Defining a Crisis: The Rhetorical Exclusion of Women in the United States AIDS Epidemic, 1981-1993

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This dissertation examines the U.S. AIDS crisis from 1981 to 1993 to understand how women came to be excluded from media and epidemiological narratives of the epidemic. While some women were visible within the Centers for Disease Control's (CDC) surveillance infrastructures and counted as AIDS cases, many were not. This was a consequence of biomedical authorities forming AIDS theories based on how it manifested in the first identified cases: gay men. This invisibility resulted in many women being unable to qualify for social security income and government benefits before their deaths, and it led to many women's AIDS-related deaths going unreported by the CDC. Thus, data about people with AIDS in this era is unable to account for a significant portion of women. By employing rhetorical criticism, close textual readings, and archival research, I argue that women's exclusion must be understood as informed by histories of women's health and as a consequence of narratives that focused on gay men. I rhetorically analyze names, definitions, and classifications in their historical context as epistemological techniques to understand how such narratives came to exist. In my historical description, I examine how the AIDS crisis was informed by and perpetuated longstanding sexism in the biomedical establishment. My first case study explores how early names for AIDS, such as "gay cancer," created affective ties between AIDS and gay men. These ties persisted throughout the 1980s, which contributed to women's inability to be seen. In my second case study, I analyze surveillance case definitions used by the CDC to define an AIDS case for epidemiological tracking. These definitions were flawed in their ability adequately to track AIDS across all populations and communicated a certainty that did not exist in practice. In my third case study, I explore how the CDC's surveillance documents obscured data that it had collected and both sexed and sexualized AIDS. This framing occurred as a result of the disproportionate information gathered about gay and bisexual men in comparison to all women. This dissertation's conclusion posits what lessons might be learned from the AIDS crisis to better understand present-day pandemics.

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Preface

This dissertation has been six years in the making, or perhaps even longer. Along the way I have received such immense support, and I want to take a moment to acknowledge those that have helped breathe life into this project.

None of this would have been possible without the financial support I have received since I began my doctorate. To the committee members who awarded me the A&S Summer Research Fellowship, the Gender, Sexuality, and Women's Studies Student Research Grant, the Cultural Studies Dissertation Fellowship, the Andrew W. Mellon Fellowship, and the Woodrow Wilson Dissertation Fellowship in Women's Studies—thank you for believing that the story of women and AIDS needs to be told. Your generosity allowed me to travel to archives across the U.S. that I would not have otherwise been able to reach and to devote myself to research that I believe matters. I am also indebted to the librarians at the University of Chicago Special Collections Research Center and the librarians and staff at the San Francisco Public Library, the GLBT Historical Society, and the University of California San Francisco's Archives. It was a privilege to research at your institutions.

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It takes a village to see a doctoral program through. I am incredibly grateful to mine. To the Octohort—Jenn, Ryan, Kaitlyn, Sam, Emily, Tomo, Curry—it was a pleasure going on this journey and embracing the ambiguity with you. I also must thank Sarah Constant, Jessica Benham, Robin Zwier, and Alvin Primack. Sarah, you and Mimi provided so much emotional support in this process. Jess, thank you for being my Disability Studies buddy and a remarkable friend. Robin, when you entered the program, I finally had someone who both shared my interests and worked in a similar fashion. Our reading group, conversations, and collaborations have meant so much. Alvin, you have become like family to me. I know I can come to you with any problem, scholarly or otherwise, and you will be delighted to help. I am so grateful. To Jennifer Reinwald, there are not words. You are the Ann to my Leslie. I mean it when I say I could not have done this, and so much more, without you.

A major thank you to my family. Mom and Dad, you had no idea when you dropped me off at OSU in 2006 that I wasn't leaving school until I earned my doctorate. While you might not get it, you have *always* supported me and been proud. Thank you for seeing me through this. To Ron and Kathy Blank, I could not have asked for more generous and encouraging in-laws. To my friends, Mae, Helen, Autumn and Bee, I've spent so many hours in front of my computer, but it hardly felt like work with your company. I owe a huge thanks to Henry, Ellie, and the cats for hours of emotional support. Finally, to my work-husband turned husband-husband, Ryan, you have been there every step of the way. You are my rock, and we've only just begun.

1.0 Introduction

"Women don't get AIDS. They just die from it," reads a large poster created by AIDS Coalition to Unleash Power (ACT UP) activists in the early 1990s.[1] The message is paradoxical—how can women die of a disease that they cannot get—and invites the reader to linger over it. By their own accounts, AIDS activists were also befuddled and then frustrated by the circumstances these dying women faced.[2] The poster illustrates one key initiative undertaken by such activists to remedy the problem: addressing the exclusion of women from the Centers for Disease Control's (CDC) surveillance case definition of AIDS. Established by the CDC, surveillance case definitions—hereafter "surveillance definitions"—consist of criteria for a disease that can then be used for public health tracking, and, as the poster suggested, these criteria for AIDS excluded many seropositive women[3] (though arguably unintentionally[4]) until 1993. One of the most direct consequences of most women's exclusion from the surveillance definition was that innumerable

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[1] "Women Don't Get AIDS" (poster), Box 15, Folder 5, ACT UP Chicago Records, University of Chicago Library, Special Collections Research Center.

[2] Lynellyn D. Long and E. Maxine Ankrah, *Women's Experiences with HIV/AIDS: An International Perspective* (New York: Columbia University Press, 1996); Nancy Goldstein and Jennifer L. Manlowe, *The Gender Politics of HIV/AIDS in Women: Perspectives on the Pandemic in the United States* (New York: New York University Press); The ACT UP/NY Women & AIDS Book Group, *Women, AIDS & Activism* (Boston: South End Press, 1990).

[3] By "these criteria excluded many seropositive women," I am specifically referring to a lack of sex-specific infections in the AIDS surveillance definition. Opportunistic infections are those that indicate a compromised immune system, and these infections are integral criteria for an HIV/AIDS diagnosis. In the case of women with AIDS, activists named acute pelvic inflammatory disease, pulmonary tuberculosis, and rapid progressing cervical cancer as sex-specific AIDS indicators that were left out of the surveillance definition. "Women Don't Get AIDS" (poster).

[4] The question of intentional or unintentional exclusion is beyond the scope of this project. However, I would be remiss if I did not include the memory of Dr. Arthur Ammann, the pediatrician who observed the first cases of infants with AIDS in San Francisco. Both in personal correspondence with the author and written his book *Lethal Decisions*, Ammann recalled an exchange he had with the CDC's James Curran. Ammann addressed the issue of women's exclusion, stating specifically that chronic and drug-resistant vaginal candidiasis was regularly seen in HIV-positive women; however, this criterion was not included in the surveillance definition. Curran explained that they had proposed including vaginal candidiasis in the definition, but the Office of Budget and Management determined that adding it would be "too costly for Medicaid/Social Security disability." The CDC did not pursue the matter further, and their decision was never explained publicly. This was a clear instance of an intentional decision made by the U.S. government to disregard AIDS in women for financial reasons. Arthur J. Ammann, *Lethal Decisions: The Uncessary Deaths of Women and Children from HIV/AIDS* (Nashville: Vanderbilt University Press, 2017).

women's deaths from AIDS—those cases that could not meet the strict CDC criteria—went unrecorded. Thus, the true scope of the epidemic[5] in those early years is incomplete in significant ways.

The indirect consequences of most women's exclusion were tragic in their own right. Because numerous organizations and government agencies used the flawed surveillance definition despite directions from the CDC not to do so, the exclusion had far reaching and immediate effects. For instance, the surveillance definition functioned as the clinical definition used by physicians to diagnose patients.[6] This meant that those whose symptoms did not match those listed in the AIDS surveillance definition could not officially be diagnosed with AIDS by their doctors. Federal officials and researchers also utilized the surveillance definition in funding allocation and research protocols.[7] Furthermore, the Social Security Administration (SSA) automatically granted social security benefits to those who met the CDC's definition. Thus, in a period where 65% of women with AIDS did not meet the surveillance definition criteria, the path to accessing government benefits and related social services was a lengthy and challenging one.[8] This, coupled with their life expectancy and related demographic factors such as race/ethnicity and class, meant that many women with AIDS died before they could obtain help to ease their final weeks of life, if they received a diagnosis at all.[9]

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[5] I refer to AIDS as an "epidemic" throughout this project since I am strictly talking about AIDS' occurrence in the U.S. rather than the global pandemic. In cases where I address AIDS globally, I will indicate that via the use of "pandemic."

[6] Office of Technology Assessment, *The CDC's Case Definition of AIDS: Implications of the Proposed Definitions* (Washington, D.C., 1992), I-1.

[7] Office of Technology Assessment, *The CDC's Case Definition*, I-1.

[8] Katherine Schantz Fleissner, "Social Policy and Women: The Response in Pennsylvania to HIV (Human Immunodeficiency Syndrome) Disease" (PhD University of Pittsburgh, 1992), 76, 86. Like many statistics offered about women with AIDS during this time period, the 65% of women with AIDS who could not meet the CDC's definition ought to be understood as an underrepresentation of the actual number of cases in the U.S. As my project argues, many women were not made visible in the early AIDS crisis, so some women died without ever being even unofficially acknowledge as part of the epidemic.

[9] For further information on women's barriers to accessing AIDS treatment and prevention during the past forty years, see Mariam Aziz and Kimberly Y. Smith, "Challenges and Successes in Linking HIV-Infected Women to

These were just some of the institutional challenges women with AIDS continued to face nearly a decade into the U.S. epidemic. The situation begs the question of how such a large segment of the population—*women*—had been overlooked systemically for *ten years* in the middle of a global health crisis. While the answers are myriad and complex, this project proposes that one way women's exclusion can be understood is through the implicit and explicit scientific and cultural framing of AIDS as a gay, male disease. From fiction[10] to non-fiction[11] and theater[12] to film,[13] the lens through which American history has framed AIDS in one focused on white, gay male subjectivities. By comparison, those accounts about women's experiences with AIDS—not even as a person with AIDS, but their general experiences—remain limited and often were published by women activists in this time period.[14]

Care in the United States," *Clinical Infectious Disease* 52, no. 2 (2011); Erica L. Gollub, "Human Rights is a US Problem, Too: The Case of Women and HIV," *American Journal of Public Health* 89, no. 10 (1999); Jennifer A. Pellowski et al., "A Pandemic of the Poor: Social Disadvantage in the U.S. HIV Epidemic," *American Psychology* 68, no. 4 (2013); Gay Men's Health Crisis, *HIV Risk for Lesbians, Bisexuals & Other Women Who Have Sex With Women*, Women't Institute at GMHC (2009); Risa Denenberg, "Unique Aspects of HIV Infection in Women," in *Women, AIDS, and Activism*, ed. ACT UP/NY Women & AIDS Book Group (Boston: South End Press, 1990); Leslie Laurence and Beth Weinhouse, *Outrageous Practices: How Gender Bias Threatens Women's Health* (New Brunswick, N. J.: Rutgers University Press, 1997).

[10] For fictional AIDS representations, see Michael Cunningham, *The Hours* (New York: Farrar, Strauss, and Giroux, 1998); Geoff Ryman, *Was* (New York: HarperCollins, 1992); Dale Peck, *Martin and John* (New York: Farrar, Straus, and Giroux, 1993); John Weir, *The Irreversible Decline of Eddie Socket* (New York: Perennial, 1991); David Feinberg, *Eighty-Sixed* (New Yrok: Grove Atlantic, 1988).

[11] For non-fiction AIDS accounts, see Larry Kramer, *Reports from the Holocaust: the Making of an AIDS Activist* (New York: St Martin's Press, 1989); Andrew Holleran, *Chronicle of a Plague, Revisited: AIDS and Its Aftermath* (New York: Da Capo Press, 2008); Andrew Holleran, *Ground Zero* (New York: Morrow, 1988); Randy Shilts, *And the Band Played On: Politics, People, and the AIDS Epidemic* (New York: St. Martin's Press, 1987); Sean Strub, *Body Counts: A Memoir of Activism, Sex, and Survival* (New York: Scribner, 2014); David B. Feinberg, *Queer and Loathing: Rants and Raves of a Raging AIDS Clone* (New York: Viking Adult, 1994); Paul Monette, *Borrowed Time: An AIDS Memoir* (New York: Harcourt Brace & Company, 1988).

[12] For plays that feature AIDS, see Tony Kushner, *Angels in America: A Gay Fantasia on National Themes* (New York: Theatre Communications Group, 1991); Larry Kramer, *The Normal Heart* (New York: Samuel French Inc, 1985); Larry Kramer, *The Destiny of Me* (New York: Grove Press, 1992); William M. Hoffman, *As Is* (New York: Dramatists Play Service Inc., 1985).

[13] For film depictions of AIDS, see *An Early Frost*, directed by John Erman (1985; United States: NBC); *Longtime Companion*, directed by Norman René (1990; United States: Samuel Goldwyn Company); *And the Band Played On*, directed by Roger Spottiswoode (1993; United States: HBO Pictures); *Philadelphia*, directed by Jonathan Demme (1993; United States: TriStar Pictures); *Dallas Buyers Club*, directed by Jean-Marc Vallée (2013; United States: Focus Features); *The Normal Heart*, directed by Ryan Murphy (2014; United States: HBO); *Angels in America*, directed by Mike Nichols (2003; United States: HBO).

[14] For texts by women about and/or with AIDS, see Gena Corea, *The Invisible Epidemic: The Story of Women and AIDS* (New York: HarperCollins Publishers, 1992); Amy Hoffman, *Hospital Time* (Durham: Duke University

The scientific establishment did not approach the epidemic with any greater care than did the media. While it had been necessary to study the emerging epidemic in the population in which it had been discovered, the CDC continued to define AIDS according to opportunistic infections (OI) found in gay men (despite noted symptomatic differences in other populations), epidemiological histories focused on men, and efforts to isolate AIDS etiology remained steadfastly focused on aspects of the "gay lifestyle," such as drug use and anal sex, despite suspicion of a viral agent. It was not until 1987 that the AIDS surveillance definition expanded to include OIs more commonly found in women. The U.S.'s first natural history study of AIDS in women did not even begin until 1987, a victory that was a hard-won battle.[15] And it was not until 1993 that the first gynecological disease was included in AIDS surveillance.[16] Given such significant delays in including and understanding AIDS in such a large portion of the population, understanding how such a situation arose is important both for comprehending past epidemics and thinking critically about how we narrativize those in the future.

