot Apartments, <http://www.abbottapartmentsmn.com/building/history.html>, accessed March 30, 2021. The source mentions the building’s time as the City of Lakes Transitional Care Center, but makes no mention that it primarily served AIDS patients.

⁵⁹ Botts, *Diary*, Vol. 1., May 21, 1996.

up to it, chess. Tuesdays were also the days he would choose his menu for the next week. That involved me reading the choices to him and checking off his selections.

While the physical environment in the facility might have been “really weird,” the care he received was excellent. On the 10th of June, my mother wrote, “to see GMB today – he is even more confused – now says it is my fault.”⁶⁰ A few days later, she noted that one of his nurses found the culprit for his confusion: “found out that Garry’s ammonia level is 95 it shud be between 11 + 35.”⁶¹ Ammonia was filling my father’s brain as his kidneys started to fail him. He would carom wildly between lucidity and confusion, catching both of us off guard. When, on the same day, my mother found out an old friend of hers had died, she wrote that she wanted to tell my father, but she was certain he wouldn’t understand. She told him anyway, and he understood. “He is trying so hard to think straight. He is trying so hard to stay alive and alert.... He really is my best friend.”⁶²

Here is a sampling of the next 11 days:

June 13th: Hanan [his doctor] agreed he isn’t going to do anything about GMB’s⁶³ ammonia level. GMB shaved his head today...it looks like hell.

June 17th: Don’t know how much longer Garry can keep on – he is so sick + so weak.

June 19th: Went to see GMB – he was totally unresponsive again.... When will it be over? – Do I really want it over? How will I handle the end?

June 20th: He called here about 9 pm – said he wanted to be left alone + that he wasn’t afraid. That he was floating toward the great beyond. When I asked if he wanted to die, he said yes.... He is down to 175 lbs – not eating or drinking.

June 21st (12:57 am): Spoke to Dr – he has taken him off all meds but Morphine, Compisine [Compazine], and quinine sulfate.... When I spoke to Nancy (RN) this

⁶⁰ Botts, *Diary*, Vol. 2., June 10, 1996.

⁶¹ Botts, *Diary*, Vol. 2., June 12, 1996.

⁶² Ibid.

⁶³ My mother would variously refer to my father as “GMB” (his initials) or “Garry.”

morning she said Garry was laying on the floor because it was cooler, she thought he had fallen. His temp was 94, sugar 50, ammonia 95 – but heart and lungs strong and solid.

June 22nd: Garry died on 21 June 96 at about 5 am. Nancy the night nurse said he slept to death. All I could say was thank God.... Pat and I went to see him before he was taken to the crematory. He looked dead! His eyes were wide open, his mouth was open, he was tinted gray. But he seemed to be at rest. I couldn't touch him, I couldn't kiss him, I couldn't do much. I went to work because I didn't know what else to do.⁶⁴

I remember the thunderstorm that morning. It was a difficult drive to go up to see him because of the rain and wind. I stood at the side of his bed; the lights were off, so the only light in the room was that which filtered through the window as the rain tapped at the glass. Unlike my mother, I did not go to work that day. At the time, I was working in the writing center of Normandale Community College. Before I went home, I stopped in to tell my supervisor that my father had died, and that I wouldn't be working that day. She had been aware that my father was close to death. I remember trying to stop myself from giggling in relief when I told her. My memory of that day ends there.

One can never truly know the thoughts of another person, but I do not believe my father ever seriously considered suicide. For him, the decision to die and end his suffering was one made over two long months. His final days were spent taking only those drugs that would ease his pain and suffering as the disease took him. In the end, my father died on his own terms. In his final act of self-determination against AIDS, he made the choice to let go.

The story of the death of my father, Garry Micheal Botts, is only one of the 35 million deaths globally from HIV/AIDS since 1981. Advances in drug therapies beginning in late 1996 have turned a diagnosis of HIV from the shame-ridden death sentence it once was to a minor inconvenience. Without the recognition of that shame early on in the crisis and the desire to

⁶⁴ Botts, *Diary*, Vol. 2.

transform it into determination, HIV very possibly would still be a death sentence. We are a long way from the 1,112 dead that Larry Kramer wrote of in 1983, but it seems fitting to emulate him and conclude with a list of 6 dead people that I knew along with the dates of their deaths:

Kevin Shore (1990)

Tommy "Guitar" Rudinsky (1990)

Jamie Canning (1992)

Joseph DePolo (1992)

Garry M. Botts (1996)

Lisa DePolo (2002)