

Fighting a Plague: Doctors' Stories of Challenge and Innovation Combatting the AIDS Epidemic in 1980s New York City

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ABSTRACT

The human immunodeficiency virus (HIV) has devastated the United States for forty years. Though there are highly effective treatments for HIV and acquired immune deficiency syndrome (AIDS) today, the early years of the HIV/AIDS epidemic in New York City (NYC) were filled with uncertainty, fear, and death—not unlike the period we are now experiencing in the COVID-19 era. Existing scholarship captures the political discourse of the HIV/AIDS era and the narratives of physicians who specialized in HIV medicine. This essay uses eight in-depth interviews of physicians of various specialties who worked in NYC to understand the uncertainties and fears in daily work during the early AIDS epidemic. Their stories provide unique perspectives into the realities of working as physicians in the epicenter of a highly politicized epidemic with limited support, information, and treatments. They illustrate that HIV/AIDS provided unique biomedical, social, and political challenges to the physicians working in NYC during the 1980s. Over the course of the decade, these physicians adapted to meet challenges using methods that have since become commonplace in their clinical practice.

KEYWORDS: HIV, AIDS, New York City, Physician, Epidemic, 1980s

On 3 July 1981, a headline appeared on page A20 of the *New York Times* which read, “Rare Cancer Seen in 41 Homosexuals.”¹ No one, including the editors of the *Times*, could have foreseen how that “rare cancer” — later known as acquired immune deficiency syndrome (AIDS) — would go on to devastate the lives of millions and trigger a social response that would forever change New York City (NYC) and the world.

1 Lawrence K. Altman, “Rare Cancer Seen in 41 Homosexuals,” *New York Times*, 3 July 1981, A20.

As the *Times* headline made clear, the pathology of AIDS was so new that language did not yet exist to describe it. At first, doctors did not know how to treat the stream of young gay patients in dense urban areas who died of previously uncommon and treatable diseases.² It was not until 1983 that researchers discovered that AIDS was the downstream result of a virus, identified as the human immunodeficiency virus (HIV), and it was not until 1987 that a medication to treat the virus was approved by the Food and Drug Administration (FDA).³ Those who contracted the virus continued to have a high mortality rate until the development of highly active antiretroviral therapy (HAART) in 1996, more than a decade after AIDS was first identified. This landmark regimen finally allowed the life expectancies of HIV-positive patients to approach those of non-infected patients.⁴

The purpose of this article is to document the mindset of frontline medical professionals working in NYC during the first decade of the AIDS epidemic. It expands the existing historical narrative of HIV/AIDS to include the personal stories of medical professionals who were thrust into the epicenter of a new epidemic. My research uses oral history interviews to ask not only what practitioners from the early years of the HIV/AIDS epidemic recalled about their experiences, but also what memories they carried with them. The essay also seeks to understand how these epidemic experiences shaped providers in their clinical skills and careers.

Much of public recollection of the early AIDS epidemic focused on the crossfire between AIDS activists and government agencies such as the Centers for Disease Control and Prevention (CDC), National Institutes of Health (NIH), and the administration of President Ronald Reagan.⁵ Critically acclaimed films contributed to such remembrance, including the documentaries *How To Survive a Plague* (2012) and *United In Anger* (2012), which examined the AIDS Coalition To Unleash Power (ACT UP) and the biopic *Dallas Buyers Club* (2013), which provided a commentary on FDA drug approval during the epidemic. Elizabeth Fee and Daniel Fox made seminal contributions to the academic analyses of sociopolitical forces surrounding the early epidemic.⁶ Their edited collections of essays illuminated the influence of previous epidemics on AIDS response, as well as the factors that shifted the perception of HIV positivity from a terminal diagnosis to a chronic disease.

The perspectives of physicians — those who saw the epidemic play out in front of their eyes — also contributed to the historical memory of the beginnings of the AIDS epidemic. Personal accounts have included memoirs by Abraham Verghese, which told of his time fighting AIDS in the late 1980s as an infectious disease physician in rural

2 “HIV and AIDS – United States, 1981-2000,” *Morbidity and Mortality Weekly Report* 50 (2001): 430-434.

3 Steven Epstein, *Impure Science: AIDS, Activism, and the Politics of Knowledge* (Berkeley: University of California Press, 1996), 70.

“Antiretroviral Drug Discovery and Development,” HIV/AIDS, National Institute of Allergy and Infectious Disease, 26 November 2018.

4 Ibid.

5 Douglas Crimp, *AIDS: Cultural Analysis/Cultural Activism* (Boston: MIT Press, 1987), 256-259.

6 Elizabeth Fee and Daniel M. Fox, ed., *AIDS: The Burdens of History* (Berkeley: University of California Press, 1988); Elizabeth Fee and Daniel M. Fox, ed., *AIDS: The Making of a Chronic Disease* (Berkeley: University of California Press, 1992).

Tennessee, as well as the one by Ross Slotten, in which he recounted his years as a family medicine-trained AIDS specialist in Chicago in the 1980s and 1990s.⁷ Perri Klass contributed notable, contemporaneous opinion pieces about her experience with the AIDS epidemic as a pediatric resident in Boston.⁸ There have also been multiple studies that explored the perspectives of professionals in the time of the AIDS crisis. For example, Wendee Wechsberg presented essays which illustrate the perspectives of various physicians, nurses, patients, historians, and social scientists.⁹ Ronald Bayer and Gerald Oppenheimer compiled an oral history of purposively recruited, AIDS-focused physicians—predominantly infectious disease, oncology, and immunology/rheumatology specialists.¹⁰ Ketil Slagstad examined the effectiveness of lesbian and gay medical professionals in Norway due to their experiences of both the medical and the queer communities.¹¹ Additionally, Thomas Blair summarized the response of San Francisco-based psychiatrists to AIDS psychiatric comorbidity management, community partnership, and epidemiology.¹²

Despite this wide variety of scholarship on the subject, there are still gaps in the historical record. This article intends to address three lacunae in the established literature by focusing on the setting of NYC, the specific period of 1980-1989, and a distinct population of surge physicians—those who directly fought the epidemic by necessity but were not infectious disease specialists. These criteria have been largely overlooked, even though NYC is especially worthy of close examination due to its tremendous significance to the early AIDS epidemic. Along with Los Angeles and San Francisco, NYC is regarded as an early epicenter of the AIDS epidemic in the United States, which is perhaps unsurprising as it had been the largest metropolitan area in the nation for two hundred years.¹³ The city's size, population density, and connection to international travel made it vulnerable to exposure to infectious disease. Moreover, NYC has often considered the birthplace of modern lesbian-gay-bisexual-trans (LGBT) rights movements because of the Stonewall Inn riots beginning on 28 June 1969, which global LGBT pride festivals continue to commemorate annually.¹⁴ Because of this history, NYC had a larger, more established, and more politically active LGBT community

7 Abraham Verghese, *My Own Country: A Doctor's Story* (New York: Simon & Schuster, 1994); Ross Slotten, *Plague Years: A Doctor's Journey through the AIDS Crisis* (Chicago: University of Chicago Press, 2020).

8 Perri Klass, "Hers; Mothers With AIDS, A Love Story," *New York Times Magazine*, 4 November 1990, 24.

9 Wendee Wechsberg, *HIV Pioneers: Lives Lost, Careers Changed, and Survival* (Baltimore: Johns Hopkins University Press, 2018).

10 Ronald Bayer and Gerald M. Oppenheimer, *AIDS Doctors: Voices from the Epidemic, An Oral History* (Oxford: Oxford University Press, 2000).

11 Ketil Slagstad, "The Amphibious Nature of AIDS Activism: Medical Professionals and Gay and Lesbian Communities in Norway, 1975-87," *Medical History* 64 (2020): 401-435.

12 Thomas Blair, "Plague Doctors in the HIV/AIDS Epidemic: Mental Health Professionals and the 'San Francisco Model,' 1981-1990," *Bulletin of the History of Medicine* 90 (2016): 279-311.

13 Harvey M Sapolsky and Stephen L. Boswell, "The History of Transfusion AIDS: Practice and Policy Alternatives," in *AIDS: The Making of a Chronic Disease*, 170-193; Edward L. Glaeser, "Urban Colossus: Why New York is America's Largest City," *Federal Reserve Bank of New York Economic Policy Review* 11 (2005): 7-24.