Press, 1997); Sarah Schulman, *My American History: Lesbian and Gay Life During the Reagan and Bush Years* (New York: Routledge, 1994); Sarah Schulman, *The Gentrification of the Mind: Witness to a Lost Imagination* (Oakland: University of California Press, 2013); Barbara Peabody, *The Screaming Room: A Mother's Journal of Her Son's Struggle with AIDS—A True Story of Love, Dedication, and Courage* (New York: Avon Books, 1987); The ACT UP/NY Women & AIDS Book Group, *Women, AIDS & Activism*; Goldstein and Manlowe, *The Gender Politics of HIV/AIDS in Women: Perspectives on the Pandemic in the United States*; Beth E. Schneider and Nancy E. Stoller, *Women Resisting AIDS: Feminist Strategies of Empowerment* (Philadelphia: Temple University Press, 1995); Nancy E. Stoller, *Lessons From the Damned: Queers, Whores, and Junkies Respond to AIDS* (New York: Routledge, 1998); Cindy Patton, *Sex and Germs: the Politics of AIDS* (Boston: South End Press, 1985); Cindy Patton and Janis Kelly, *Making It: A Woman's Guide to Sex in the Age of AIDS* (Ithaca, N.Y: Firebrand Books, 1987); Cindy Patton, *Last Served?: Gendering the HIV Pandemic* (New York: Taylor & Francis, 1994); Cindy Patton, *Fatal Advice: How Safe-Sex Education Went Wrong* (Durham: Duke University Press, 1996).

[15] Corea, *The Invisible Epidemic*, 104.

[16] The timeframe on the third revision to the CDC's AIDS surveillance definition is somewhat confusing. The major legislation, like activists' efforts, occurred in 1991 and 1992; however, the changes to the surveillance definition did not go into effect until early 1993. Throughout this project, both years are used to refer to the same definition revision.

1.1 Reframing an Epidemic

The consistent framing of AIDS as a gay man's disease in expert and non-expert discourse has contributed to the limited scholarship in rhetoric specifically and communication more generally about women with AIDS in the U.S. from 1981 to 1993. In part, one challenge scholars interested in the question of women with AIDS face is that one is effectively studying what is *absent* rather than what is present. Rhetoricians, then, may have decided in the past to research those rhetorical artifacts that do exist and that have had immense impact on social movement studies, for instance. Communication scholars working in media and health in the U.S. have also shown an interest in AIDS and women, especially with regards to risk communication. In interdisciplinary fields such as gender and sexuality studies, women with AIDS have drawn more interest than communication or rhetoric specifically. However, much scholarship on the early AIDS epidemic in the U.S. remains committed to researching AIDS vis-a-vis homosexuality.

It is unclear why the U.S. AIDS epidemic's first decade has not been reframed or its narrative critically challenged in scholarship. Scholars have not rejected nor been hostile towards alternative histories or scholarship that hopes to fill the period's absences. Instead, it appears to be largely a matter of the work not being done as opposed to a dismissal of the work itself.[17] As I have already mentioned, researching absence provides unique challenges for scholars in that it

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[17] Over the course of this project, I have experienced what I would characterize as anxiety by anonymous reviewers about this research and what it would mean to do a history in this country during this time period that "left out" gay men. This has resulted in the need to carefully couch the project to demonstrate that my goal is not to diminish the trauma experienced by gay men or somehow claim that they were not disproportionately affected by the epidemic. Rather, I see this project's purpose as complimenting existing scholarship about the gay community that does exist and has been widely written about. In this sense, I make a "yes, and" move to uncover a history that has largely remained invisible. I have found other scholars working on topics related to women and AIDS—for instance Paula Treichler and Catherine Warren as well as Nancy Goldstein and Jennifer Manlowe—make a similar, carefully worded statement in their research that they are not trying to suggest that gay men did not suffer by instead talking about women. In this sense, there may be some pushback to researching AIDS and women in instances where such a statement about gay men is not made incredibly explicit.

requires reading around a topic and analyzing a multitude of related primary sources in order to get at the absence itself. In the case of women with AIDS in the U.S., understanding the absence of knowledge entails poring over what Susan Leigh Star and Martha Lampland affectionately called "boring things," or those infrastructures and documents that standardize life as we know it.[18] These boring documents—epidemiological forms and surveillance reports—then have to be put into conversation with activist accounts in order to make sense of how such documents were perceived in the fight to make women with AIDS more readily visible.

While researching the origins of absences more generally and women with AIDS' absences specifically offers unique challenges, the research is important for at least four reasons. First, understanding the invisibility of women with AIDS helps explain how nearly half the population can come to be ignored in the middle of a pandemic. Second, the topic demonstrates what happens when diseases become sexed and sexualized[19] and how populations come to be included and excluded as well as upon what grounds. Third, the project explores how knowledge about women (though limited) was created through infrastructural documents and how activists arrived at a moment where they had to fight for women's inclusion. Finally, this project's focus remains important because—as our present pandemic illustrates—issues about in/visibility, non/knowledge, scientific objectivity, and at-risk populations are perennial concerns for a globalized world.

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[18] Martha Lampland and Susan Leigh Star, *Standards and Their Stories: How Quantifying, Classifying, and Formalizing Practices Shape Everyday Life* (Ithaca, N.Y.: Cornell University Press, 2008), 11.

[19] By "sexed" and "sexualized," I mean that AIDS was associated with a particular sex (male) and a particular sexuality (homosexuality). This is similar to the gendered disease hysteria, which I will discuss at length in Chapter 2, that is coded feminine, or the implicitly sexed and raced diagnosis of ADHD in young, white boys.

1.1.1 AIDS Scholarship Today

Scholarship about HIV/AIDS between 1981 and 1993 in Communication and related interdisciplinary fields tends to fall into four topical categories: (1) activism, (2) politics/legislation; (3) media; and (4) science and medicine. This section offers an overview of this literature that—while not always in direct dialogue with this project—has informed both my thinking and the (inter)disciplinary awareness of AIDS in this era. Most often research in these fields about women and AIDS appears in discussion of activism, particularly ACT UP, and occasionally women are featured in work on print media, like that of Paula Treichler.

1.1.1.1 Activism

Scholars interested in AIDS activism in this period typically have focused their research on ACT UP given the organization's unique structure and contributions to later social movements. In her lengthy account of the organization, Deborah Gould tracked the lifecycle of ACT UP through key affective moments—such as the shifts from shame, to pride, and to anger—and their radical potentiality. Gould briefly addressed how ACT UP members working on women's issues felt that sexism became a barrier to accessing important governmental authorities, like Dr. Anthony Fauci, and articulated frustration over other activists' disregard for how treatment needs might differ in different bodies.[20] Like Gould, Ann Cvetkovich's work in affect studies gave space for queer trauma by exploring lesbian activism in ACT UP as a case of neglected trauma. Through recuperative work, Cvetkovich offered an alternative narrative of ACT UP. Cvetkovich challenged the notion that ACT UP was an organization of privileged, gay male activists by highlighting the

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[20] Deborah B. Gould, *Moving Politics: Emotion and ACT UP's Fight Against AIDS* (Chicago: University of Chicago Press, 2009), 349-68.

roles women and people of color played in the group.[21] Researching at the intersection of affect and memory studies, Alexis Shotwell wrote explicitly about the ACT UP campaign to change the CDC's surveillance definition to include women. Shotwell argued that classification has material consequences, and that the campaign to change the definition was ultimately a campaign about remembrance—that is, to be classifiable is to be memorable.[22]

Based on her experiences within San Francisco AIDS organizations, Nancy Stoller examined five community-based AIDS organization as they evolved from volunteer-led, grassroots groups to a more bureaucratic model. Stoller argued that these organizations were more effective when they were embedded within the community and provided more services to those people—women, people of color, addicts, and those in poverty—often left behind when an organization shifted into a bureaucracy.[23] In *Last Served? Gendering the HIV Pandemic*, Cindy Patton argued that women have been largely invisible in the global pandemic in part due to their characterization as either innocent recipients or transmitters of the virus. However, Patton suggested that because women do not share a common identity, the solution for their invisibility is not visibility as such a category does not exist.[24] Unlike previous scholars mentioned here who examined activism through ACT UP, Dan Brouwer (1998) suggested visible, self-stigmatizing, HIV/AIDS tattoos' performativity contributed to enhanced visibility (along with its associated power) and challenged stereotypes about normativity and health.[25]

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[21] Ann Cvetkovich, *An Archive of Feelings: Trauma, Sexuality, and Lesbian Public Cultures* (Durham: Duke University Press, 2003).

[22] Alexis Shotwell, "“Women Don't Get AIDS, They Just Die From It”: Memory, Classification, and the Campaign to Change the Definition of AIDS," *Hypatia* 29, no. 2 (2014).

[23] Stoller, *Lessons*.

[24] Patton, *Last Served*.

[25] Dan Brouwer, "The Precarious Visibility Politics of Self-Stimatization: The Case of HIV/AIDS Tattoos," *Text & Performance Quarterly* 18, no. 2 (1998).

1.1.1.2 Politics and Legislation

Scholars who have researched political aspects of AIDS in this era have frequently focused on key pieces of policy or legislation. For instance, Jeffrey Bennett researched the gay blood ban that began in the 1980s and remains in effect to this day in the U.S. Bennett argued that blood donation is a form of ritual citizenship which hails gay men as U.S. citizens only to foreclose that civic participation at the donation center.[26] In *Risky Rhetoric*, J. Blake Scott claimed that HIV antibody testing's identity-based rhetoric produced material harm. Scott reasoned that testing not only produces a diagnosis, but also value-laden subjectivities—deviant or normal, threatening or safe—that do not necessarily comport with individuals' risky or safe practices.[27] Jennifer Brier's *Infectious Ideas* took to task traditional narratives of the AIDS epidemic in the U.S. to suggest that AIDS became political not only due to increasing numbers of cases, but also because AIDS actors articulated an alternative world view. Brier suggested that AIDS began to undermine conservatism, and the various activist organizations offered a vision of what progressive politics might be.[28] In *the Boundaries of Blackness*, Cathy Cohen claimed that black community leaders largely ignored the AIDS epidemic throughout the 1980s and never successfully transformed AIDS into a black political issue. Cathy Cohen attributed this to pressure faced by black elites to conform to white values and respectability politics.[29]

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[26] Jeffrey A. Bennett, *Banning Queer Blood: Rhetorics of Citizenship, Contagion, and Resistance* (Tuscaloosa: University of Alabama Press, 2009).

[27] J. Blake Scott, *Risky Rhetoric: AIDS and the Cultural Practices of HIV Testing* (Carbondale: Southern Illinois University Press, 2003).

[28] Jennifer Brier, *Infectious Ideas: U.S. Political Responses to the AIDS Crisis* (Chapel Hill: University of North Carolina Press, 2009).

[29] Cathy J. Cohen, *The Boundaries of Blackness: AIDS and the Breakdown of Black Politics* (Chicago: University of Chicago Press, 1999).

1.1.1.3 Media

Much media scholarship about AIDS in the early era has focused on quantitative approaches to understanding AIDS reporting. In 1991, David Colby and Timothy Cook examined nightly news coverage of AIDS across three major network news stations. They argued that there was immense diversity in coverage and frequency of reporting within the first decade, noting that coverage peaked only when the "general population" was thought to be at risk.[30] In "HIV/AIDS Coverage in Black Newspapers, 1991-1996," Kathryn Pickle et al. analyzed five Black newspapers across the U.S. and discovered that these papers most often discussed AIDS as a health issue, but also critiqued government and "AIDS establishment" responses to AIDS interventions in marginalized communities.[31] These newspapers also featured alternative theories on etiology and treatment, particularly that AIDS was a plot to kill Black Americans.[32] Alexandra Juhasz's "The Contained Threat" explored the challenge mainstream media faced with rising numbers of women with AIDS and an investment in perpetuating the myth of white, middle-class male safety. Juhasz argued that mainstream AIDS documentaries achieved this by showing women as contained threats through privileging men's voices and controlling women's depictions in those instances

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[30] David C. Colby and Timothy E. Cook, "Epidemics and Agendas: The Politics of Nightly News Coverage of AIDS," *Journal of Health, Policy and Law* 16, no. 2 (1991).

[31] Kathryn Pickle, Sandra Crouse Quinn, and Jane D. Brown, "HIV/AIDS Coverage in Black Newspapers, 1991-1996: Implications for Health Communication and Health Education," *Journal of Health Communication* 7 (2002).

[32] As it has been widely discussed, the Black community's distrust in the medical establishment and government in particular is rooted in the legacy of the Tuskegee Syphilis Study and other related medical atrocities against black and brown people in the U.S. For a more in-depth account of these histories, see: James H. Jones, *Bad Blood: The Tuskegee Syphilis Experiment* (New York: The Free Press, 1993); Susan M. Reverby, *Examining Tuskegee: The Infamous Syphilis Study and Its Legacy* (Chapel Hill: University of North Carolina Press, 2009); Deidre Cooper Owens, *Medical Bondage: Race, Gender, and the Origins of American Gynecology* (Athens: University of Georgia Press, 2017); Harriet Washington, *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present* (New York: Harlem Moon, 2006); Allen M. Hornblum, *Acres of Skin: Human Experiments at Holmesburg Prison* (New York: Routledge, 1998); Dorothy Roberts, *Killing the Black Body: Race, Reproduction and the Meaning of Liberty* (New York: Vintage Books, 1997).

where they did appear.[33] In "Counterpublicity and Corporeality in HIV/AIDS Zines," Daniel Brouwer analyzed how two U.S. AIDS zines constituted a counterpublic via differences in serostatus and political ideology.[34] Brouwer explained that, through corporealities of the erotic, sexual, and grotesque, the writers of these zines were able to make their bodies visible.

1.1.1.4 Science and Medicine

Finally, scholars focused on the scientific dimensions of AIDS have most often examined HIV-related controversies or shown concern about the role that culture plays in scientific knowledge. In her essay collection *How to Have Theory in an Epidemic*, Treichler analyzed two problems across an array of AIDS case studies to demonstrate how language not only reflected, but also created disease. First, Treichler argued that discursive, cultural dichotomies permeated scientific theories, sex education, public health information, and treatment about HIV/AIDS. Second, Treichler contended that science, medicine, and the media had a large role in obscuring how the AIDS epidemic was culturally informed.[35] Carol Reeves argued that, in early AIDS reports in the *New England Journal of Medicine*, gay men became the archetypical AIDS patient due to the authors' explanation of the epidemic's etiology through preexisting knowledge about gay men's health. In this framing, AIDS was not surprising due to sexually transmitted infection rates among gay men.[36] In *AIDS, Rhetoric, and Medical Knowledge*, Alex Preda examined early scientific articles about AIDS to argue that AIDS risk was rhetorically constructed in a way that

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[33] Alexandra Juhasz, "The Contained Threat: Women in Mainstream AIDS Documentary," *The Journal of Sex Research* 27, no. 1 (1990).

[34] Daniel C. Brouwer, "Counterpublicity and Corporeality in HIV/AIDS Zines," *Critical Studies in Media Communication* 22, no. 5 (2005).

[35] Paula Treichler, *How to Have Theory in an Epidemic: Cultural Chronicles of AIDS* (Durham: Duke University Press, 1999).

[36] Carol Reeves, "Establishing a Phenomenon: the Rhetoric of Early Medical Reports on AIDS," *Written Communication* 7, no. 3 (1990).

determined what knowledge could be scientifically produced. This knowledge then had consequences for AIDS policy and prevention.[37] Steven Epstein's *Impure Science* analyzed how one gains authority to speak on a scientific issue such as AIDS's etiology and drug treatment and what kind of knowledge is believable. Steven Epstein argued that, through credibility struggles and their ability to speak the language of science, AIDS activists won hard fought battles in treatment because researchers could no longer dismiss their arguments.[38]

1.1.1.5 Projects in Dialogue

I understand this dissertation as living at the intersection of pre-existing scholarship on activism, legislation, media, and science. This project is concerned with activism in so far as activists fought for women with AIDS to be recognized. To greater or lesser degrees, Gould, Cvetkovich, Shotwell, Patton, and Stoller all wrote about women being largely excluded from the CDC's surveillance definition and activists' efforts to make women more visible. However, these researchers did not significantly attend to how women with AIDS' situation reached a point where activists needed to fight for their visibility. Moreover, though this scholarship identified a problem with the CDC's surveillance definition, no author closely examined the definitions or their language across time. My project fills that gap. Second, my dissertation is only concerned with legislation in a limited capacity and as it relates to women. As I explained in my opening anecdote, the CDC's surveillance definition and the surveillance reports created from that definition influenced how government bodies responded to the epidemic via laws, funding, and policy. This project is not concerned with those governmental responses themselves, but the influence the

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[37] Alex Preda, *AIDS, Rhetoric, and Medical Knowledge* (Cambridge: Cambridge University Press, 2005).

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

CDC's epidemiological infrastructures may have had in the creation of such responses. Third, this project does address the media's influence on the AIDS narrative in Chapter Three. While I incorporate some of the above sources into that analysis, my primary concern is not about macro-level trends across the 1980s, nor do I delve very deeply into newspapers or alternative media coming from marginalized communities. Instead, I focus on how names for AIDS that originated prior to the CDC's official release of the name "AIDS" came to influence the country's AIDS narrative. Finally, while influenced by the work of researchers interested in AIDS and science, I examine only a very narrow portion of the AIDS and science topic. For instance, unlike Preda and Epstein, I do not look at HIV for reasons that I will explain shortly. It is a scientific project in that I interrogate how three types of epidemiological documents produced non/knowledge about people with AIDS. Yet, much of the science and related controversies are outside this project's scope.

While it is informed and inflected by the above-mentioned scholarship, this dissertation ought to be understood as novel from other work in that it is a project of *before*—before activism, before key legislation, before widespread media coverage, before significant scientific knowledge about HIV. That is, much of the work cited above begins in the late 1980s and continues on into the 1990s and beyond. By comparison, my project is coming to a close at that point. I am interested in the earliest days of the epidemic, particularly 1981-1983—a period where limited archival materials exist, and which typically gets cited in passing in much of the above scholarship. This dissertation, in part, asks the question: how did AIDS *become* AIDS.

1.1.2 Identifying the Absences

Having explained how this dissertation fits in larger discussions of AIDS in the discipline and beyond by addressing what it does not do, I now want to clarify what it is that I do in this project. Across a thick description of the history of women's health and three case studies, I examine how women with AIDS came to be systemically unrecognizable as part of the epidemic except in those rare cases when they fit into the cultural and scientific definition of the AIDS patient. My focus on in/visibilities or the un/recognizability of a group joins in other projects focused on agnotology—or the production of "culturally-induced ignorance."[39] Jennifer L. Croissant wrote that decisions made and processes employed to create knowledge are just as responsible for what we do *not* know as what we do.[40] Knowledge and non-knowledge are "shaped by particular histories, local and global priorities, funding patterns, institutional and disciplinary hierarchies, personal and professional myopia," meaning that they are culturally and politically inflected, constructed, situated, and sustained.[41] As will become apparent through this project's case studies, systemic issues such as lack of resources, institutional bias, and opportunities for prestige "led to blind spots, and prioritization of data" in the AIDS epidemic as it has elsewhere.[42]

Drawing on archival research and employing grounded theory, I rhetorically analyze how women became implicitly excluded as a result of AIDS' early names, epidemiological definitions, and classification on disease surveillance forms—those early infrastructural tools used to understand the epidemic. I draw from science and technology studies, the history of medicine, media studies, rhetorical studies, surveillance studies, and gender studies to interpret my texts. These sources include newspapers and wire service reports, epidemiological case definitions, epidemiological reporting forms, and AIDS surveillance reports. Over the course of the dissertation I make the following arguments:

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[39] Londa Schiebinger, "Agnotology and Exotic Abortifacients: The Cultural Production of Ignorane in the Eighteenth-Century Atlanta World," *Proceedings of the American Philosophical Society* 149, no. 3 (2005): 320.

[40] Jennifer L. Croissant, "Agnotology: Ignorance and Absence of Towards a Sociology of Things That Aren't There," *Social Epistemology* 28, no. 1 (2014): 7.

[41] Schiebinger, "Agnotology," 320; Nancy Tuana, "The Speculum of Ignorance: The Women's Health Movement and Epistemoogies of Ignorance," *Hypatia* 31, no. 3 (2006): 3.

[42] Tuana, "The Speculum of Ignorance," 3; Croissant, "Agnotology," 15.

(1) Women's exclusion from the early AIDS epidemic in the U.S. must be understood, in part, within the context of historical treatment of women by the medical establishment.

(2) As interrelated rhetorical techniques, names, definitions, and classifications often become conflated in research. However, I demonstrate how, by treating them as separate, yet still related techniques, rhetoricians can understand what is unique about each technique through my case study of the AIDS epidemic.

(3) Part of the gay, male AIDS narrative in the U.S. can be attributed to media and epidemiological documents constructing the epidemic in such a way. This is not to suggest that gay men did not suffer disproportionately, but to argue that individuals constructing infrastructural documents developed schemas that would confirm what they anticipated they would see. Through this confirmation bias, there was no "objective" data (a) to make women more readily visible, or (b) to use as evidence in demonstrating a need for systemic change on behalf of women with AIDS.

Through this dissertation, I hope to offer an alternative narrative of the early AIDS epidemic. Though I cannot necessarily document what happened to women to the fine details, I do explore how our current history is not reflective of the reality of the AIDS epidemic in the U.S. nor should such a history be considered enough. As sexism and heterosexism informed our telling of the AIDS narrative, we have an ethical imperative to those stigmatized—gay men—and to the forgotten—women, the poor, folks of color, and people who use drugs—to make that *absence* visible.

1.2 A Word on Words

1.2.1 “Women”

Since this project’s inception, I have struggled with how to speak about its subjects—cisgender, non-intersexed, heterosexual (or heterosexual-passing) women. Throughout the dissertation, I use phrases like “women” or “female” and refer to various bodies and body parts. These terms are, of course, not without their problems and have been theorized and re-theorized by gender studies scholars for decades.[43] In the process of writing, I have tried to avoid doing violence with my language. At one point, I considered adopting terms like “people with vaginas” to more accurately reflect the dissertation’s subjects without falling victim to misgendering. I decided to forego this language for two reasons.

First, due to my primary source material, I can only make claims about cisgender women. Moreover, most of these cisgender women were coded as heterosexual. In the 1980s, government documents did not (and still do not) have a capacious understanding of sex or gender as spectrums. As I will explain in greater detail in Chapter Four, case forms and reports only included “male” and “female” as classificatory options for sex, and thus only produced data about those sexes.

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[43] For scholarship that addresses gender, sex, and the body, see: Judith Butler, *Gender Trouble: Feminism and the Subversion of Identity* (New York: Routledge, 1990); Judith Butler, *Bodies That Matter: On the Discusive Limits of ‘Sex’* (New York: Routledge, 1993); Claire Colebrook, “From Radical Representations to Corporeal Becomings: The Feminist Philosophy of Lloyd, Grosz, and Gatens,” *Hypatia* 15, no. 2 (2000); Moira Gatens, *Feminism and Philosophy: Perspectives on Difference and Equality* (Bloomington: Indiana University Press, 1991); Elizabeth Grosz, *Volatile Bodies; Toward a Corporeal Feminism* (Sydney: Allen and Unwin, 1994); Elizabeth Grosz, “Notes Towards a Corporeal Feminism,” *Australian Feminist Studies* 5 (1987); Elizabeth Gross, “Irigaray and Sexual Difference,” *Australian Feminist Studies* 2 (1986); Luce Irigaray, *Speculum of the Other Woman*, trans. Gillian C. Gill (Ithaca: Cornell University Press, 1985); Genevieve Lloyd, “Women as Other: Sex, Gender, and Subjectivity,” *Australian Feminist Studies* 10 (1982); Genevieve Lloyd, *The Man of Reason: ‘Male’ and ‘Female’ in Western Philosophy* (London: Methuen, 1984); Victoria Pitts-Taylor, *Mattering: Feminism, Science, and Materialism* (New York: New York University Press, 2016); Stacy Alaimo and Susan Hekman, *Material Feminisms* (Bloomington: Indiana University Press, 2008).

Intersex and transgender people were likely included in the data I analyzed by virtue of being as, if not more, vulnerable to AIDS than those populations typically considered as at risk. However, there were no categories in the source material to make them visible. Scholarship on the early AIDS crisis and these vulnerable communities needs to be written, but it is not within the boundaries of this project, as it has been constructed, to do so.

Second, I believe that the category of woman—however messy and despite its shortfalls—can still be useful in referring to a group of people with related, though differing, embodied and cultural experiences. Throughout the dissertation I also use "female bodies" or "women's bodies" to refer to bodies with particular biological capabilities. In using these terms, my intention is not to erase or re-inscribe sex and gender onto bodies with these biological capabilities. Rather than writing cisgender, non-intersexed women each time I want to refer to this population, I have opted to simply use terms like "woman" and "female" that encapsulate far more people than those under discussion here and that are far more messy terms than I would ideally like to use. My hope is that by addressing this explicitly in this introduction that I will avoid any reader assumptions that this might be a trans-exclusionary project or that my feminist politics stray towards essentialism. Instead, I only want to suggest that certain organs present in certain bodies impact disease manifestations in particular ways. These organs are not social constructions, but material realities; however, society has placed immense meaning on these organs, and that meaning matters as well.

1.2.2 HIV/AIDS

Presently, it is common to talk about the epidemic by referring to it as "HIV/AIDS." For the purpose of this dissertation, however, I call it only the "AIDS" epidemic and address the issue of "AIDS," except in those instances where I mean HIV. This is done so intentionally. As I will explain in greater detail in Chapter Four, for epidemiological purposes HIV and AIDS were tracked separately in the U.S. until 2008 when they were combined into a single, epidemiological entity for disease tracking. Concerns over confidentiality led to HIV being tracked in only certain states, but not at the federal level. In the era I focus on in this dissertation, I can only make claims about *AIDS* since my source material originates from the CDC. Furthermore, I try to be as historically accurate in my terminology as possible, which means that in some cases I use the phrase "AIDS virus" to refer to the virus from its discovery in 1983 until its official naming in 1986.[44]

1.3 Project Boundaries and Chapter Overview

As evidenced by the existing literature about AIDS, there is much one could examine about the first twelve years of the epidemic in the U.S; however, this project has clear boundaries that have guided my writing. In determining the timeframe for the dissertation, I decided to begin as early as 1981 due to the relative inattention those first few years of the crisis received. The decision to end in 1993 was informed by the inclusion of the first gynecological abnormality in the AIDS surveillance definition along with several other benchmarks that I discuss in the dissertation's conclusion. While much progress still needed to be made after, early 1993 was a historical moment where meaningful change for women with AIDS began.

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[44] Between 1983 and 1986, the AIDS virus was referred to as "human t-cell lymphotropic virus type III" (HTLV-III), lymphadenopathy associated virus (LAV), and the combined HTLV-III/LAV. The different names resulted from the separate laboratories that isolated the virus, one in the U.S. and one in France. This remarkably controversial, high stakes naming controversy is explored in chapter four of Alex Preda's *AIDS, Rhetoric, and Medical Knowledge*.