14 *Stonewall Uprising*, Public Broadcasting Service, 2011.

than other US cities, which undoubtedly shaped how the epidemic played out in the city's streets and hospitals.

The chronological focus of this study, the decade of the 1980s, is also worthy of consideration. Over the course of these ten years, the epidemic evolved from scattered case reports to a well-known epidemic with an isolated causative agent, established modes of transmission, attendant legislation, and emergent testing, treatments, and protocols.¹⁵ However, by the close of 1989, a prognosis of imminent death remained for those who contracted HIV. I argue that both the accompanying hysteria and the evolving information of this period warrant deeper analysis. As we experience the COVID-19 pandemic in the present, we are reminded that new infectious agents will continue to arise, as will such periods of misinformation and fledgling fact-finding. Turning to the epidemics of our recent past may help us anticipate the uncertainties in those of our future.

In order to address my research question, under university institutional review board approval, I have collected oral histories with eight in-depth, semi-structured interviews of physicians who worked in NYC during the 1980s. My intention was to give voice to the subject physicians' perspectives on the historic events of the AIDS crisis and to interrogate if and how these events made the participants evolve. I purposively recruited subjects by three methods: three interviewees were personal contacts, two were recruited via social media, and three were references of the participants themselves. All participants were graduates of allopathic medical schools in the US and practitioners in both inpatient and outpatient settings in NYC during the 1980s. Their training levels varied from residents (junior trainees), to attendings (fully trained physicians). I recruited subjects comprising a range of specialties: one neurologist, two intensivists, three general internists, one ophthalmologist, and one nephrologist. I intentionally excluded from this project infectious disease specialists and oncologists in order to capture voices previously unheard in the literature: physicians who fought the epidemic directly out of necessity, but who were not previously trained to do so. In this way, this study is intended to capture the epidemic's initial surge, enveloping and altering a wide range of physicians who were forced by circumstance to treat a new and little-understood disease. The workplaces of the subjects spanned multiple hospitals and clinics across Manhattan: Columbia-Presbyterian Hospital (Washington Heights), Harlem Hospital (Harlem), Mount Sinai Hospital (East Harlem), Lenox Hill Hospital and Manhattan Eye, Ear and Throat Hospital (Upper East Side), New York University/Bellevue Medical Center (Kips Bay), and St. Vincent's Hospital and two ambulatory clinics in Greenwich Village.

The interviews were audio recorded and conducted in-person if possible, but due to geographical restrictions, most were performed remotely. While conducting these interviews, I attempted to get into the mindset these subjects had during the 1980s. Each interview began with standard questions designed to examine some of the greater biomedical and sociopolitical challenges that the AIDS epidemic presented to these physicians. However, because participants' medical specialization differed, I varied my

15 Epstein, *Impure Science*, 70, 237.

subsequent questions in order to obtain the best understanding of each of their distinct perspectives. Reliving the decade was emotionally difficult for participants; some potential subjects refused to participate because of the painful memories this project brought up.

It is important to mention the limitations of this study. My own subject position and intrinsic biases as a White, gay-identified, cisgender, male physician with no personal experiences with intravenous drugs—despite my intention to remain objective—color my analyses. The scope of this project is also limited by the relatively few number of interviews conducted. I intentionally interviewed a smaller group of physician subjects to give greater space to the deeper opinions of the subjects, as well as to enable the reader to understand how their individual stories and professional trajectories shaped their opinions. Because of these choices, this study does not extrapolate pervasiveness of the physician subjects' opinions or the breadth of NYC physician opinion, which would require a much larger pool of interviewees. I assert that the sample size is appropriate given the nature of the research question at hand, purposive method of recruitment, and richly textured perspectives.

This research is also influenced by my decision to include the identities of the physicians, which was intended to highlight their credibility and expertise, as well as to contextualize their perspectives. This choice may have affected the honesty of the participants' responses, as they may have withheld potentially embarrassing thoughts or actions. This possibility may be compounded by my relation to three of the physicians interviewed—Maria DeVita, Michael DeVita, and Sharon Kiely—and by subject matter, as the interviewees were asked to reflect on very sensitive topics, such as death, homophobia, and the limits of their profession. In order to mitigate such a threat to the authenticity of the interviews, I allowed the physicians studied the opportunity to review the final quotations to be included in the study so that their thoughts were accurately represented. Though this carried the potential of participants redacting responses that they later regretted, this did not occur. A limitation of any oral history is its intrinsic bias towards what individual respondents find memorable years after the fact. The interviews were conducted in 2013-2014, over twenty years after the period in question. Though this time may grant perspective into the impact of this period on career trajectory and clinical practice of the physician subjects, there is also the potential for altered or distorted memories. I attempted to minimize such bias through corroborating interviews through alternative sources, but we must approach all oral histories with a certain level of skepticism.

Although no two interviews were the same, there are some common threads connecting the narratives of these physicians. Based on the interviews I have completed, combined with secondary research on the AIDS epidemic, it is evident that HIV/AIDS provided unique biomedical, social, and political challenges to the physicians working in NYC during the 1980s. These physicians, over the course of the decade, adapted to meet these challenges using methods that have since become commonplace in their clinical practices.

A NEW PLAGUE: BIOMEDICAL CHALLENGES

The AIDS epidemic tested physicians in unexpected and unpredictable ways; HIV was a new disease without definition or treatment. We now know that HIV is a retrovirus, which was only isolated in humans in the early 1980s.¹⁶ The novel biology led to distinct biomedical issues for the physicians, such as staffing, patient volume, opportunistic disease treatment, and new classes of medications. The interviewed physicians recalled their adaptations to meet these challenges: epidemiological reporting became more commonplace, specialized wards emerged, experimental treatments and universal precautions were implemented, and the epidemic was reframed. Some of the skills and practices persisted throughout the physicians' medical careers.

Disease Reporting

One of the largest problems was that many of the physicians in the US had no experience operating within an epidemic. Most of the interviewed physicians had



Dr. Sharon Kiely, MD -
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Dr. Kiely

only studied American epidemics in history lessons and had never experienced one firsthand. One such physician was Sharon Kiely, who moved to NYC in 1984 to attend the internal medicine primary care residency program at St. Vincent's Hospital, where she remained until July of 1988. Kiely recounted the medical community's mindset leading up to the epidemic and said, "Remember there wasn't anything like this in anybody's experience because all of the big epidemics like polio, measles, and all of this stuff were behind us. Tuberculosis was gone. There were decades and decades of health."¹⁷



Dr. Craig Keyes, MD -
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Dr. Keyes

Another physician subject, Craig Keyes, first moved to NYC for his undergraduate studies at Columbia University and returned for his medical school rotations at Mount Sinai Hospital, NYU/Bellevue Hospital, and Columbia-Presbyterian in 1982. He began a neuroradiology residency at Columbia University, but as the AIDS crisis mounted, he switched to an internal medicine program at Lenox Hill Hospital where he eventually ran the AIDS ward. Keyes, a gay-identified man whose brother died of AIDS in 1993, remembered being discouraged from focusing on HIV:

¹⁶ Ibid, 71.

¹⁷ Sharon Kiely, interview by author, 6 November 2013.

I will never forget what the chairman of medicine at Lenox Hill said to me after I finished my residency – [The hospital] wanted me to come and run the AIDS unit at Lenox Hill Hospital. The Chairman of Medicine said “I think you’re going to really regret [taking the position] because AIDS is really popular right now and a gold mine for getting funding. And everybody else is getting cheated out of their funding. It’s not going to be the focus forever. You’ve got to decide if you’re going to go with it and run that risk or expand and get a broader skill set.” I didn’t like that and reacted negatively to it. I was shocked that somebody in that position would even think that let alone express it.¹⁸

Such sentiment expressed how the some in the medical community viewed infectious disease epidemics at this time: a passing phase or funding fad.



Dr. Michael DeVita, MD -
Reprinted with permission from
Dr. DeVita.