In addition to narrowly constraining the time period in which I focus, I have also constructed the dissertation around names, definitions, and classifications, which I approach as rhetorical techniques that are employed to make the unknown intelligible and thus determine how we interact with phenomena in the world. This choice stemmed from the repeated reference to the AIDS surveillance definition across scholarship, which was consistently articulated as problematic in its failure to include women, but such problems were not explained in depth nor were the definitions themselves examined. Because the definition was tied up within larger epidemiological surveillance structures (and beyond, as I discuss in Chapter Four), I selected the "Case Report Form" as an object of analysis for the purposes of understanding how AIDS classifications worked. In the research process, I discovered that one could not adequately explain activists' concerns without also looking at the AIDS *Weekly Surveillance Report*, which is the end product of the "Report Form." Much as was the case with the definition, early names are also frequently cited in AIDS literature with limited additional exploration. Names are an implicit part of any definitional or classificatory processes, often occurring before or as part of these processes. In the case of AIDS, I wanted to discover how early names, such as gay cancer, may have informed the larger AIDS narrative.

1.3.1 Chapter Overview

My dissertation begins with Chapter Two "'It's All in Her Head': The History of the Female Patient in the U.S. and Her Legacy in the AIDS Epidemic." Here, I offer a historical account of women's relationship to medicine from the late nineteenth century to present day in order to understand how this relationship may have contributed to women's exclusion during the AIDS epidemic. In part one, I describe historical work on the conceptualization and treatment of gynecological organs and the origins and evolution of hysteria. In part two, I reveal the challenges that women face in medical research, both in terms of participation and knowledge produced about their bodies. By drawing from these historical accounts, I argue that we must examine the cultural underpinnings of women's health to begin to theorize why women were deprioritized in early epidemiological interventions in the AIDS epidemic. I further assert that such cultural foundations offer explanations for why, in the face of etiological uncertainty, biomedical experts reverted to sexist ideas about female bodies in order to make sense of women's experiences in the crisis.

In Chapter Three "Rhetorical Legacies of 'Gay Cancer': The Affective Influence of AIDS Media Coverage in Sexualizing an Epidemic," I bring together rhetorical and onomastic studies with affect theory in order to understand the role the name "gay cancer" played in constructing the early, U.S. AIDS narrative. After explaining the theoretical groundings of this chapter, I summarize the interconnected nature of newsprint media in the 1980s with regards to AIDS, including major daily newspapers, wire services, and the gay press. My close textual analysis examines how "gay cancer" was employed in major dailies and wire services from 1981-1992. I argue that though it only functioned as a name for AIDS for a year, gay cancer's continued circulation generated an affective attachment between AIDS and gay men in U.S. culture that persists to this day.

In Chapter Four "Women Who Do Not Count as Women: The CDC's AIDS Surveillance Definition and the Exclusionary Criteria that Defined an Epidemic," I turn to the often-mentioned AIDS surveillance definitions to understand how women came to be excluded within one epidemiological surveillance tool. I begin by exploring the rhetorical dimensions of definitions to reveal their persuasive force in constructing a particular reality. I then write more in-depth about the definitional controversy so often cited in AIDS literature from this time period. Using rhetorical topoi as a framework, I concur with AIDS activists that the definition barred many women from AIDS surveillance. Furthermore, I argue that the restrictions placed upon disease criteria—that they be specific at the cost of sensitivity—did not necessarily mean gynecologic abnormalities could not be included. Rather, there was rhetorical space to include such diseases that went unharnessed.

In Chapter Five "Categorically Other: Case Report Forms, Surveillance Reports, and the Creation of (Non-)Knowledge about Women and AIDS Through Classification," I explore the roles that the AIDS "Case Report Form" and *Weekly Surveillance Report* played in artificially suppressing data about women with AIDS. The chapter first puts rhetoric in dialogue with classification and surveillance studies to understand how classifications and surveillance systems are politically and culturally influenced to offer particular kinds of evidence about a subject. In this section, I explain what is unique to epidemiological surveillance and articulate activists concerns with how the CDC collected AIDS data about women. In the first part of my case study, I analyze the CDC's "Case Report Form" to understand what classifications were used to collect data about AIDS cases. Here I argue that the form had the potential to be more inclusive than the case definitions discussed in the previous chapter. In the second part of my case study, I turn to the *Weekly Surveillance Report*, which was produced with the information from the "Case Report Forms," and argue that it was the *Report* that was dominated by sexism and heterosexism rather than the "Report Forms." This challenges popular activist accounts of these documents and the problem of epidemiological surveillance of women with AIDS.

In my conclusion, I revisit the three overarching arguments I have forwarded in this introduction. I begin by briefly explaining several formative events that occurred in and around 1993 that began to shift the tide for women with AIDS. After, I discuss the three central arguments of this dissertation, articulating each and summarizing my finds through the relevant chapters. I close this project with my preliminary thoughts about what my project and the AIDS epidemic more generally can tell us about our current Covid-19 pandemic.

2.0 “It’s All in Her Head”: The History of the Female Patient in the U.S. and Her Legacy in the AIDS Epidemic

In 1993, a woman named Beverly, newly diagnosed with HIV, was interviewed for an ABC *World News Tonight* segment on the growing number of women with AIDS. Beverly had been suffering from symptoms for some time, seeing physician after physician with no answers for what was causing her illness. Finally, one physician tested her for HIV, and Beverly’s test came back positive. During her interview, Beverly told the reporter that “[the doctors] never looked for this disease in me… being as how they thought it was a gay men’s disease.”[1] During the 1980s, U.S. government leaders and biomedical experts such as the Surgeon General and CDC never stated that women could not get AIDS, nor did they explicitly direct physicians to only look for AIDS in gay men. Their messages instead emphasized “early and often that *no group* should feel complacent about [the] epidemic,” including women.[2] However, women with AIDS’ testimonies were lost in the cacophony of voices crying for national attention in the AIDS epidemic. The silence surrounding women with AIDS was furthered by “institutions long accustomed to overlooking women—medicine, the media, state and federal legislatures” who had no time “for a hypothetical future problem of women with AIDS in the face of federal indifference, CDC cutbacks, media passivity, and ambiguous data.”[3] The problem of women with AIDS’ infrastructural exclusion would only begin to be addressed after the inclusion of women-specific conditions in the CDC’s AIDS surveillance case definition in 1993.

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[1] Paula Treichler and Catherine Warren, “Maybe Next Year: Feminist Silence and the AIDS Epidemic,” in *Gendered Epidemic: Representations of Women in the Age of AIDS*, ed. Nancy L. and Katie Hogan Roth (New York: Routledge, 1998), 109.

[2] Treichler and Warren, “Maybe Next Year,” 111.

[3] Treichler and Warren, “Maybe Next Year,” 111.

The silence surrounding women with AIDS in the earliest years of the epidemic must be understood as one case among many in the complex history of biomedicine's treatment of women and the sexism it perpetuates. However, biomedical sexism is not easily made legible for at least two reasons. First, knowledge appears objective when embedded in discourses of objectivity. As Donna Haraway writes in her theorization of the "god trick," knowledge itself is not objective, but the discourse surrounding knowledge production obfuscates subjectivity and renders the knowledge seemingly bias-free.[4] Second, sexism undermines women's accounts of their own lived experiences, and such testimonies occur—among other places—between patients and biomedical experts. Leigh Gilmore defines testimony as "verbal acts in which a person bears witness to harm in a public forum," particularly in the legal system and court of public opinion.[5] Testimonial truth has little to do with the facts of the case and is instead "indexed…to power" where the weight of stigmatization renders a marginalized witness as deceitful and subject to legitimate violence.[6] For women in particular and those who have suffered sexual violence specifically within the system, public shaming and distrust existed before the act of violence even occurred; women step into the role in which discourse already constructs them as liars or temptresses.[7]

Though the scene and scope differ between testimony in public spheres of judgment and accounts of one's health to medical practitioners, understanding the former reveals similarities with the latter. Rather than refer to women's accounts of their experience as testimony, I refer to them in the medical context as a "complaint."[8] In this context, a complaint not only means an

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[4] Donna Haraway, "Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective," *Feminist Studies* 14, no. 3 (1988): 584.

[5] Leigh Gilmore, *Tainted Witness: Why We Doubt What Women Say About Their Lives* (New York: Columbia University Press, 2017), 3.

[6] Gilmore, *Tainted Witness*, 6, 15.

[7] Gilmore, *Tainted Witness*, 5, 7.

[8] In some cases, and especially in cases of violence against women, the terms testimony and complaint can refer to the same act, but the scene and actors differ.

ailment or disease, but also the act of communicating about the illness to a medical professional who renders judgment, whether it be a diagnosis—and thus an affirmation of the patient's bodily experience—or a dismissal. Complaints are a particular type of testimony that occur in particular settings (doctor's offices, public health agencies) with a much smaller audience (health professionals and public health officials). However, the act of speaking about one's personal experience to individuals whose judgment about one's experience can have significant impact upon how a person exists in the world remains the same. Sexism and its manifestations of disbelief and blame function similarly but can appear in different form. Within medical discourse for instance, doctors may dismiss very real complaints as they did with Rebecca Denison in 1983 who had AIDS. When Denison reported to two separate doctors that she was experiencing fevers, fatigue, throat sores, and unexplained vaginal bleeding, they "had no idea what was happening…so they told [her] it was all in [her] head."[9] As Denison's case suggests, not only can complaints go unheard by doctors, but they can also result in medical professionals undermining a patient's bodily experience and reality instead of articulating etiological uncertainty.

By understanding how the complaint and god trick contribute to biomedical sexism's invisibility, historical instances of such sexism come into sharper relief. In this chapter, I put forth examples from the history of women's health to demonstrate that such historical approaches to women's healthcare still had legacies in the 1980s. These examples inform how two significant issues for women with AIDS came to be. First, they show how failure to account for women in morbidity and mortality statistics is part of a long history of women's exclusion from biomedical research and that such exclusion from data also led to further absence of research. Second, the inability to see how women were excluded from morbidity and mortality rates and research is a

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[9] Laurence and Weinhouse, *Outrageous Practices*, 141.

result of prioritizing and pathologizing gynecologic organs. This illegibility allows for medical professionals to see gynecological problems where there is infectious disease. I argue that we must examine the cultural underpinnings of women's health to begin to theorize why women were excluded from early epidemiological intervention in the epidemic. Such cultural foundations explain why, in the face of etiological uncertainty, some physicians, public health officials, and epidemiologists reverted to sexist ideas about women's bodies in order to make sense of the crisis.

In this chapter, I begin by describing historical instances of privileging and pathologizing women's reproductive organs over other parts of their bodies to demonstrate how these historical practices influenced women's treatment in the AIDS crisis. I then turn to historical and contemporary cases of women's treatment in medical research to show the impact exclusionary practices had on epidemiological intervention for women in the epidemic. Throughout this account and evidenced further in later chapters, I suggest that the AIDS crisis occurred during a period of U.S. history when women's uteruses, ovaries, and gynecological diseases were a source of biomedical disinterest except in instances where they could not be avoided (i.e., maternal health). In this emerging era of sex blindness, many biomedical experts treated women as if there were no biological or genetic differences between them and cisgender men, and therefore cisgender men were suitable subjects for knowledge production about both men and women. This conflation resulted in gynecological AIDS symptoms becoming obfuscated from biomedical recognition. I conclude by emphasizing how historical practices of women's health continue to have repercussions for contemporary health crises.

2.1 A History of the Privileging and Pathologizing of Female Reproductive Organs

Women's exclusion from governmental and epidemiological interventions during the AIDS epidemic has roots in the historical treatment of the female medical subject in American medicine. Longstanding beliefs about women's bodies—how they are constituted and what is the necessary medical intervention—informed twentieth century medical practices. In Western religious and philosophical traditions, men have nearly always been synonymous with "wholeness, strength, and health," and women portrayed as the "misbegotten male, weak and incomplete."[10] Such traditions and their sexism influenced a vast array of discourses, including those belonging to medicine. In medical discourse specifically, women's weakness and incompletion manifest as sickness, rendering women and femininity both inherently ill and potentially contagious.[11] By the late nineteenth-century, medical explanations for women's inferiority grew more popular, at times even usurping religious rationales for maintaining women's submission. Barbara Ehrenreich and Deidre English even suggest that, during this era of medical discovery, physicians' medical intervention for women did far more to perpetuate sexism and patriarchal influence than to cure women of disease.[12]

In this section, I examine two subjects in the history of women's health that are instrumental in revealing historical medical beliefs about the female body: gynecology and hysteria. The histories of gynecology and hysteria serve as a foundation for medical sexism in the U.S. They contributed to distrust in female patients and women's underdiagnosis, which became startlingly visible during the AIDS epidemic. In part, it is through the development of gynecology

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[10] Barbara Ehrenreich and Deirdre English, *Complaints and Disorders: The Sexual Politics of Sickness* (New York: The Feminist Press at CUNY, 2011), 32.

[11] Ehrenreich and English, *Complaints and Disorders*, 55, 57.

[12] Ehrenreich and English, *Complaints and Disorders*, 80; Carroll Smith-Rosenberg, *Disorderly Conduct: Visions of Gender in Victorian America* (Oxford: Oxford University Press, 1985), 183.

and the invention of hysteria that doctors became the primary arbiters of women’s health. In overviewing the history of gynecology, it becomes clearer how doctors were taught how to view female sex organs and how doctors’ hyper-focus on these organs came at the expense of understanding the rest of the female body. As the classic disease of female sex organs, hysteria’s role in the history of women’s health exposes the way in which physicians would leverage this disease to discipline women’s non-normative behavior by diagnosing them as ill and in need of treatment.

Together, the histories of gynecology and hysteria show that testimony by women about their own experiences, both social and physical, have been obfuscated via medical diagnoses. Women’s accounts of their body have been rendered unbelievable on the grounds of hypochondria, narcissism, and failure to adhere to gender norms. While the relationship between women and medicine had evolved between the nineteenth century and the beginning of the AIDS crisis, understanding how the female patient has been historically constructed and understanding its lingering influence allows us to theorize (1) why women were underdiagnosed with AIDS; (2) why women’s accounts of their health were not taken seriously; and (3) how physicians—educated in a sexist system—rendered judgment on the state of a woman’s health that could perpetuate social norms.

2.1.1 Gynecology, Obstetrics, and Medical Beliefs About Female Reproductive Organs

Since Western antiquity, philosophers and physicians have frequently attributed women’s personalities and health to the state of their reproductive organs. However, beginning in England’s medieval period, medical professionals began to both frame women’s reproductive organs as their defining feature and privilege their organs over the women themselves. One way through which this definition and privileging occurred was through medical and anatomical texts. In her research on the disappearance of women from the gynecologic-obstetric encounter, Nora Doyle explains that "the male body was generally understood to be the norm from which the female body deviated…the female body was interesting only in the ways that it differed from the male body."[13] Since "the male body expressed the full range of the human form" in anatomical literature of the sixteenth and seventeenth centuries, "the female body was not needed to display other parts such as muscles, heart, or brain" as women were "understood solely in terms of [their] reproductive parts and generative capacity."[14] When women appeared in sixteenth-century anatomical texts, the most common rendering featured a woman's entire body with "the skin and muscles of her abdomen gently peeled back to reveal the inner reproductive organs or a fetus;" however, women gradually became first headless and limbless and then reduced to their pelvises and uteruses as anxiety over the new profession of man-midwifery rose.[15]

At the start of the mid-eighteenth century, scientific and philosophical thinkers, inspired by the Enlightenment, "recast the female identity as being rooted in women's reproductive organs," specifically the uterus.[16] Gradually, this belief shaped medical practice, and by the mid-nineteenth century, the uterus dominated medical discussions about women occurring both in Europe and the United States.[17] Unlike women, medical professionals did not imagine a tightly knit relationship between men and any one organ in their bodies; the male body remained "a mechanism with a wide range of components, each with its own role in the system… [none of which] single-handedly defined men's subjectivity, behavior, or social roles in the way that the

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[13] Nora Doyle, *Maternal Bodies: Redefining Motherhood in Early America* (Chapel Hill: University of North Carolina Press, 2018), 25. Thomas Laquer, *Making Sex: Body and Gender from the Greeks to Freud* (Cambridge, MA: Harvard University Press, 1992), 3-4.

[14] Doyle, *Maternal Bodies*, 25.

[15] Doyle, *Maternal Bodies*, 28, 32.

[16] Doyle, *Maternal Bodies*, 33.

[17] Doyle, *Maternal Bodies*, 35.

womb defined women."[18] Throughout the nineteenth-century, growing knowledge about the female reproductive system allowed doctors to more easily explain women's physical potentialities and, by extension, dictate their role in society through biological justification.[19] For instance, medical experts used menstruation as a justification for barring women from universities because, they argued, a healthy reproductive system required concentrated blood flow to the uterus, which brain function would jeopardize.[20] Gynecologic phenomena and diseases controlled most if not all aspects of a woman's life, rendering women frail and nervous. According to one nineteenth-century U.S. physician, "Women's reproductive organs are pre-eminent… They exercise a controlling influence upon her entire system, and entail upon her many painful and dangerous diseases. They are the source of her peculiarities, the centre of her sympathies, and the seat of her diseases. Everything that is peculiar to her, springs of her sexual organization."[21] Some physicians specifically identified the uterus as the source of all ills while others would blame the ovaries; however, according to Laurence and Weinhouse, the predominant thought of the era appeared to be that women were "collections of reproductive organs, with everything else quite incidental."[22] Where men would receive treatment for ailments at the appropriate location on the body, women could expect treatment for headaches, digestive issues, sore throats, and curvature of the spine administered to the uterus or ovaries.[23]

Physicians focused on puberty as an important moment in child development, particularly so for young girls. During puberty, young girls were expected to comport themselves in ways that assured proper development of their reproductive organs. In nineteenth-century America, it was

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[18] Doyle, *Maternal Bodies*, 34-35.
[19] Smith-Rosenberg, *Disorderly Conduct*, 183.
[20] Smith-Rosenberg, *Disorderly Conduct*, 186-87.
[21] John Wiltbank quoted in Smith-Rosenberg, *Disorderly Conduct*, 22-23.
[22] Laurence and Weinhouse, *Outrageous Practices*, 14.
[23] Laurence and Weinhouse, *Outrageous Practices*, 15; Ehrenreich and English, *Complaints and Disorders*, 69.

believed that proper sexual development required concentration and regulation, which were well within the control of the patient.[24] A girl was expected, for example, to regulate her menstrual cycle through focus and appropriate conduct. Gender norms dictated how young girls ought to behave, and those who transgressed were threatened with "a dire chain of pain and disease…even sterility" if she did not change her behavior.[25]

With the onset and cessation of menstruation, physicians diagnosed women with a wide variety of diseases. Doctors associated menstruation with insanity, describing menstruating women as going "berserk, destroying furniture, attacking family and strangers alike, and even killing their infants" to the point that those women suffering greatly from menstruation-related insanity be "incarcerated for the length of their menstruating years."[26] Failure to adhere to social norms of the era during their reproductive years meant that women could expect increased risk of menopausal diseases according to physicians. Such taboo behaviors included using birth control, failure to properly take care of her home and family, and advocating for women's right to vote. In these instances, the association between challenges to patriarchal authority and subsequent diagnosis of disease to mark non-normative behaving women as deviant or Other is clearly illustrated. Diagnoses in such cases function solely as a disciplining mechanism to punish women who dare to assert control of their reproductive capacities and seek to contribute to public life. When she became menopausal, a woman could expect her physician to blame all her health problems on menopause.[27] [28] Thus, throughout her reproductive lifetime, women's reproductive

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[24] Smith-Rosenberg, *Disorderly Conduct*, 187.

[25] Smith-Rosenberg, *Disorderly Conduct*, 186.

[26] Smith-Rosenberg, *Disorderly Conduct*, 190-91.

[27] Smith-Rosenberg, *Disorderly Conduct*, 191.

[28] According to Smith-Rosenberg, menopausal diseases included: flushes, dyspepsia, diarrhea, severe vaginitis, vaginal inflammation, prolapsed uterus, rheumatic pains, paralysis, apoplexy, erysipelas to uterine hemorrhaging, tumors, uterine and breast cancer, tuberculosis, scrofula, diabetes, irritability, depression, hysteria, melancholy, and episodes of severe emotional withdrawal and insanity. Smith-Rosenberg, *Disorderly Conduct*, 191.

organs would in one sense be re-envisioned based on her reproductive capacity by doctors in order maintain patriarchal control. By re-envisioning, I mean that sexist systems—of which the medical establishment was one—accounted for the changes within women's bodies when developing ideas about disease, such as the onset and cessation of menstrual bleeding as related to blood flow in the body. However, the need to discipline non-normative and threatening behavior and the symptoms associated with women's reproductive disease remain largely consistent throughout the era.

While medical discourse created an overarching narrative of who the female patient was and from what she suffered, medical narratives that contributed to sexism also had to conform to racist and classist notions of nineteenth-century America. According to Laura Briggs' research on race and hysteria, women fell into two social categories that influenced the way the medical establishment perceived their bodies. The "overcivilized" woman was white, upper-middle or upper-class, and viewed as sickly, weak, and incapable of any strenuous tasks. In their most generous assessments, many physicians felt that they were too delicate and frail to bear children.[29] In their worst, these women "withheld sexuality and avoided maternity through birth control or by deceiving physicians into aborting them…[and sought] higher education and employment."[30] In contrast, the "savage" woman was typically working class, an immigrant, and/or a woman of color. She was healthy, strong, gave birth easily, and remarkably fertile.[31] Because she rarely pursued higher education, the savage woman's reproductive capacity was protected from strenuous mental exercises that took blood away from her ovaries and uterus. Conveniently, race- and class-

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[29] Laura Briggs, "The Race of Hysteria: 'Overcivilization' and the 'Savage' Woman in Late Nineteenth-Century Obstetrics and Gynecology," *American Quarterly* 52, no. 2 (2000): 265.

[30] Briggs, "The Race of Hysteria," 265.

[31] Briggs, "The Race of Hysteria," 265.

appropriate work—such as factory work, field work, and indentured servitude—did not jeopardize their reproductive capacities.[32]

Many physicians offered medical explanations for supposed bodily differences between the overcivilized woman and the savage woman. One proposed difference between them was the placement of the hymen. According to one physician, the hymen "was misplaced in African American women, such that its presence could not vouch for virginity."[33] Another means through which doctors achieved this is pelvimetry,[34] similar to the more widely known craniometry/phrenology[35] employed for racist and eugenic ends. Some physicians believed that women of color "had wide [pelvises], more like that of the female gorilla than like those of European females," which led to easier births but rendered them less-evolved on the evolutionary scale.[36] The frailty and nervousness that characterized white women was a symptom of a civilized race, but resulted in lower birth rates. Per Briggs, many physicians believed that uncivilized persons—women of color, immigrants, poor, working-class, or women from rural areas—had easier pregnancies and childbirths due to their lack of "nerves."[37] Pelvis size also contributed to the belief that uncivilized women, and particularly black and poor women, felt little to no pain.[38]

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[32] Briggs, "The Race of Hysteria," 265.

[33] Briggs, "The Race of Hysteria," 261.

[34] See: Elizabeth O'Brien, "Pelvimetry and the Persistance of Racial Science in Obstetrics," *Endeavor* 37, no. 1 (2012); Miriam Rich, "The Curse of Civilised Woman: Race, Gender and the Pain of Childbirth in Nineteenth-Century American Medicine," *Gender & History* 28, no. 1 (2016).

[35] See Garland E. Allen, "The Misuse of Biological Hierarchies: the American Eugenics Movement, 1900-1940," *History and Philosophy of the Life Sciences* 5, no. 2 (1983); Andrew Bank, "Of 'Native Skulls' and 'Noble Caucasians': Phrenology in Colonial South Africa," *Journal of Southern African Studies* 22, no. 3 (1996); Reginald Horsman, "Scientific Racism and the American Indian in the Mid-Nineteenth Century," *American Quarterly* 27, no. 2 (1975); William Stanton, *The Leopard's Spots: Scientific Attitudes Towards Race in America, 1815-1859* (Chicago: University of Chicago Press, 1960); Nancy Rose Hunt, *The Colonial Lexicon: Of Birth Ritual, Medicalization, and Mobility in the Congo* (Durham, N.C. : Duke University Press, 1999).

[36] Briggs, "The Race of Hysteria," 257-58.

[37] Briggs, "The Race of Hysteria," 258, 61.

[38] Briggs, "The Race of Hysteria," 262.

Based on this historical overview, observations can be made about cultural beliefs surrounding women's reproductive organs and their associated diseases. First and foremost, physicians had the capacity to treat a variety of ailments and disease at the time, but many *chose* to identify the source of a medical problem differently in men than in women. For instance, a man who complained of cough could reasonably expect to have a doctor assess the state of his lungs. As a general rule, a woman might receive a complete physical examination by a physician, but she could more often than not expect the diagnosis to be related to her uterus or ovaries. As a result of this medical practice, women suffered worse treatment options, and their reproductive organs became the site of most medical knowledge produced about women's bodies.

Second, the belief that women differed biologically from men only in their reproductive organs created a further issue that would come into relief in the late twentieth and early twenty-first centuries: the association of women health with reproductive health. If the presence of a uterus and ovaries defined sex difference and if the male body was accepted as the standard body, then it follows that biomedical practitioners could research the male body to learn nearly everything they needed to know about the human body. What remained—the ovaries and uterus—defined what would later be named *women's health*. Thus, women's healthcare became inextricably linked with reproductive healthcare generally, but most prominently with maternal-fetal health. This association would have important implications for the women's research and treatment in the AIDS crisis as nearly all funding and research on women and AIDS fell under pediatrics.

Finally, the hyper-focus on the uterus and ovaries as the source of most health problems, both physical and mental, also functioned to link all socially normative or non-normative behavior to the reproductive organs and biologically essentialist ways of thinking about sex difference. It is through this process that things like perceived irritability, unreasonableness, or even anger over sexist behavior get attributed to menstruation and hormones, delegitimizing women's experiences and maintaining patriarchal power structures. The causal relationship between women's reproductive organs and her ailments also had implications for race- and classed-based arguments. The composition of female anatomy served to justify discriminatory and violent treatment. For example, a black woman could always be portrayed as sexually active, and therefore sexually available to white men, if the presence of an intact hymen had no biological bearing on her virtue.

2.1.2 Hysteria

The long history of associating women's reproductive organs with inferiority and ailments shared an equally storied history with one of the most culturally salient female maladies—hysteria. While it manifested differently across eras according to social norms, hysteria was consistently characterized as a feminine disease.[39] The connection between female reproductive organs and hysteria began with Hippocrates' *On the Diseases of Women* where the uterus was understood to be a "small, voracious animal" that "had dried up, lost weight, and come unhooked" in order to seek nourishment in other areas of the body.[40] When the wandering womb attached itself to various other organs, women experienced a range of illnesses. For instance, the uterus at the heart resulted in anxiety or vomiting and in the arms and legs in paralysis. [41] In ancient times, physicians treated hysterical women by "uterine fumigation," which brought the uterus back into the pelvis, or by prescribing marriage and, thus, sexual satisfaction.[42] With the rise of monotheism and Christianity

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[39] Rachel P. Maines, *The Technology of Orgasm: "Hysteria," the Vibrator, and Women's Sexual Satisfaction* (Baltimore: Johns Hopkins University Press, 1999), 21.

[40] Elisabeth Bronfen, *The Knotted Subject: Hysteria and Its Discontents* (Princeton, N.J.: Princeton University Press, 1998), 105.

[41] Bronfen, *The Knotted Subject*, 105.