Despite their lack of training, the interviewed physicians were tasked with making clinical decisions for the increasing number of AIDS patients. Michael DeVita, for example, moved to NYC for a one-year internal medicine internship at St. Vincent’s Hospital in 1981. He returned to St. Vincent’s for his fellowship in critical care in 1984, where he stayed until 1988. DeVita remembered the difficulties of diagnosis when the first few AIDS patients came into the intensive care unit (ICU) of St. Vincent’s Hospital in 1981, the first year of the epidemic:

There weren’t a lot of people. . . . It was a really rare disease at that point. We didn’t know there were opportunistic infections. They had diarrhea that we couldn’t diagnose, then they had pneumonia that we couldn’t diagnose, then they had skin lesions that turned out to be Kaposi’s sarcoma that was so rare that people couldn’t believe it.¹⁹

With their inability to diagnose the illness, they enlisted the help of the CDC. DeVita remembered his correspondence with the CDC with regard to one of his patients during the first year of the epidemic:

When I was in the ICU, I had a patient with pneumocystis and I had to call the CDC to report it and the CDC flew a medicine to JFK [Airport], and I had to call for someone in the hospital to pick up the drug, pentamidine, and bring it to the hospital. The patient died. It was that rare and that weird that we had to call the CDC to get the drug, which wasn’t released. We had [use of] it special on a compassionate use protocol. That told me that the

18 Craig Keyes, interview by author, 5 February 2014.

19 Michael DeVita, interview by author, 1 November 2013.

government and CDC knew about it and had done enough investigation on it to know what the treatment should be.²⁰

This quotation revealed a perceived disconnect between the CDC and the interviewed physicians at the time. Before AIDS, the interviewed physicians felt reporting procedures to be rare, and it was ambiguous what conditions were reportable.

Although there were reports of abnormal medical cases, a federal system of mandatory infectious disease reporting was not developed until May 1989.²¹ Keith Sanders, another physician subject, moved to NYC in 1988 for his neurology residency at Columbia-Presbyterian Hospital and Harlem Hospital, where he stayed until 1991. He critiqued the disorganization of the field at that time and said, “Each physician and each hospital across the country would not have a common means of sharing data. What each little silo was experiencing was not effectively collated until years later. There should have been a better epidemiological means of tracking that. . . there could have been a more concerted effort earlier on.”²²

Kiely explained how the experience of working through the AIDS epidemic heightened the understandings of which cases were worthy of reporting for herself and her colleagues: “I think our ability to report has improved substantially. I think that people now know that if you see something odd in medicine, you report it. There is more understanding of what is reportable and what is not.”²³ The physicians emerged from the era with heightened knowledge of when to report and with new means to do so.

Safety Precautions

Health providers were also challenged by the risk to their own health. At first, no one knew how a person contracted AIDS, though they knew it almost certainly led to death. With such uncertainty, the interviewed physicians recalled initially implementing the highest amount of safety precautions when treating AIDS patients.

Another NYC doctor working during the epidemic was Dennis Greenbaum, who was raised in Brooklyn and completed his medical residency at St. Vincent’s Hospital in the 1970s. He worked there until the hospital’s closure in 2010, when he was the ICU chief and chairman of medicine. He edited the 1993 issue of *Critical Care Clinics*, “Management of the AIDS Patient in the ICU.” He remembered early personal protective equipment (PPE) procedures:

Everybody was concerned about catching it because nobody had any idea of what was causing it. . . We used extraordinary precautions when we went to see a patient - this was the doctors, the nurses, and everybody. We wore total body gowns – everything was covered. We wore goggles, we wore masks, and we

20 Ibid.

21 “Mandatory Reporting of Infectious Diseases by Clinicians,” *Morbidity and Mortality Weekly Report* 39 (1990): 1-11.

22 Keith Sanders, interview by author, 27 December 2013.

23 Kiely interview.

had covers over our heads, blue plastic full body garb, and gloves. That was the only way we went in to see those patients.²⁴

However, such precautions were not only limited to hospitals. Greenbaum continued that, “When these guys went to court, they were put in this booth to be separated from the jurors and everyone else. There was no way to keep everyone else isolated, so they put the suspected HIV patient into that booth.”²⁵ Greenbaum’s statement illustrated the extremity to which safety precautions were taken during the early AIDS epidemic in NYC, both inside and outside of clinical spaces.

The medical community understood that the virus was transmitted through bodily fluids, primarily through condomless sex or infected syringes, by September of 1983.²⁶ As more and more information about HIV transmission became clear, debate arose among the doctors caring for AIDS patients about reducing PPE. The garments had an alienating effect on patients who already experienced extreme levels of bias and social stigma. Doctors began to speak out against such extensive precautions. Michael DeVita remembered a colleague of his at St. Vincent’s Hospital, Joyce Wallace, who spoke out to increase the quality of AIDS patient care. He said, “Joyce thought it was immoral to wear gloves and masks and gowns because people were dying. They needed humanity and not sterility.”²⁷ Over time, the gowns became less commonplace, though there were occasional confrontations. Kiely recalled,

One night I went into the room of a patient being admitted with AIDS and at that point we knew you didn’t need to dress up like a man going into outer space. The senior resident [physician] had a mask, goggles, hair net – I mean, he looked like a cartoon character. He said I needed to gown up to go into the room, and I asked “why?” even though he was my superior.²⁸

Over time, the gowns became less common in the AIDS wards. The interviewed physicians left the decade with the understanding of how to balance personal protection with empathetic connection to patients.

Part of such balance was through the development and heightened adoption of universal precautions. With no cure or effective treatment for HIV, physicians became extremely cautious when working with bodily fluids. Sanders remembered the lack of precautions before AIDS:

In those years we weren’t using gloves all of the time. For example, now when you would draw blood you would never not wear gloves no matter what you did, no matter who the patient. In those days you would draw blood and

24 Dennis Greenbaum, interview by author, 18 December 2013.

25 Ibid.

26 “Current Trends Update: Acquired Immunodeficiency Syndrome (AIDS) – United States,” *Morbidity and Mortality Weekly Report* 32 (1983): 465-467.

27 Michael DeVita interview.

28 Kiely interview.

sometimes you would get a little blood on your hands. The gloves were restraining and constricting, making it harder to find veins.²⁹

With the onset of AIDS, medical workers had a growing fear of needlesticks. Sanders elaborated and said that, “In the early years, when the virus was identified and there wasn’t an effective treatment, there was a vast fear amongst [my colleagues] that if you got a needle stick, maybe you were going to die. There was that fear that you had a risk of getting HIV and you could die from it. We didn’t know that the risks were low.”³⁰ Almost all of the physicians interviewed shared the same fear of needle sticks. Kiely also commented, “Now when you get stuck with a needle you put people on prophylaxis. Back then we didn’t have that—you just didn’t have sex with your partner, not donate blood, and basically sit and wait until maybe you got sick. It was very, very scary.”³¹ Here, Kiely referred to post-exposure prophylaxis, which is an antiretroviral regimen developed in the mid 1990s to prevent seroconversion from occurring after a possible HIV exposure.³² Many of the physicians commented on this fear with stories of extreme care when performing procedures and subsequent sleepless nights.

Healthcare workers needed to minimize risk of needle sticks and other forms of bio-hazard exposure. It did not take long to recognize that strict universal precautions should be adopted by healthcare workers for all patients because it was not possible to know who might present a risk of infection. Physicians began to take seriously the practice of universal precautions, such as washing hands before and after treating every patient as well as wearing gloves. Kiely explained, “[AIDS] gave us a blueprint for universal precautions. The whole idea in health care is that you don’t just ask about the disease if you’re gay or use injection drugs, but you treat everyone as if they potentially have it. That all blood is potentially hazardous. . . .”³³ The CDC established recommendations for such universal precautions in their November 1985 issue of *Morbidity and Mortality Weekly Report* (MMWR).³⁴ The interviewed physicians left the era with the adoption of universal precautions that enabled them to treat patients equitably while still protecting themselves from nosocomial infection for the remainder of their careers.

Patient Volume

In the epicenter of the American AIDS epidemic, hospitals became increasingly crowded with patients suffering from AIDS complications. Kiely recalled the scale of the work she faced at St. Vincent’s: “It was exhausting because where I was working,

29 Sanders interview.

30 Ibid.

31 Kiely interview.

32 Binta Sultan, Paul Benn, and Laura Waters, “Current Perspectives in HIV Post-Exposure Prophylaxis,” *HIV/AIDS – Research in Palliative Care* 6 (2014): 124-158.

33 Kiely interview.

34 “Recommendations for Preventing Transmission of Infection with Human T-Lymphotropic Virus Type III/ Lymphadenopathy-Associated Virus in the Workplace,” *Morbidity and Mortality Weekly Report* 34 (1985): 682-868.

the hospital was bursting at the seams. . . You would admit patients at night, and it was nothing to admit twenty-five patients a night on call. Now, the residents are capped at eight or ten. . . I remember the night it hit thirty; I couldn't see all of those people. I was moving as fast as I could."³⁵ Greenbaum, when commenting on the rising census at St. Vincent's, noted that between 1981 and 1985, one out of every six patients diagnosed with HIV in the US was diagnosed at St. Vincent's hospital alone.³⁶ At one point in the epidemic, the number of hospitalized patients in NYC rose so much the city even considered devoting an entire hospital solely to the care of AIDS patients:

In the mid 1980s, we had an eight bed ICU in the Department of Medicine at St. Vincent's and we had an average of six patients [out] of eight beds belonging to AIDS patients. There was a lot of thought of identifying a concentrated hospital so that a hospital – I think they were talking about Cabrini [Medical Center] – could become New York City's AIDS hospital. Then, once a patient was reasonably stabilized, the patients could be moved to one place, because there was no room for any patients other than AIDS patients when the volume was so high.³⁷

The idea of dedicating a whole medical center to a single infectious disease illustrates the full scale of the epidemic at this time in NYC.

The interviewed physicians recalled the restructuring of their individual hospitals in order to create new AIDS wards, which led to much debate. Michael DeVita considered the dedicated AIDS wards afforded to be altruistically motivated and attributed the shift to patient protection: "They were definitely quarantining AIDS patients. Once we knew it was transmissible via blood and secretions, they were careful about putting patients in isolation. That is very common in medicine though—it goes back to year zero."³⁸ However, not all of the physicians shared the belief that hospitals designed such quarantine procedures based simply on epidemiological precedent. As fear of the transmission of the disease grew, so too did the stigmatization of infected patients. Peter Zeale remembered that HIV-negative patients were nervous that they might contract the fatal virus while they were in the hospital. Originally from the Bronx, Zeale was an internal medicine resident at St. Vincent's hospital from 1979 to 1983, after which he opened a private practice in the Greenwich Village/Chelsea neighborhoods of Manhattan. He recalled one of his patients expressing fear of acquiring HIV from his hospital roommate:

Somebody came in with pneumonia. His roommate came in that night and he began asking, "You know, that guy's coughing. Am I going to get it?" And you knew the guy had HIV. At that time, they weren't quarantining anybody and there were a fair number of patients who were mixed in together. It was . . .

35 Kiely interview.

36 Greenbaum interview.

37 Ibid.

38 Michael DeVita interview.

difficult because you wanted to protect the privacy of the HIV patient and you would say to the other patient, “Well, he has pneumonia and we’re treating him.”³⁹

Craig Keyes, too, described how fear of both infection and adverse publicity led to creation of HIV wards:

The argument publicly was that all the special needs could be served. Effectively all of the experts were on the same floor. All the support services and the infrastructure were all on one floor. Many of us knew at the same time that that sort of quarantining or isolation was also for the benefit of the public relations department that didn’t want to have to deal with all of these movie stars at Lenox Hill having to be on the same floor or [in] the room next door to somebody with AIDS. Those people just didn’t want the ventilation risk – coming up through the heater or the walls or something.⁴⁰

These recollections support the notion that the wards in fact provided a dual function, providing specialized care for patients suffering from AIDS while at the same time quelling the paranoia of patients who feared contracting the fatal disease.

The interviewed physicians also recalled advocating for AIDS patients to be able to leave the hospital during the end stages of the disease. Michael DeVita remembered such efforts: “We were campaigning, trying to get the patients taken care of in a way that wouldn’t require them to be in the hospital. We wanted them to be able to stay in a nursing home or their own homes because there wasn’t much we could do for them in the hospital.”⁴¹ Though the notion of sending a patient home may sound like doctors giving up, the intention was more humane. With no drugs effective in fighting the virus itself, some physicians believed it would benefit patients to occupy a more comfortable space than a hospital, which presented not only the risk of iatrogenic infection but also a decreased quality of life. Michael DeVita recalled such experiences as a shift in his ideological paradigm, eventually leading him to pursue a career in palliative care.

Medical Staffing

The interviewed physicians also recalled challenges with staffing in the early AIDS epidemic. Greenbaum remembered a drastic downward trend in residency applications to St. Vincent’s Hospital: “Residents weren’t applying to St. Vincent’s because they were afraid to come [to Greenwich Village] because they were afraid they would die. Visitors wouldn’t show up. Patients with other conditions would elect to go to other hospitals.”⁴² Kiely, a 1984 medical school graduate, shared this memory of decreased desire to complete residency training in Greenwich Village: “There weren’t a lot of people in

39 Peter Zeale, interview by author, 11 January 2014.

40 Keyes interview.

41 Michael DeVita interview.

42 Greenbaum interview.

my medical school class that wanted to train at St. Vincent's in NYC." Applicants to nursing internships in the NYC region were also low.⁴³ Because hospitals in the US often rely on trainees to operate, such dramatically decreased interest carried the potential of worsened outcomes for patients.

Hospitals were further stressed by healthcare workers avoiding or refusing care to AIDS patients, events that some interviewed physicians recalled though most cited as rare. Michael DeVita recalled such anxiety amongst healthcare workers: "Everybody was concerned. There were some people that were so concerned that they wouldn't even go into the patients' rooms."⁴⁴ Though such acts may not have been overt, a 1988 survey conducted by New York University Hospital polled residents in seven NYC hospitals, and found that twenty-five percent would not care for AIDS patients if given the choice.⁴⁵

Healthcare providers took steps to ensure adequate staffing for the influx of AIDS patients. Attempting to solve the issue of recruitment, the physicians recalled reframing the epidemic in order to attract applicants. The medical professionals shifted the frame from the popular conception that providers would be risking their lives in a futile effort to lengthen the lives of gay men and drug users, to the notion that a young practitioner would gain firsthand experience with a new pathology and be a witness to the significant advancement of modern medicine. Greenbaum described such efforts:

We had a new chairman of medicine that . . . publiciz[ed] the fact that we had a very special disease here. He twisted the situation to make it more favorable to have people who were interested in infectious disease, that patient population, or the concept of fighting a brand-new disease. . . . So, the number of applicants for the residency program was restored, came back up, and returned to its usual high level.⁴⁶

Additionally, though care refusal was infrequent, hospitals such as St. Vincent's adopted new rules to prevent such behavior. Michael DeVita recalled, "The hospital actually made a policy that you couldn't refuse to care for patients. You would be fired for doing so. This came about because it was a Catholic hospital and they wanted to take care of people. The policy came about in the midst of AIDS, as soon as they found out about it. There was a bit of discussion, but they stopped it."⁴⁷ Governing bodies followed suit. In 1987, the American Medical Association ruled that doctors were obligated to treat AIDS patients.⁴⁸ In 1988, the American College of Physicians published

43 Anthony Preus, "AIDS: The Duty to Treat, A Philosopher's Prospective," *Mount Sinai Journal of Medicine* 56 (1989): 254-258.

44 Michael DeVita interview.

45 RN Link, AR Feingold, MH Charap, K Freeman, and SP Shelov, "Concerns of Medical and Pediatric House Officers about Acquiring AIDS from Their Patients," *American Journal of Public Health* 78 (1988):455-459.

46 Greenbaum interview.

47 Michael DeVita interview.

48 Robert Pear, "A.M.A. Rules That Doctors Are Obligated to Treat AIDS," *New York Times*, 13 November 1987, A14.

a position paper on the debate, which provided the organization's "explicit acknowledgment of the ethical imperative to care for all patients."⁴⁹ Such precedents continue to guide clinical ethics today.