[42] Bronfen, *The Knotted Subject*, 105.

in the Middle Ages, hysteria's etiology shifted from the natural to the spiritual. Suffering became associated with evil and original sin, and hysteria was a sign of illness in the soul.[43] In this period, the hysteric became tied with notions of deceit as she was "in the guise of a normal person… [but] in fact she was the dangerous host of evil [and demonic] spirits."[44] Physicians in the Middle Ages treated the hysteric by subjecting her to confession, interrogation, and bodily harm.[45] By the seventeenth century, physicians reconceived hysteria as occurring when bad vapors emanating from the womb affected other body parts, especially the brain; thus, the vapor-afflicted brain created problems in the mind, for the senses, and for movement.[46] Some of these symptoms included fainting, spasms, hallucinations, and loss of hearing. By the eighteenth century, physicians no longer accepted vapors as hysteria's cause but viewed it as a nervous disorder characterized by hypersensitivity and excitement, giving rise to symptoms such as shivering, fainting, and giddiness.[47]

In the late-eighteenth and early-nineteenth centuries, hysteria saw another important shift as it was once again culturally reimagined. The hysterical woman had become "a sensitive creature, prone to dreaming, melancholic somnambulance, or febrile insomnia but also capricious, fantastic, unforeseeable, deceitful and lustful."[48] Some physicians even suggested that hysteria had reached epidemic proportions in this era.[49] The influx of patients led to an economic boom for physicians. One American doctor specializing in hysteria, Russell Thacher Trall, wrote in 1873 that "'more than three fourths of all the practice of the profession are devoted to the treatment of diseases

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[43] Bronfen, *The Knotted Subject*, 106.

[44] Bronfen, *The Knotted Subject*, 106.

[45] Bronfen, *The Knotted Subject*, 107.

[46] Bronfen, *The Knotted Subject*, 108.

[47] Amy Koerber, *From Hysteria to Hormones: A Rhetorical History* (University Park: Pennsylvania State University Press, 2018), 52-57; Bronfen, *The Knotted Subject*, 111.

[48] Bronfen, *The Knotted Subject*, 111.

[49] Maines, *The Technology of Orgasm*, 22.

peculiar to women [of which hysteria was one]' and that of the annual estimated aggregate income of the United States physicians of more than $200 million, 'three-fourths of this sum—one hundred and fifty millions—our physicians must thank frail women for.'"[50] Rachel Maines writes that "during the decade in which Trall wrote these lines [about women's economic investment in medicine], the proceeds of treating women would have equaled just under half of the entire federal budget [of the United States]."[51] The accounts of hysteria as an epidemic coupled with financial reports suggest that hysteria remained a culturally-salient disease.

As in previous centuries, nineteenth-century physicians did not view hysteria as solely a female disease, but continued to associate it with the feminine. In men, hysteria was considered a "morbid state," but in women, it was their "natural state" determined by their anatomy and influenced by their reproductive cycle.[52] Hysterical women were those who most frequently felt overwhelmed by the responsibilities foisted upon her by society: household management, childbirth, and child-rearing.[53] The characterization of the hysterical woman was one antithetical to the norms and values of the era. Both expert and non-expert audiences understood the hysteric woman as: idle, self-indulgent, emotionally indulgent, morally and physically weak, unable to apply herself or persevere, superficially or morbidly suggestable, exhibitionistic, dramatic, dependent, desperate for sympathy, and impulsive.[54] Hysterical women's "intellectual abilities were meager, their powers of concentration eroded by years of self-indulgence and narcissistic introspection."[55] Effectively, the social view of hysterical women rendered these women as

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[50] Maines, *The Technology of Orgasm*, 38.

[51] Maines, *The Technology of Orgasm*, 38.

[52] Smith-Rosenberg, *Disorderly Conduct*, 206; Andrew Scull, *Hysteria: The Biography* (Oxford: Oxford University Press, 2009), 94-95.

[53] Smith-Rosenberg, *Disorderly Conduct*, 199, 204.

[54] Smith-Rosenberg, *Disorderly Conduct*, 205-06, 12; Jane M. Ussher, *The Madness of Women: Myth and Experience* (New York: Routledge, 2011), 9.

[55] Smith-Rosenberg, *Disorderly Conduct*, 205-06.

"children, and ill-behaved, difficult children at that" who were "filled with self-doubt, constantly in need of reassurance and attention from others."[56] Notably, the characteristic traits of this "child-woman"—self-doubt, desperation for reassurance, and attention-seeking—were the very characteristics encouraged by society in girls and young women.[57]

Historical accounts of hysteria suggest that doctors and the medical establishment frequently viewed the hysteric as a social menace. Though physicians sometimes approached these women with a degree of sympathy, thinking them respectable but ailing, many did not. Doctors described the hysterical woman as "egocentric in the extreme" with "consistently superficial and tangential" relationships and, paradoxically, appeared "sexually stimulated and attractive" while actually being "asexual…and frigid."[58] Some physicians even believed that these women might be "only clever frauds and sensation seekers—morally delinquent and, for the physician, professionally embarrassing."[59] One neurologist reportedly characterized his hysterical patient as "a willful, self-indulgent, and narcissistic person who cynically manipulated her symptoms."[60] Hysterical women's characterization as manipulative and fraudulent would come to color women more generally as hypochondriacs.

Despite viewing these women unfavorably, doctors still had the responsibility of treating their patients, and their diagnoses had the ability to socially sanction or condemn the hysteric's behavior as appropriate or not. With a diagnosis of hysteria, a doctor could give license to a woman to neglect her role as wife and mother. Nineteenth-century doctors reported that "many women enjoyed this power [over her family] and showed no inclination to get well" and described

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[56] Smith-Rosenberg, *Disorderly Conduct*, 205-06, 12.
[57] Smith-Rosenberg, *Disorderly Conduct*, 212.
[58] Smith-Rosenberg, *Disorderly Conduct*, 202.
[59] Smith-Rosenberg, *Disorderly Conduct*, 202, 04.
[60] Smith-Rosenberg, *Disorderly Conduct*, 207.

women's behavior as "trials, tears, tricks, and tantrums."[61] This language is an explicit example of the way physicians portrayed women as child-like, using words indicative of immaturity or explicit infantilization. For those patients who refused to recover from hysteria, doctors suggested "suffocating hysterical women until their fits stopped, beating them across the face and body with wet towels, ridiculing and exposing them in front of family and friends, [and] showering them with icy water."[62] When a patient responded positively to treatment, doctors felt they could adopt the role of ally or savior and use positive reinforcement to elicit socially normative behaviors.[63]

With a medical diagnosis for hysteria, women could assume the role of the patient, which entitled her to possibilities not otherwise available to her as a wife and mother. The hysterical woman "no longer… [had to] devote herself to the needs of others, acting as self-sacrificing wife, mother, or daughter," and this necessarily meant that someone in the household had to take on those responsibilities.[64] The breakdown of social roles within the family frequently created tension throughout the household as women asserted control of their relatives, particularly their male family members. Even the doctors most successful at treating hysteria described these women as "the pests of many households…who furnish those annoying examples of despotic selfishness…and in unconscious or half-conscious self-indulgence destroy the comfort of every one about them."[65] While hysteria allowed women to subvert gender roles and gain aspects of control over family life in ways that would have been improper for a woman otherwise, their victories were often short-lived and treatment severe. Male relatives and physicians often responded with aggression towards the hysterical woman, punishing her with threatened or

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[61] Smith-Rosenberg, *Disorderly Conduct*, 209-10. Scull, *Hysteria: The Biography*, 93.
[62] Smith-Rosenberg, *Disorderly Conduct*, 211; Scull, *Hysteria: The Biography*, 93.
[63] Smith-Rosenberg, *Disorderly Conduct*, 211.
[64] Smith-Rosenberg, *Disorderly Conduct*, 208.
[65] Smith-Rosenberg, *Disorderly Conduct*, 207.

actualized “pain, disability, and an intensification of woman’s traditional passivity and dependence.”[66]

In the first half of the nineteenth century, hysteria was most commonly manifested as a hysterical fit. This seizure-like symptom could occur gradually or immediately and was often proceeded by symptoms such as depression, anxiety, or sadness.[67] A fit would begin with “pain and tension, most frequently in the uterine area” before the woman “sobbed and laughed violently, complained of palpitations of the heart, clawed her throat as if strangling, and at times abruptly lost the power of hearing or speech” before she might experience a “death-like trance.”[68] By the latter half of the nineteenth century, however, hysteria would be categorized by a much larger number of symptoms. With the decreasing popularity of the hysterical fit, hysteria began to be categorized by “loss of sensation in part, half, or all of the body, loss of taste, smell, hearing, or vision, numbness of the skin, inability to swallow, nausea, headaches, pain in the breast, knees, hip, spine, or neck, as well as contracture or paralysis of virtually any extremity.”[69] So capacious was the diagnosis of hysteria that one doctor created a non-exhaustive list of hysteria symptoms of seventy-five pages.[70] Effectively, hysteria became a catch-all diagnosis for women’s embodied and social complaints.[71]

Before its removal from the *Diagnostic and Statistical Manual* in 1980, hysteria underwent a final transformation with psychoanalysis’ popularization. Freud and his mentor Charcot retained some of hysteria’s sexual nature. Hysteria was “associated [in both sexes] with contractures and

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[66] Smith-Rosenberg, *Disorderly Conduct*, 207; Elaine Showalter, *The Female Malady: Women, Madness, and English Culture, 1830-1980* (New York: Penguin Books, 1985), 81.

[67] Smith-Rosenberg, *Disorderly Conduct*, 201.

[68] Smith-Rosenberg, *Disorderly Conduct*, 201.

[69] Smith-Rosenberg, *Disorderly Conduct*, 201-02.

[70] Briggs, “The Race of Hysteria,” 247.

[71] Roy Porter, “The Body and the Mind, the Doctor and the Patient: Negotiating Hysteria,” in *Hysteria Beyond Freud*, ed. Sander L. Gilman et al. (Berkeley: University of California Press, 1993).

functional paralysis" due to "juvenile exposures to sexuality, whether real or imagined."[72] The shift away from previous theories that characterized hysteria as symptomatic of sexual dissatisfaction in adulthood and to childhood sexuality "entirely exculpated" the male partners of adult women for inadequate sexual performance.[73] Maines argues that "[Freud's] definition was retroactively applied to all supposed cases of hysteria, modern or ancient, couched in terms that made it sound almost like a respectable disease."[74] However, in the years between Freud's rearticulation and its demedicalization, hysteria once again became an amorphous disease. One mid-twentieth-century, American medico-legal professor, George Swetlow, for instance, described hysteria as "'a strange disorder in that it takes a position midway between truth and deceit—not only may hysterical symptoms caricature almost any known disability due to actual tissue alteration, but at the same time it presents features hardly distinguishable from fraud.'"[75] Significantly, hysteria maintained its association with deceit since the Middle Ages, which informs why understanding hysteria is vital to women's place in medicine.

While I have briefly traced hysteria's history since the classical period, one particular point of nuance must be addressed. Beginning in the eighteenth century, physicians began associating hysteria most often with upper-middle and upper-class white women. Laura Briggs argued that hysteria was a disease of "over-civilization" enmeshed in discourse about race and reproduction. According to physicians, women in the upper echelons of society grew increasingly more comfortable with greater time to worry, which led to these women becoming "weak, frail, and nervous" as well as "soft and decadent"—overcivilized.[76] Women's nervous energy led to

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[72] Maines, *The Technology of Orgasm*, 44.

[73] Though certainly in the minority, some experts such as Wilhelm Reich continued to attribute hysteria to women's sexual dissatisfaction. Maines, *The Technology of Orgasm*, 44.

[74] Maines, *The Technology of Orgasm*, 45.

[75] Maines, *The Technology of Orgasm*, 45.

[76] Briggs, "The Race of Hysteria," 254; Scull, *Hysteria: The Biography*, 49-50.

reproductive problems, weakness, and decreased fertility, and these problems were then given the medical diagnosis of hysteria. The construction over the overcivilized upper-class white woman contrasted with both working-class women, immigrants, and women of color. Many physicians believed women in the latter category to be "strong, hardy, and prolifically fertile"—undercivilized or savage, and therefore a remarkably unlikely sufferer of hysteria.[77] Briggs suggests that this binary offered justification for the advancements of obstetrics and gynecology where white women would benefit from knowledge produced by doctors vis-à-vis the women of color, immigrants, poverty-stricken, and disabled women who so often were the experimental subjects for such scientific advancements.[78]

Hysteria makes three significant contributions to our understanding of the female medical subject in the late twentieth century. First, hysteria offered various cultures ways to pathologize women (or non-normative behaving men) to maintain patriarchal power. The dominating force of women's uterus and ovaries served as biological justification for women's inferiority as I have already discussed. However, the invention of hysteria allowed society to draw connections not only between women and inferior bodies, but also women and disease. The United States has a rich history of social and political movements linking marginalized communities to disability in order to justify continued oppression since disability and non-normativity have remained states from which all others want to distance themselves.[79] Through hysteria, women's oppression thus increased.

Second, hysteria, in part, helps us understand why women's medical complaints are often trivialized or dismissed by physicians. By tracing its evolution across centuries, I have shown

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[77] Briggs, "The Race of Hysteria," 247.

[78] Briggs, "The Race of Hysteria," 247.

[79] Douglas C. Baynton, "Disability and the Justification of Inequality in American History," in *The Disability Studies Reader*, ed. Lennard J. Davis (New York: Routledge, 2013).

which hysteric ideas or symptoms from each era remained "stuck" to the disease. One of the most important attributes is the association between the hysteric and deceit beginning in the Middle Ages. While over time the biological etiology supplanted the religious, fraud resided in hysteria's cultural construction. No longer were hysteric women disguising the devil within their bodies, but a desire to reject their social roles which manifested as fraudulent illness. Thus, if we accept that female reproductive organs dominated most ways of approaching women's health and that hysteria had an influence on how women's health was perceived culturally, it follows that, in the past several hundred years, women have been marked as deceptive in medical or bodily contexts.

Finally, hysteria reveals significant information about the relationship between doctors and female patients, including how power differentials manifest between the two. Hysteria allowed physicians to make claims about women's maturity and worthiness of being treated as an adult that were based on biological evidence. By portraying hysterical women as "ill-behaved children"—not just any children, but the worst of them—doctors reinforced their claims to power over their female patient. With more women reporting sicknesses, the need for doctors—and, therefore, doctors' financial interest in women's plight—became greater.[80] When doctors treated women, they confirmed for the women that they were, indeed, sick. The cycle then appears something like this: (1) wealthy women learned from authority figures that they are the frail sex; (2) these women internalized this message and begin to make claims about illnesses, real or imagined; and (3) doctors visited these women to confirm or reject their sickness, thus perpetuating and profiting from the system. In the eighteenth and nineteenth centuries, sickness became a sign of affluence in particular, socially desirable ways, and hysteria cases reach such proportions that the number of cases can hardly be believable (and, indeed, were not believed). Doctors' expertise

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[80] Ehrenreich and English, *Complaints and Disorders*, 58, 81.

and training already gave them a degree of influence, but by assuming the rationale adult role within the new adult-child configuration with their female patients, doctors could further exert their influence.