Opportunistic Infections/Events

We now know that when HIV decreases a person's CD4 T-cell level to below 200 (as defined by the World Health Organization), the patient is particularly vulnerable to a slew of illnesses called "opportunistic infections" and is diagnosed with AIDS.⁵⁰ With a suppressed immune system, previously benign infections can become lethal. Working with limited-yet-evolving understandings of the pathophysiology of HIV and the increased prevalence of the opportunistic pathologies, the interviewed physicians adapted through the development of new diagnostic measures and experimental treat-



Dr. Vincent Patalano II, MD -
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Dr. Patalano.

ments. Vincent Patalano II recalled such new diagnostic techniques. He completed medical school at Boston University in 1988 before moving to New York to complete his ophthalmology residency at Manhattan Ear and Throat Hospital from 1989-1992. He also rotated at New York University/Bellevue Medical Center and Columbia-Presbyterian Medical Center. Patalano remembered novel diagnostic procedures during the epidemic: "People even did things like retinal biopsies. You should know that retinal biopsies are essentially unheard of. It's not a tissue you usually biopsy—it usually causes complications to biopsy—but people were doing it to figure it out. Those turned out to be PCP, pneumocystis carinii of the lung, which can actually cause a choroidal infiltrate."⁵¹ When discussing opportunistic infections in AIDS patients, Greenbaum commented on the response to pneumocystis pneumonia in the ICU:

There were a lot of findings that also improved the outcome of the disease without affecting the retrovirus itself. . . We saw that people weren't dying anymore of pneumocystis when we had little control of the immune system but better control of pneumocystis, especially when we knew there were other medications that could be added to the treatment such as steroids, which could make the patient better. So, toward the end of the 1980s the presenting manifestation of HIV was no longer pneumocystis. We began to see cardiac

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49 Theodore C. Eickhoff, "The Acquired Immunodeficiency Syndrome (AIDS) and Infection with the Human Immunodeficiency Virus (HIV)," *Annals of Internal Medicine* 108 (1988): 460-169.

50 Nathan Forda, Graeme Meintjes, Marco Vitoria, Greg Greened, and Tom Chiller, "The Evolving Role of CD4 Cell Counts in HIV Care," *Current Opinion in HIV and AIDS* 12 (2017): 123-128.

51 Vincent Patalano II, interview by author, 22 January 2014.

abnormalities – cardiac failure and other conditions that needed to be treated with truly experimental therapy.⁵²

In this way, physicians learned to treat the symptoms and sequelae of the virus.



Dr. Maria DeVita, MD -
Reprinted with permission from
Dr. DeVita.

One such doctor, Maria DeVita, moved to NYC for her internal medicine residency and nephrology fellowship at Lenox Hill Hospital. She commented on her own work monitoring the bodily fluids and electrolytes of AIDS patients, who commonly had renal injury caused by opportunistic infections and their treatments. She recalled:

Most of the people with AIDS in the 1980s would have renal failure because the Bactrim they took can be nephrotoxic. They could have either high sodium levels or low sodium levels because of all the diarrhea they're having from their cryptosporidiosis, and also potassium perturbations. The typical consult would be for some sort of electrolyte abnormality, and then dehydration. We just helped by guiding the fluids.⁵³

Through monitoring bodily fluids, using steroids, and developing sound procedures for fighting the onslaught of opportunistic events, the physicians prolonged the lives of AIDS patients. The physicians also carried with them the experience of adapting therapies for novel pathologies. However, such care often felt futile, as it was only a temporary extension of life because physicians could not fight the agent of AIDS: the retrovirus HIV.

Finally in 1987, medical response to HIV changed forever with the FDA approval of the first antiretroviral drug, azidothymidine (AZT). Early single medication regimens of antiretroviral medications such as AZT presented significant problems. First and foremost, they were expensive and had large pill burdens with major side effects. Worse, the virus mutated to become resistant to early AZT treatments.⁵⁴ Still, the doctors interviewed all remarked upon the joy and satisfaction they felt with the advent of antiretroviral medications such as AZT. Maria DeVita contextualized what their discovery meant to her: "Oh my God, it was like a miracle. All of a sudden you would give people a pill and they would live. It was really amazing. . . I had never been in something as dramatic as that. It was like when penicillin was invented. It was amazing."⁵⁵ AZT was

52 Greenbaum interview.

53 Maria DeVita, interview by author, 25 January 2014.

54 Kiely interview; Greenbaum interview.

55 Maria DeVita interview.

the long-awaited breakthrough that allowed physicians to fight the virus itself. It was not until 1996, however, that HAART, a regimen combining of three antiretroviral medications, raised the life expectancy of HIV+ patients to be nearly equal to those without HIV.⁵⁶

SOCIOPOLITICAL CHALLENGES

Many of the social challenges physicians working in NYC faced arose from the existing healthcare system, the political climate of the 1980s, and the stigmatization of the groups in which AIDS first proliferated. The medical community now knows that needle sharing during injection drug use and receptive anal intercourse have an HIV transmission rate eight and seventeen times higher respectively than penile-vaginal sex, which helps to explain the early epidemic's prevalence in injection drug users and gay men.⁵⁷ However, such data was unavailable at the time. Instead, much of American society perceived the early epidemic as the result of ostensibly illicit behaviors by minority groups.

The physicians were also, in part, limited by the American healthcare system, which provided unequal access to medicine. To this day, enrollment in any sort of insurance in the US takes concerted effort and most require some type of financial contribution. Most Americans gain private health insurance through their or their spouse's salaried jobs.⁵⁸ The major federal options are Medicare, a federal government program for all Americans over sixty-five years of age and those with disabilities, and Medicaid, a joint federal and state government program for those with limited incomes. In addition, various programs are available for veterans in active or past military service.⁵⁹ In 1980, 71% of Americans under age sixty-five had private insurance offered through their employer, 8% purchased private insurance, 7% had Medicaid, 1.4% had Medicare, 2% had another public option, and 12% were uninsured.⁶⁰

Marginalized groups most affected by AIDS, such as gay men and injection drug users, faced barriers to medical care. LGBT populations were then and continue to be less likely to have health insurance.⁶¹ In the 1980s, LGBT groups were less likely to hold salaried jobs that provided health insurance benefits, and were often not old enough to qualify for Medicare. State mandated requirements left sixty percent of the poor below the federal poverty line without Medicaid coverage.⁶² In the 1980s, same-sex marriage was not yet legal, and LGBT-identified people were barred from openly serving in the military. Injection drug users were similarly uninsured, as insurance

56 Ibid.

57 Sultan et al., "Current Perspectives," 124-158.

58 Robert A. Cohen, Diane M. Makuc, Amy B. Bernstein, Linda T. Bilheimer, and Eve Powell-Griner, "Health Insurance Coverage Trends, 1959-2007: Estimates from the National Health Interview Survey," *National Health Statistics Reports* 17 (2009): 1-25.

59 Nancy De Lew, George Greenberg, and Kraig Kinchen, "A Layman's Guide to the U.S. Health Care System," *Health Care Financing Review* 14 (1992): 151-169.

60 Cohen et al., "Health Insurance Coverage Trends," 9.

61 *Affordable Care Act Enrollment Assistance for LGBT Communities: A Resource for Behavioral Health Providers* (Washington, DC: Substance Abuse Mental Health Services Administration, 2014), 11.

62 De Lew et al. "A Layman's Guide," 151-169.

companies were not required to cover treatment for substance use disorders until the 2010 Patient Protection and Affordable Care Act.⁶³ For these reasons, those who first contracted AIDS had impeded access to the healthcare system, making medical outreach more difficult.

Lack of government support brought its own challenges, as supplemental funding to respond to the epidemic was delayed. In NYC, Democratic Mayor Ed Koch had allocated only \$24,500 to AIDS response by 1984, three years into the epidemic.⁶⁴ At the federal level, Republican President Ronald Reagan did not publicly mention AIDS until 1985, four years into the epidemic.⁶⁵ In 1987, the US Senate in a ninety-four to two vote, restricted the CDC from providing “AIDS education, information, or prevention materials and activities that promote, encourage, and condone homosexual sexual activities or the intravenous use of illegal drugs.”⁶⁶ In such a volatile political climate, physicians were forced to face the many social challenges AIDS presented with a dearth of both funding and public understanding.

Medication Access

Due to the dramatically disparate health insurance rates in America, access to medication became an issue for the populations disproportionately infected by HIV in 1980s NYC. When the first antiretroviral AZT became available in 1987, it was priced at \$8,000 per year—making it the most expensive drug ever on the American market.⁶⁷ Without existing government subsidies, many of the interviewed physicians took outreach into their own hands. Keyes, for example, obtained a grant through the National Healthcare Service Corps to start his own sexually transmitted illness (STI) and HIV clinic within the Lesbian and Gay Community Services Center in the West Village (on West 13th Street, between 7th and 8th Avenues).⁶⁸ He remembered the limitations AZT presented at his clinic: “I was in a clinic that was able to dispense it and had a bunch, so I had access to it, but no, it was not unlimited. I had a limited amount to give and if you ran out, you were just out of luck. People who had insurance were O.K., but it’s all the uninsured or underinsured that had trouble.”⁶⁹ Keyes responded to the limited supply of AZT by recruiting as many patients as possible to his clinic. He hoped to gain the attention of the pharmaceutical companies so that they would trial new medications there. In this way, he was able to secure the “biggest stash [of AZT] in the city by far.”⁷⁰ Even so, the supply was still finite. Staff scrutinized the flow of medications to

63 Thomas J. Stopka, Marguerite Hutcheson, and Ashley Donahue, “Access to Healthcare Insurance and Healthcare Services Among Syringe Exchange Program Clients in Massachusetts: Qualitative Findings from Health Navigators with the iDU (“I do”) Care Collaborative,” *Harm Reduction Journal* 14 (2017): 1-9.

64 David France, “Ed Koch and the AIDS Crisis: His Greatest Failure,” *New York Magazine*, February 2013.

65 Philip Boffey, “Reagan Defends Financing for AIDS,” *New York Times*, 18 September 1985, B7.

66 US Senate, *S.Amdt.963 to H.R.3058, S.P.963*, 100th Congress, introduced in Senate 14 October 1987.

67 *How to Survive a Plague*.

“AZT’s Inhuman Cost,” *New York Times*, 28 August 1989, A16.

68 Keyes interview.

69 *Ibid.*

70 *Ibid.*

ensure that the available medications were used as efficiently as possible. He said, “I remember very clearly it was tightly controlled and I had to approve any of the exceptions that people gave more than two weeks at a time. At the time you would think, ‘Why would you give them a month’s worth of medication if you’re not even sure they were going to live that long?’ That’s how crazy it was.”⁷¹ In addition to rationing medication, he secretly allocated antiretrovirals for patients who otherwise would not have access to it. Through such action, Keyes and the other physicians operating in his clinic were able to care for the needs of marginalized people, despite the lack of national or city-wide healthcare policy. Keyes carried such skills with him, as he continued to work to improve healthcare coverage and medical cost management.

Societal Stigmatization

The poor prognosis of AIDS, coupled with the lack of early information, created a tremendous social stigma in greater NYC society, even outside of clinical spaces. This stigma and fear led people to avoid testing, treatment, or disclosure, which in turn facilitated the virus’s spread.⁷² As more information about the epidemic became public, society reacted. For example, when people heard HIV was blood-borne, there was a fear that it could be transmitted via mosquitoes. Kiely recounted, “There was this big rumor going around that if a mosquito was going around that had just bit a person with HIV and bit you, it could transmit. So people were closing their windows and looking for ultra-thin screens and using bug sprays because there was this horrible rumor going around.”⁷³

With such widespread fear and limited knowledge of HIV, unaffected people were reluctant even to visit Greenwich Village, to the detriment of the historically gay neighborhood’s economy. Zeale recalled that his new private practice there suffered.⁷⁴ According to Greenbaum, “The restaurants in Greenwich Village were all closing. Nobody wanted to go to the village to have dinner. There were all kinds of ridiculous concepts and fears that were all based on the fact that nobody knew what it [HIV] was.”⁷⁵ The rumors even led residents of the community to leave. Keyes recalled, “Nobody wanted to be in the West Village anymore. I think that’s why Chelsea was born. It was just too painful, too unpleasant.”⁷⁶

The interviewed physicians also recalled that the panic around AIDS exacerbated the homophobia and stigma of substance use in the epidemic’s first decade, when an AIDS diagnosis carried with it the automatic assumption that the patient was either gay or an illicit drug user. Michael DeVita recalled having different conversations with patients and their families to avoid outing his patients:

71 Ibid.

72 Epstein, *Impure Science*, 21, 78.

73 Kiely interview.

74 Zeale interview.

75 Greenbaum interview.

76 Keyes interview.

A lot of them hadn't told their parents that they were gay, let alone sick. It made it tough. . . . It was hard because you want[ed] to be honest, and people have the right to not present their sexual affinities. Normally, it wouldn't be an issue. I mean, I was not telling families that their children were gay for years – that wasn't the issue. The problem was that now their sons were dying, and families wanted to know why their sons were dying, and if you say he's dying of AIDS, they know he's gay. If you say he's dying of pneumocystis, they know he's gay, and it became an issue.⁷⁷

The interviewed physicians recalled adapting to societal stigmatization through confidentiality and offering anonymous services. Keyes remembered offering such services at his clinic and said that, "We had a huge number of guys that contracted HIV from contaminated needles who worked for the New York Department of Sanitation. . . . They knew that they could come see us and not disclose their actual identity. We had probably forty or fifty of them. . . ."⁷⁸

HIV testing and results were kept in extreme secrecy in an era before national patient confidentiality laws such as the 1996 Health Insurance Portability and Accountability Act (HIPAA). Kiely noted, "I think doctors learned [in the early epidemic] to be cautious; that medical record information is sacred between the doctor and the patient. We have learned that insurance companies and employers could use it against the patient. So, I would say that doctors were doing things to protect patients' privacy before the laws changed."⁷⁹ It was years before laws protecting the rights of those with HIV were enacted. Kiely described how these laws codified what physicians were already doing: "Over time, confidentiality regarding [HIV] diagnosis [gained] special status in medical records, and permission to share this information requires permission apart from general permissions, similar to psychiatric and drug and alcohol abuse medical history."⁸⁰ Thus, the interviewed physicians hoped to increase patient comfort with HIV care by reducing anxiety about their status being disclosed to family, friends, or other medical staff. These physicians honored the importance of such physician-patient confidentiality, now enforced by patient protection legislation, as their careers progressed.

Gay Community

AIDS had a disproportionate impact on NYC's gay community at the precise moment that it was gaining political traction. The Stonewall riots occurred just twelve years prior to the epidemic, in June 1969 in Greenwich Village.⁸¹ Homosexual behavior was defined as a mental disorder in the American Psychiatric Association's *Diagnostic and*

77 Michael DeVita interview.

78 Keyes interview.

79 Kiely interview.

80 Ibid.

81 *Stonewall Uprising*.

Statistical Manual of Mental Disorders (DSM) until 1973.⁸² Anti-sodomy laws were struck down in NYC just one year before the epidemic struck, in the 1980 New York Court of Appeals ruling, *People v. Ronald Onofre*.⁸³ The gay political mobilization that began during the gay liberation movement of the late 1960s and 1970s subsequently shifted into AIDS activism during the 1980s and 1990s, pushing gay people out from underground spaces into public discourse.⁸⁴ But AIDS was used as an excuse for backlash against such social mobility. It was not uncommon for the disease to be characterized as a just punishment for the promiscuous homosexual behavior that was central to the politics and aesthetics of gay liberation.⁸⁵ Disproportionate HIV rates persist in the US, as men who have sex with men comprise seventy percent of all new HIV diagnoses.⁸⁶

The interviewed physicians reflected on the changing climate of homophobia in NYC hospitals. Maria DeVita recalled hearing homophobic remarks about AIDS patients, saying, “It was definitely not hospital-wide. I think it was just a few people in the doctor’s lounge sort of making snide remarks . . . but I definitely heard it more than once.”⁸⁷ She went on to discuss the discretion of her colleagues at Lenox Hill, who chose to not outwardly identify as gay, remaining closeted out of fear of the repercussions of homophobia. She said, “There were a few guys that were actually very closeted, like even three guys that I worked with got AIDS and died. . . They were gay, but they weren’t openly gay . . . so I was like ‘Oh my god, I didn’t even know he was gay.’ And then all of a sudden he had AIDS and died.”⁸⁸ Other interviewed physicians had a different experience. For example, none of the four interviewed physicians who worked at St. Vincent’s recalled overt homophobia, which they attributed to their location in the West Village. However, Kiely criticized the inertia of the national medical community: “I think had they been farm boys in Wisconsin dropping dead, I do believe we would have reacted faster.”⁸⁹ The interviewed physicians thus remembered varying levels of bias towards gay AIDS patients across different NYC hospitals and the wider US.