By the late 1960s, feminist activists began to critique the biomedical establishment's paternalism, particularly its withholding of knowledge about women's health from women themselves. While problematic for those moments when it adopted a gender essentialist position, the Women's Health Movement harnessed the power of embodied difference as a way of knowing.[81] One of its triumphs was the Boston Women's Health Collective's book *Our Bodies, Ourselves*, which "was revolutionary not only for its attack on the medical establishment, but also for its creation of an alternative knowledge base structured around personal stories."[82] Thus, counter-discourses to biomedicine's epistemic preeminence existed and began to do the important work of challenging sexist medical infrastructures in the decade prior to AIDS. However, in part due to the sexing and sexualizing of AIDS, such feminist discourses did not gain traction.

2.1.3 The Female Patient in the AIDS Epidemic

The introduction to this chapter included the story of Rebecca Denison, who reported a series of symptoms to her doctors in 1983 and later discovered she had AIDS. Despite her very real symptoms, two different doctors could not find the source of her ailments and, according to her personal account, told her that it was "all in her head." In offering histories of hysteria and the female reproductive system, I have developed explanations for how situations like Denison's could

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[81] Wendy Kline, *Bodies of Knowledge: Sexuality, Reproduction, and Women's Health in the Second Wave* (Chicago: University fo Chicago Press, 2010).

[82] Kline, *Bodies of Knowledge: Sexuality, Reproduction, and Women's Health in the Second Wave*, 11.

occur in the 1980s. By putting AIDS in context with the much longer history of women and medicine, I specifically aim to offer preliminary findings on (1) how women came to be underdiagnosed/misdiagnosed; (2) why women's medical complaints were frequently not taken seriously or outright dismissed; and (3) how doctors, by rendering judgment about women in particular ways, continued to perpetuate sexist cultural norms about women's healthcare.

First, one significant problem identified in literature on women and AIDS is the issue of women's misdiagnosis and underdiagnosis. Doctors' failure to identify sets of symptoms in women as AIDS symptoms, as was the case for Denison, leads to AIDS rates being much higher than reported. Importantly, my claims about what doctors did and did not do is not about praise or blame, per se, but to identify trends in medical practice at the time with the caveat that some doctors may have readily tested women for AIDS. The historical account offered in this chapter gives one persuasive rationale for why misdiagnosis/underdiagnosis occurred and has two important implications. Historically, physicians and philosophers have conceived of females as males with different sex organs effectively; the male body was the norm from which the female deviates. In part, this led physicians to privilege the uterus and ovaries in the female body. One long-standing consequence of such privileging was that womanhood became linked to the uterus' and ovaries' reproductive function. Thus, *women's* health became *reproductive* health, which by the end of the twentieth century became maternal-fetal health with fetal health taking primacy. The second consequence more directly related to AIDS was that, if the male body was considered to be the norm and the only difference between male and female were the sex organs as has been historically the case, then one might expect AIDS to manifest similarly in men and women with the exception of sex-related diseases. Additionally, the fact that AIDS was a sexed and sexualized disease—that it was framed as one found in gay men—may have further solidified the idea that AIDS ought to manifest similarly across sex or that sex-specific abnormalities were of little concern. In an era when some biomedical experts seemed to begin treating sex differences as negligible in research (as I will discuss in the next section), this may have led to a misrecognition of AIDS in women as women's symptoms differed than those seen in gay men. For instance, Kaposi's sarcoma was a common manifestation of AIDS in gay men, but women with AIDS rarely were diagnosed with Kaposi's sarcoma.

Second, the AIDS epidemic is one crisis among many where women's accounts of their health may not be taken seriously. Denison had myriad and very real symptoms to which she could point in the doctors' offices, yet their response to fevers and unexplained vaginal bleeding was that it was "all in her head." While the etiology of such symptoms may not have been able to be identified by the physicians, that does not mean that no underlying cause existed. The history of hysteria offers one particularly persuasive reason as to why women's complaints could be so easily dismissed. For centuries, one of the most prevalent female maladies—hysteria—has been associated with fraud and deceit. Hysteria framed women as either possessed by demons, but passing among their communities as upstanding women, or as irresponsible women who wanted to escape their social roles and therefore faked illnesses. In coding such behavior as spiritual or embodied illness, patriarchal power structures had greater authority to discipline their behavior, both on the grounds of their sex and their non-normative behavior. By the late twentieth century ideas about women's fraudulent behavior as it relates to the health permeates United States culture. For instance, a woman's irritability might be associated with menstruation, or a woman might be accused of faking a headache in order to avoid sex with her partner. These, I argue, have clear ties to hysteria's influence on Western society since the Middle Ages. In light of this history, Denison's doctors' diagnoses make more sense because the female patient is already coded as being an untrustworthy patient.

Finally, this history contextualizes doctors' responses to women in the United States' AIDS epidemic. One might read Denison's account of her doctors' dismissals—and the countless other unreported cases of women being underdiagnosed—as bad, uncompassionate medical practice. While the phrase "it's all in your head" has an affective stickiness that may linger for any reader of Denison's account and may inspire charges of sexist behavior on the part of the physicians, Denison's story is part of a larger history. In 1983 when Denison went to these doctors, the AIDS crisis was still in its infancy and few physicians were thinking about AIDS in women. Though this misrecognition was an important problem, a significant, but less obvious question is: how could doctors have such an arcane, sexist response to women's medical complaints in an emerging epidemic? One answer is that these doctors were trained in a system that has held certain beliefs about women and their bodies for centuries, and these beliefs have remarkable staying power. Medical sexism offers an explanation for why a gay man with a rare cancer and a cough can go into a physician's office and it can start an epidemic, and when a woman goes into a physician's office with a cough and unexplained vaginal bleeding be told it is a figment of her imagination. In a culture with a prevalent history of medical injustice, physicians can rely on sexism to explain a patient's case in the face of etiological uncertainty and mystery.

2.2 Research's Role in the Absence of Women's Morbidity and Mortality Statistics in the AIDS Epidemic

The biomedical establishment's inability to recognize AIDS symptoms in women created several challenges for defining and quantifying the epidemic in the United States. This was particularly true for biomedical research, which played a pivotal role in AIDS' epidemiological recognition. In order to establish early AIDS criteria for their surveillance definition, the CDC relied on epidemiological research to demonstrate a causal relationship between the AIDS virus and an opportunistic infection. However, research into particular opportunistic infections—especially sex-specific infections—was underfunded because such infections were not part of the CDC's AIDS surveillance definition.[83] Put more simply, researchers relied on the CDC's AIDS definition for funding, and those petitioning for changes to the CDC's AIDS definition required data to support their claims for inclusion. This Catch-22 resulted in remarkably little research conducted on AIDS in women generally. However, key conditions in the decades leading up to the AIDS epidemic made access to research and trials for and about women even more restrictive when the epidemic began. In this section, I describe how the lack of research on women in the AIDS epidemic was only one problem among many in a system replete with medical sexism, both explicit and insidious. First, I examine the ways women could and could not participate in biomedical research and the origins of such participation barriers. Next, I offer an overview of why, historically, women's healthcare has been underfunded. Finally, I address women's exclusion from AIDS research specifically and how this exclusion fits into century-long lack of commitment to women's healthcare.

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[83] Laurence and Weinhouse, *Outrageous Practices,* 147.

2.2.1 Women and Research in the Late Twentieth Century

Before describing several key moments in the history of late twentieth century medical research for women, one must understand that accounting for sex difference in biomedical research is not without controversy. Researchers in gender and science studies have cited at least two grounds upon which the inclusion of such differences might be problematic. First, focus on sex differences reinforces gender essentialist notions that there are only two biological sexes and those two sexes are so distinct that they have little in common biologically.[84] This issue is further complicated because, if research findings show a difference along sex categories, those differences are likely to be attributed to sex. In her work on sex differences, Susan Leigh Star wrote, "The very fact of dividing subjects into male and female categories for research purposes may serve to reify and perpetuate a socially created dichotomy. The search for differences can help create the differences; if you are looking for something you are likely to find it."[85] However, these differences might not be relevant to the study in any significant way.[86] As Steven Epstein explains, the problem with including sex and racial difference in research is that "we assume that the ways of differing that are most socially salient and 'obvious' are necessarily the ones that carry the most explanatory weight."[87] Consequently, commonalities between the sexes can be overlooked when men's and women's diseases are treated as etiologically unrelated, and differences *within* sex categories are often unnoticed or noted only as an afterthought.[88] Second, health disparities between the sexes in

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[84] Steven Epstein, *Inclusion: the Politics of Difference in Medical Research* (Chicago: University of Chicago Press, 2007), 252-53.

[85] Susan Leigh Star, "Sex Differences and the Dichotomization of the Brain: Methods, Limits, and Problems in Research on Consciousness," in *Genes and Gender II*, ed. Ruth Hubbard and Marian Lowe (New York: Gordian Press, 1979).

[86] Judith Lorber, "Believing is Seeing: Biology as Ideology," *Gender & Society* 7, no. 4 (1993): 571.

[87] Epstein, *Inclusion*, 250.

[88] Epstein, *Inclusion*, 250.

research run the risk of being attributed to *biological* differences. By emphasizing sex and/or genetic differences, researchers risk overlooking the way that *social* and *cultural* differences contribute to determining health.[89] Findings ought to be situated within cultural contexts to best understand a phenomenon's occurrence.

While these concerns are well-founded and must be carefully weighed by biomedical researchers, equally as important are the ways in which women have both not been included or problematically been included in research. In the late 1970s and early 1980s, numerous inquiries and ethical investigations into state and federal biomedical research institutions found significant disparities between how men and women were being treated in all stages of and environments in the research process. For instance, in a study on the link between heart disease and caffeine, Harvard researchers recruited 45,000 men, but no women, despite the fact that heart disease is the leading cause of death among women in the United States.[90] In another, especially perplexing example, a Rockefeller University pilot study about the effect of obesity on breast and uterine cancers was conducted entirely on men.[91] In instances such as these, the reason for sex-inclusive research design becomes clear, as do the ways in which women have been left out of studies that have important implications for their health and well-being. However, it would be a mistake to assume that researchers had no barriers to designing sex-inclusive research during the AIDS epidemic.

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[89] Epstein, *Inclusion*, 254.
[90] Laurence and Weinhouse, *Outrageous Practices*, 61.
[91] Laurence and Weinhouse, *Outrageous Practices*, 61.

2.2.2 Historical Barriers to Women's Participation in Biomedical Research

During the era in which the Harvard and Rockefeller studies took place, researchers faced limitations on how women could be incorporated into research design, particularly those who received funding through the National Institutes of Health (NIH). These limitations were put into place by the Department of Health and Human Services and NIH after women experienced adverse reactions to thalidomide and diethylstilbestrol (DES) in the 1960s and 1970s.[92] Thalidomide—used to treat morning sickness—and DES—used to prevent miscarriage and premature labor—caused birth defects, cancers, and various reproductive abnormalities in the children of women prescribed these drugs during pregnancy. As a result, government agencies developed research guidelines to protect women and their fetuses. The earliest of these was the Food and Drug Administration's (FDA) *General Considerations for the Clinical Evaluation of Drugs* published in 1977 that restricted which women and when women could participate in drug trials. The FDA excluded all "women of childbearing potential" from Phase I[93] and early Phase II[94] trials, meaning that "approval of new drugs, devices, and interventions studied from that point forward was based almost solely on studies of men or postmenopausal women or both."[95] The FDA made exceptions only in cases where the disease was life-threatening or had severe morbidity.[96]

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[92] Regina M. Vidaver, et al. , "Women Subjects in NIH-Funded Clinical Research Literature: Lack of Progress in Both Representation and Analysis by Sex," *Journal of Women's Health & Gender-Based Medicine* 9, no. 5 (2000): 496.

[93] In Phase I, a small pool of research subjects, who are typically healthy or short-term patients. Researchers study preliminary effectiveness results, metabolism, and pharmacokinetics. Ruth B. Merkatz, et al. , "Women in Clinical Trials of New Drugs: A Change in Food and Drug Administration Policy," *The New England Journal of Medicine* 329, no. 4 (1993): 293.

[94] Phase II trials are the first controlled trials conducted on a few hundred subjects. These trials assess the drug's safety and effectiveness. Merkatz, "Women in Clinical Trials," 293.

[95] Vidaver, "Women Subjects," 496.

[96] J. Claude Bennett, "Inclusion of Women in Clinical Trials — Policies for Population Subgroups," *The New England Journal of Medicine* 329, no. 4 (1993): 289.

The NIH made two attempts to correct the problem of women's exclusion prior to the 1993 revision of the *General Considerations*. In 1985, the U.S. Public Health Service Task Force on Women's Health found that "the historical lack of research focus on women's health concerns has compromised the quality of health information available to women as well as the health care they receive."[97] This resulted in the NIH issuing "a policy urging the inclusion of women of childbearing potential[98] in federally funded clinical research."[99] However, women-inclusive research continued to be a problem. In 1990, the General Accounting Office (GAO) found that the NIH had not enforced their guidelines and women continued to be underrepresented in clinical research.[100] After the GAO report, NIH officials stated that "the agency's policy on expanding study populations was inadequately publicized as well as substantively feeble, simply recommending that investigators proposing studies 'consider' the inclusion of women and minority groups."[101] The NIH had "continued to review numerous proposals that either gave no information on the gender of their study populations, or proposed all-male studies without a rationale for doing so," and, despite not being mandated to adhere to the policy, "a small group of NIH staff still had 'disdain' for the policy encouraging inclusion."[102] Even when women had been included in research trials, GAO found that rarely were results analyzed according to sex.[103] In 1990, the NIH established new guidelines for grants that required women and minorities be included in research studies unless there was a justifiable reason to exclude them; however, these

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[97] Vidaver, "Women Subjects," 496.