In spite of commonplace homophobia, the interviewed physicians reflected on the impacts of LGBT community activism on patient care in NYC. Though promiscuity initially led to the virus’s spread, the sexual openness of the gay community also allowed it to develop and adopt safe sex practices.⁹⁰ This movement toward education is exemplified by the Gay Man’s Health Crisis (GMHC), founded in 1982, which provided a variety of resources and support to the AIDS community of NYC. They

82 Ronald Bayer, *Homosexuality and American Psychiatry: The Politics of Diagnosis* (New York: Basic Books, 1981), 132.

83 *People v. Onofre*, 51 N.Y. 2d 476 (1980).

84 Robert A. Padgug and Gerald M Oppenheimer, “Riding the Tiger: AIDS and the Gay Community” in *AIDS: the Making of a Chronic Disease*, 245-278.

85 *How to Survive a Plague*.

86 Centers for Disease Control and Prevention, “Estimated HIV Incidence and Prevalence in the United States, 2015–2019,” *HIV Surveillance Supplemental Report* (26).

87 Maria DeVita interview.

88 *Ibid.*

89 Kiely interview.

90 Crimp, *AIDS*, 253.

developed safe sex comics, provided emotional support, supported research fundraisers, and educated the public on general HIV and AIDS awareness.⁹¹ Greenbaum recalled the tangible impact that the GMHC had on the AIDS epidemic in NYC:

The GMHC handled HIV in a way that other conditions rarely see. They took control of everything. . . They visited the men at home. They worked as social workers and like family to the gay men who didn't have family. . . This community-based group was unlike any other that I was ever aware of, [and] really took the disease by the horn. They are clearly responsible for most if not all of the initial response to the epidemic and are still active.⁹²

LGBT community members also became politically engaged. ACT UP was particularly vocal in their calls to redress the flaws in national AIDS policy. They staged “die-ins” in churches, “kiss-ins” in hospital emergency rooms and pharmaceutical-companies, and even stormed the NIH and shut down the FDA for a day.⁹³ Such activism disrupted everyday life and communicated a sense of urgency. To be effective, ACT UP members stayed educated on the latest discoveries about the virus, treatments, and clinical trials.⁹⁴ Keyes recalled Larry Kramer, one of the founders of ACT UP and GMHC, protesting in his clinic:

Larry was just so angry at anybody who was working within any kind of infrastructure. He would come into the clinic and just start screaming at us because we were part of the federal health system, [saying] “Don't you know Reagan is trying to kill everybody?!” We would say, “We're not trying to kill anybody, Larry.” We were trying to help. But he was just nuts. I had known him from before and so it wasn't that difficult.⁹⁵

Through disruptive actions such as these, LGBT community activism raised new criticism of and brought support services to patient care in NYC.

In part because of this political advocacy, the interviewed physicians also observed how their patient/caregiver dynamic changed during the late 1980s, becoming more equitable and holistic. As patients gained more knowledge about their illness than before, they also gained agency in their healthcare, questioning their caregivers on treatment strategies and advocating for their own unique care goals. Keyes noted this change in the patient dynamic: “It forced the medical community to have to work with a higher proportion of patients who were really smart about their condition. It forced the medical community in particular to act more in a partnership than in a more dictatorial frame of mind. I think that was a good thing for medicine.”⁹⁶ Keyes's perspective on the change in his

91 Ibid., 250-264.

92 Greenbaum interview.

93 *How to Survive a Plague*.

94 Ibid.

95 Keyes interview.

96 Ibid.

clinical practice was echoed by changes in medical education and clinical research.⁹⁷ Learning from these relationships, the physicians explained how the early AIDS epidemic and gay activism led to a more collaborative patient-provider dynamic.

Injection Drug Users

The interviewed physicians recalled a different narrative when caring for the second population most affected by AIDS in 1980s NYC: injection drug users (IDUs). IDUs, like members of the gay community, occupied a fringe position in society and suffered from poverty, homelessness, and joblessness. However, unlike the gay community, IDUs not only lacked community support and political organization, but also faced increasing social and legal stigma in this period. A wave of public anti-drug sentiment arose during the crack cocaine epidemic in the urban areas of the US of the 1980s, and anti-drug laws gained support across the political spectrum.⁹⁸ A 1989 *New York Times* article blamed the crack epidemic for increasing the homicide rate by ten percent in NYC, and for tripling cases of abuse and neglect by parents under the influence.⁹⁹ The city responded by establishing Tactical Narcotics Teams and doubling drug arrests, which nearly doubled the city's prison population from 10,000 in 1985 to 18,000 in 1989.¹⁰⁰ On a national level, President Reagan expanded the federal War on Drugs, and in 1986, Congress (with overwhelming bipartisan support) passed the Anti-Drug Abuse Act of 1986, which allocated \$1.7 billion to the War on Drugs and established a series of mandatory minimum prison sentences for various drug offenses.¹⁰¹ This Act led to mass incarceration for nonviolent drug offenses, ballooning from 50,000 people nationally in 1980 to 400,000 in 1997.¹⁰²

With the backdrop of an escalating war on drugs, NYC had an especially poor early response to the spread of HIV amongst drug users.¹⁰³ Serum samples from IDUs entering substance use treatment, retrospectively analyzed, indicate that seroprevalence of HIV rose rapidly, from less than twenty percent in 1980 to about fifty percent in 1983.¹⁰⁴ The rapid rise has been attributed to the influx of heroin to the region during the 1970s and 1980s, as well as the existence of shooting galleries, where people rented (and reused) injection paraphernalia.¹⁰⁵ With such dramatic infection rates, government agencies began to debate syringe exchange programs. The New York Department of Health briefly established a program in 1988 that was dismantled only two years later with the 1990 election of Democratic Mayor David Dinkins. Critics of

97 Epstein, *Impure Science*, 346.

98 Editors, "War on Drugs," *Encyclopaedia Britannica* (Encyclopaedia Britannica, 2020).

99 Michel Marriott, "After 3 Years, Crack Plague In New York Only Gets Worse," *New York Times*, 20 February 1989, A1.

100 Ibid.; City of New York Police Department, *Comprehensive Law Enforcement Drug Strategy* (1991).

101 "War on Drugs"; US House of Representatives, *Anti-Drug Abuse Act of 1986*, H.R.5484, 99th Congress, introduced to House 8 September 1986.

102 "War on Drugs."

103 Don C. Des Jarlais, Samuel R. Friedman, and Jo L. Southeran, "The First City: HIV Among Intravenous Drug Users in New York City," in *AIDS: the Making of a Chronic Disease*, 279–295.

104 Ibid., 280.

105 Ibid., 281.

the program argued that they condoned drug use or claimed it diverted funding from underfunded treatment programs.

The interviewed physicians recalled the intense stigma against drug users, which was prevalent in the clinical setting; many of them felt at that time unprepared to combat the specific needs of a patient population so socially and legally marginalized. Zeale bluntly noted the challenges that IDUs presented to those in charge of their health:

Often times they would want more drugs. They would be more nasty to you. A lot of the time they would sign out of the hospital against medical advice and in all honesty, you were happy to get them off of your service. They were often times more trouble than they needed to be. Looking back at those patients, I would say that we did treat them differently. I think we had less tolerance.¹⁰⁶

Such an unequal treatment could be due to the changing perceptions of addiction at the time. In the 1980 *DSM-III*, substance use disorder was deemed its own primary mental illness.¹⁰⁷ Before that designation, the medical community viewed substance use as sequelae of another primary psychopathology. Nonetheless, substance use disorder treatment was not well incorporated with treatment of other medical pathologies in NYC hospitals during this period, and the anti-drug climate of this political period reinforced existing social prejudices.¹⁰⁸

As higher rates of IDUs were admitted into hospitals with AIDS complications, the interviewed physicians became familiar with the previously underground injection drug culture. Sanders commented on his initial lack of understanding and training in the care of patients with substance use disorder:

With the injection drug users, you had two diseases already. You had the viral infection, and then you were dealing with addiction that was difficult to break. We were not able to treat the addiction. . . I remember one specific time when a patient was not in his room and was found dealing or buying drugs in the public area down the hall. We were so naïve, like “Holy crap! He’s a drug user!” Well duh – that’s why he was in the hospital. We were surprised that he continued it in the hospital, but he was addicted. That’s what addicts do.¹⁰⁹

The interviewed physicians expressed the educational merit of such exposure, which changed their understandings of substance use disorder and subsequently their clinical practices. Keys recalled such adaptation at his clinic:

106 Greenbaum interview.

107 Sean M Robinson and Bryon Adinoff, “The Classification of Substance Use Disorders: Historical, Contextual, and Conceptual Considerations,” *Behavioral Sciences* 6 (2016): 18.

108 Des Jarlais et al, “First City,” 282.

109 Sanders interview.

There's just a lot of soft tissue issues coming through primary care when you're dealing with IV users that you never encounter anywhere else. I mean there's all these abscesses and all this weird stuff and the smell of it . . . It's just really hard to get your head around it until you get used to understanding just what it is. Once you get used to treating [injection drug users] it was fine.¹¹⁰

The interviewed physicians also became more comfortable asking previously stigmatized questions, now routine in a medical history gathering. Zeale discussed how he could make a more informed diagnosis while probing with these questions: "We always question people's drug use and sexual habits [now] because you never know when someone presents in your office with a febrile illness who has been ill for a while. Could it be HIV? So it makes you delve a little more into those questions."¹¹¹ Because of the novel nature of the disease, the AIDS epidemic pushed the interviewed physicians to recognize conditions associated with two stigmatized groups and to ask socially sensitive questions, which in turn allowed them to make more informed inferences and thus to deliver more specialized care.

Impacts on Physicians and Physician Wellness

For many of the interviewed physicians, the experience of combating an epidemic with few tools and relatively little governmental or societal support was mentally and physically taxing. Keyes remembered prognosis discussions as one of the hardest parts of his tenure caring for AIDS patients in NYC: "For me the most difficult moments were talking to a patient who didn't want to die. We had to talk about what we would do if we weren't successful and that's how we were going to work together and manage it all."¹¹² He also commented, "God, I haven't thought about a lot of this for a long time. Cause it's really tough to relive all of this."¹¹³ Zeale had a similar experience with such doctor-patient conversations. When asked what first came to mind when he thought of the AIDS epidemic, he spoke of one instance of delivering the diagnosis:

It was a very difficult case — a young girl. I was attending, so it was probably around 1986 or 1987. She was the daughter of a patient of mine, and she was probably around eighteen or nineteen. She came in with certain symptoms of fever, sweats, and I actually ended up having to do an HIV test and it ended up positive. . . This was her first sexual contact according to her, and she eventually did die several years later. I can vividly remember sitting down with her and her mother and telling her this, and it was quite difficult.¹¹⁴

110 Keyes interview.

111 Zeale interview.

112 Keyes interview.

113 Ibid.

114 Zeale interview.

Patalano described how vividly these memories continued to live in his mind, as well as its impact on his approach to patients:

I remember specific patients, experiences, interactions very clearly. We're talking about twenty-five years ago, and I can remember very specifically having to go into a room and having to take care of a patient who could barely communicate, and was basically lying there in the bed weighing sixty-five pounds, having to tell this person that I had to do an eye exam to figure out what's going on and I remember the experience very clearly. They colored your whole life, they colored your whole professionalism, your whole approach to people and patients forever.¹¹⁵

With death all around them, the interviewed physicians expressed an overwhelming sense of frustration and futility. They were constantly losing patients, friends, and coworkers to a virus that was completely out of their control.

After months fighting the epidemic turned into years, the emotional labor took a toll on the physicians. Maria DeVita commented,

I'm not good at disassociating, just going there, doing it, and leav[ing]. I'm pretty attached to my patients, sort of wear my heart on my sleeve type thing, so I always found it very exhausting. But you know it's just what I did, you try to make the best of it and then you sort of just moved on with everything. . . I think as you got to know a [patient] and you have social connections with that person, and then friends of the patient would come in, it definitely had an emotional toll - I mean, it wears you down. You know, it's not good to keep taking care of people if they're all going to die. It's really sad.¹¹⁶

Greenbaum noted that even living in NYC at the time forced him to confront the death of colleagues and neighbors, which weighed on him and other medical staff: "We lost a lot of staff people and we lost a lot of neighbors. My next-door neighbors had four men in the apartment, and they all died. Especially if you lived in [Greenwich Village] and had a lot of contact in that area, you lost a lot of friends. There were a lot of memorial masses to go to."¹¹⁷ He later continued, "But the impact on their coworkers was horrible. . . Here were coworkers who were dying—people who they worked with for years. . . These were their friends, their whole experience."¹¹⁸ Devastated by the deaths of patients, coworkers, and friends, the interviewed physicians, despite their own suffering, continued to combat the epidemic.

The interviewed physicians recalled improving their own mental wellness, despite such devastation, through community support. Maria DeVita spoke of the impact her

115 Patalano interview.

116 Maria DeVita interview.

117 Greenbaum interview.

118 Ibid.

colleague Craig Keyes had on her: “Craig didn’t have any fears about it, and he was sort of overwhelmed even at the time—some of his friends would come in and his brother was sick, so I indirectly identified with him. I said, ‘Well if Craig can do it, then I can do it.’”¹¹⁹ Kiely expressed a similar sense of community at St. Vincent’s Hospital. While she was pregnant, Kiely remembered that her peers would even put themselves at risk on her behalf: “Colleagues of mine offered to do certain procedures for me because I was pregnant. It was one thing to put yourself in risk as a doctor, but another when you’re carrying a baby. My environment was very supportive of me having a child.”¹²⁰ Such a support system was vital when working in the center of an epidemic such as AIDS, as the physicians needed to stay strong for their patients.

Regulations directed toward physician wellness were instated during this period, though not directly as a repercussion of AIDS. In March 1984, at New York Hospital, eighteen year old Libby Zion died from an accidental medication error made by residents on thirty-six hour shifts.¹²¹ In 1987, the Bell Commission (founded out of public outcry) subsequently mandated limitations on resident work hours in New York hospitals to eighty hours per week and in shifts of no more than twenty-five consecutive hours.¹²² Physician wellness remained a central conversation, emphasized in hospitals, residency programs and medical schools.

CONCLUSION

2021 marked the fortieth year of the AIDS epidemic in America. By now, HIV has spread across the nation to affect all races and socioeconomic levels, and there are policy and resources in place at all levels of government. This was not always the case. As we look back at the early days of the AIDS epidemic in NYC, we uncover a period not so different from ours during the ongoing COVID-19 pandemic. As in the 1980s, physicians face the similar challenges of evolving scientific knowledge, overcrowded hospitals, healthcare worker staffing and personal safety, widespread misinformation, and damaging political policy. Physicians are building upon the lessons learned from the early AIDS epidemic while again creating innovative solutions to the challenges COVID presents. It is crucial to examine such periods of struggle in medical history so that we, as a medical community, can learn from them and achieve success in future pandemics. Future research could compare early AIDS and COVID-19 response, comparing and contrasting the challenges physicians face against novel infectious diseases. Without discussion of both the challenges and the progress that can be made, history is doomed to repeat itself.

In hearing the perspectives of these physicians who were caught in the epicenter of the epidemic in 1980s NYC, we are able to uncover their humanity. These physicians were normal people trying their best in spite of enormous adversity. Though there was

119 Maria DeVita interview.

120 Kiely interview.

121 “Duty Hours and Patient Safety,” Agency for Healthcare Research and Quality: US Department of Health & Human Services, September 2019.

122 Ibid.

plenty of failure as the decade progressed, their stories tell of unique biomedical, social, and political challenges distinct to AIDS and its historical moment. The physicians, over the course of the 1980s, adapted to meet these challenges using methods and skills that they carried with them as they moved forward in their careers. This paper is dedicated to those who have fallen victim to the human immunodeficiency virus as well as to those who have fought against it.

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