[98] This restriction meant that only women who were surgically sterilized, had hysterectomies, or who were post-menopausal could be included in most drug trials. Because most studies placed an age limit of sixty-five on research participants, this further narrowed the pool of women capable of participating in trials. (Laurence and Weinhouse 72)

[99] Vidaver, "Women Subjects," 496.

[100] Vidaver, "Women Subjects," 496; Rebecca Dresser, "Wanted Single, White Male for Medical Research," *The Hastings Center Reports* 22, no. 1 (1992): 24.

[101] Dresser, "Wanted," 24; Laurence and Weinhouse, *Outrageous Practices*, 60.

[102] Dresser, "Wanted," 24.

[103] Vidaver, "Women Subjects," 486.

guidelines would not become law until the 1993 passage of the NIH Revitalization Act and not effective until 1994.[104]

Researchers and officials frequently relied on three common arguments to justify exclusionary research design. First, they argued that the more demographic information shared by research subjects, the more clearly effects can be attributed to the medical intervention under study. In addition to the variables introduced by a mixed-demographic research pool, the hormone changes associated with menstrual cycles would unnecessarily "complicate" a study.[105] Second, researchers cautioned against women's inclusion because women could become pregnant during the study. By excluding women, researchers felt they avoided risk of miscarriage and birth defects in participants as well as the legal ramifications of such effects.[106] Third, investigators cited difficulty recruiting women as a barrier to inclusion. However, recruitment issues may be attributed to the study population researchers have selected, the inability to recognize a disease in women, and claims that women were not interested in participating in research.[107]

Despite arguments that women-inclusive research complicates the research process and findings, over the past several decades researchers have discovered important, sex-based differences in treatment efficacy. Such differences occur in the "incidence, prevalence, symptoms, age at onset and severity" of a number of diseases, including, among others: rheumatoid arthritis, lupus, major depressive disorder, schizophrenia, asthma, and cancer.[108] For instance, research suggests that menstrual cycles can influence the effectiveness of asthma medication; different dosage may be required at different points in the cycle in order to prevent further increase in

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[104] Vidaver, "Women Subjects," 496.

[105] Dresser, "Wanted," 25.

[106] Dresser, "Wanted," 25.

[107] Dresser, "Wanted," 26.

[108] Alison M. Kim, Candace M. Tingen, and Teresa K. Woodruff, "Sex bias in trials and treatment must end," *Nature* 465 (2010): 688.

premenstrual, asthma-related deaths.[109] Propranolol—a drug used to treat conditions such as high blood pressure and irregular heart rate—metabolizes slower in women than in men, which may be due to hormonal regulation of metabolic enzymes.[110] Researchers have also discovered that it takes longer for drugs such as benzodiazepines, aspirin, and acetaminophen to clear from female bodies.[111] With documented differences in treatment efficacy, it becomes apparent that—when analyzed mindfully—sex is an important demographic characteristic that ought to be included in most research design. Otherwise, treatments are approved and available to significant portions of the population on whom such treatments have never been tested. In these instances, risk grows to include not a small sample of female research participants, but the entire female population.

2.2.3 Historical and Ongoing Challenges to Women's Health and Biomedical Research

The barriers to women-inclusive research practices have ties to how women's health has been situated in the United States more generally, especially to women's roles as mothers. Beginning in the early twentieth century, newly enfranchised women leveraged their position as mothers or future mothers to participate in public life and campaign for healthcare needs.[112] Thus, "any social benefits for women in these legislative victories were achieved through emphasizing their maternal role in the nation's hierarchy."[113] By the Depression Era, maternal and child health took on a social imperative as it was understood as a marker of societal wellness.[114] Though ensuring that poor women had access to healthcare was socially imperative, typically women only

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[109] Dresser, "Wanted," 27.

[110] Merkatz, "Women in Clinical Trials," 293.

[111] Merkatz, "Women in Clinical Trials," 293.

[112] Miranda Waggoner, *The Zero Trimester: Pre-pregnancy Care and the Politics of Reproductive Risk* (Oakland: University of California Press, 2017), 107.

[113] Waggoner, *The Zero Trimester*, 107.

[114] Waggoner, *The Zero Trimester*, 108.

had access to healthcare when they became pregnant.[115] With the passage of Title V in 1935 and the Social Security Act in 1965, women continued to be ensured comprehensive healthcare during pregnancy and as mothers.[116]

In her research on pre-pregnancy healthcare, Miranda Waggoner interviewed clinicians, public health experts, and researchers about the state of women's health and role that pregnancy plays in healthcare. One "distinguished expert" explained that, "We have been so reluctant in the United States to really elevate the importance of the health of women. And every time we even speak [about doing] it, it's always in the context of pregnancy. No one [seems] to really care about a woman's health unless she is pregnant. I mean if you examine, historically, the policies, once you become pregnant you get a lot of help but prior to that you're sort of out there on your own."[117] While women's health programs exist widely across the United States at every level of government, obstetrician and public-health expert Hani Atrash stated "There's no money [for women's health], there are no programs, there are no resources, there are no activities. We just have the name on the door."[118] Thus, in order to combat the fallout of a "real systematic under-investment in women's health" and politicians who "easily turn up their nose at women," experts have rhetorically finessed the discourse surrounding women's health to reframe it as pre-pregnancy or maternal health.[119]

The underinvestment of women's health can be most readily demonstrated through the NIH budget. In 1987—approximately six years into the AIDS crisis—the NIH budget only allowed 13.5 percent for the study of "diseases that exclusively, predominantly, or more seriously affect

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[115] Waggoner, *The Zero Trimester*, 108.
[116] Waggoner, *The Zero Trimester*, 108-09.
[117] Waggoner, *The Zero Trimester*, 117.
[118] Waggoner, *The Zero Trimester*, 120.
[119] Waggoner, *The Zero Trimester*, 119-20.

women, or that have different risk factors or treatments in women."[120] This is despite the fact that women used healthcare more than men. This 13.5 percent of the budget also went towards the study of breast cancer, all gynecological cancers, infertility, pregnancy, and contraception"[121] NIH research into fibroid tumors, endometriosis, menstrual cramps, and premenstrual syndrome effectively did not exist, nor did research into diseases that predominantly effected women, such as osteoporosis and Alzheimer's.[122] Despite being the only national institute to conduct research on contraception, infertility, and pregnancy, the National Institute of Child Health and Human Development received "only 5 percent of the total NIH budget and spends less than 10 percent of this on departments of [obstetrics and gynecology]."[123] In fact, women's health was so deprioritized at the NIH that the 1990 GAO audit revealed that only *three* gynecologists were on staff for the entire NIH in comparison to *thirty-nine* veterinarians.[124] This is particular egregious considering that gynecologic organs have held a preeminent place in women's health historically, accounting for all manner of diseases. The deprioritization further indicates a shift towards sex-blindness in biomedicine just before and throughout the AIDS crisis, resulting in women being in a unique position as disease sufferers in an epidemic.

2.2.4 Women's Exclusion from AIDS Research

The absence of research and funding for women's health remained a persistent problem in the AIDS epidemic. In the first several years of the epidemic, financial support for AIDS research was limited, and President Reagan did not include AIDS research in his budget until 1985.

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[120] Laurence and Weinhouse, *Outrageous Practices*, 63.
[121] Laurence and Weinhouse, *Outrageous Practices*, 62.
[122] Laurence and Weinhouse, *Outrageous Practices*, 62.
[123] Laurence and Weinhouse, *Outrageous Practices*, 62.
[124] Laurence and Weinhouse, *Outrageous Practices*, 62.

However, government budget restrictions at all levels could not necessarily account for other complications researchers cited as contributing to the erasure of women from the epidemic. For instance, between 1983 and 1984 Drs. Judith Cohen and Zena Stein both attempted to secure funding for research on women and AIDS. In their case, there was neither interest nor funding available for the project: "None from the city or county of San Francisco. None from the state of California. None from the university itself."[125] Cohen recalls her department chair telling her that "[s]tudying AIDS in women was a waste of time."[126] In another project, Dr. Zena Stein and Robin Flam, her graduate student, faced similar challenges to acquiring funding through the NIH and the American Foundation of AIDS Research (AMFAR). AMFAR rejected Stein and Flam's proposal on scientific grounds. Stein recalled that she could not understand what those scientific grounds were because "there were no scientific reasons for doing *any* of the studies except to look[;] so little was known about the new disease that *all* studies were speculative."[127] After repeated rejections, Stein and Flam stopped all projects related to AIDS and women.

A further complication arose when researchers finally secured funding for women: most research on AIDS in women was funneled through pediatrics. Given the storied history of women's reproductive organs taking preeminence in their healthcare and the rising anxiety over reproductive rights, the reason for situating women and AIDS research through pediatrics becomes clearer. Additionally, pediatric AIDS was a source of national interest,[128] and cases of AIDS in women could not be divorced entirely from that problem. Thus, researchers studied women and AIDS through women's roles as mothers, which can be easily demonstrated through organizational

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[125] Corea, *The Invisible Epidemic*, 25.

[126] Corea, *The Invisible Epidemic*, 24.

[127] Corea, *The Invisible Epidemic*, 39.

[128] When the CDC reported a small number of pediatric AIDS cases in December 1982, the announcement drew more media coverage than any other report about the epidemic since its beginning. Corea, *The Invisible Epidemic*, 16.

hierarchy. For instance, at the Massachusetts Department of Public Health, Maternal and Child Health included a subdivision focused on women's health.[129] Within the AIDS Clinical Trial Groups (ACTGs), Obstetrics and Gynecology was a subdivision of the Pediatric Committee. While nineteen ACTGs tracked treatment efficacy in children, *no* trial existed to track the effectiveness of treatments for AIDS and related OI in women.[130] Despite the immense focus on pediatric AIDS, there was a failure to recognize that pediatric AIDS cases were symptomatic of AIDS cases in women, not the inverse.[131] Except in certain circumstances like transfusion-transmitted cases, *all* infants born with HIV/AIDS had an infected mother, but not all mothers transmit the AIDS virus to their fetuses. Thus, cases of AIDS in women were greater than those pediatric cases that caused immense panic and warranted significant research funding.

Though significant barriers existed to drawing attention to the problem of women and AIDS, the media and research made some women visible. In 1984, for instance, Elizabeth Prophet—a young, African American woman who engaged in sex work and had a drug addiction—was brought to San Francisco General Hospital by police to be tested for AIDS. Though doctors refused to perform the test, Prophet's presence at the hospital was enough to cause alarm; the following day, on the front-page of local headlines, the public learned that AIDS might infect the male heterosexual community.[132] In the case of Prophet and countless women like her, it was not "[her] health that was a concern. It was the health of the men who used her."[133] By 1985, the association between sex workers and AIDS grew, dominating concerns about AIDS and women more generally. For instance, when Dr. Judith Cohen, Dr. Constance Wofsy, and Lori Hauer began

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[129] Corea, *The Invisible Epidemic*, 46.
[130] Corea, *The Invisible Epidemic*, 50.
[131] Corea, *The Invisible Epidemic*, 45.
[132] Corea, *The Invisible Epidemic*, 25-26.
[133] Corea, *The Invisible Epidemic*, 25-26.

a study of HIV in women in San Francisco, some of their male colleagues referred to it as "The Prostitute Study."[134] A year later when the data was presented in Paris at the International AIDS Conference, the study was perceived to offer valuable information on prostitutes and HIV.[135] So popular was "The Prostitute Study" that the researchers were invited to continue to give the presentation after the Paris conference.[136] Despite its designation, *fewer* than *one-third* of the study's 180 participants were sex workers, and sex work had *never* been a criterion for inclusion in the study.[137]

In the twentieth century, the United States demonstrated a lack of commitment to supporting biomedical research about women. Studies about women's healthcare remained underfunded or ignored, and women's health itself was compromised for the sake of a potential fetus. Even though a new epidemic emerged in the late twentieth century, the indifferent response from government and other research institutions persisted. In many instances in the AIDS crisis, women were overlooked or explicitly dismissed by researchers. When they were included in research, women appeared to be a secondary concern. Partly, this may have stemmed from institutional organization where women's health units were frequently housed within maternal and pediatric health divisions. This structure allowed women to be prioritized as mothers and how their health as mothers negatively or positively impacted their children's health. As is the case historically in health crises, women were included in interventions most frequently when their health directly affected the men or children in their lives.

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[134] Corea, *The Invisible Epidemic*, 44.
[135] Corea, *The Invisible Epidemic*, 44.
[136] Corea, *The Invisible Epidemic*, 44.
[137] Corea, *The Invisible Epidemic*, 44.

2.3 Conclusion

Biomedical responses to marginalized communities in the midst of emerging epidemics do not occur in a vacuum. Contemporary readers, myself included, may read the accounts of women with AIDS like Beverly or Rebecca Denison and be dismayed by doctors' dismissals of their very real symptoms. How, one might ask, does something like that happen in an emerging epidemic? In this chapter, I have offered brief historical accounts of the history of women's health in order to begin answering such a question. To contextualize biomedical responses to women with AIDS within the history of women's health is to demonstrate the centuries-long stain of sexism on healthcare. By tracing the evolution of biomedical sexism in its myriad manifestations, one better understands both how, in the face of an epidemic, biomedical experts reverted to sexist beliefs about women's health and how these same beliefs may affect current healthcare for women.

In the 1980s, longstanding, biomedical sexism manifested in several ways in response to the AIDS epidemic in women. First, I have argued that, for centuries, the biomedical community viewed a woman as nothing more than a man with a womb; with medical professionalization's rise, she lost her humanity, transforming from *a man with a womb* to simply *a womb*. In citing this history, I have asserted that the exclusion of research on women and AIDS is based on the historical belief that women are simply men with slightly different organs and to whom research performed on men can be applied. I have also claimed that the limited research conducted on women via pediatric AIDS research is a byproduct of the historical privileging of women's reproductive capacities. It was not the woman herself that is of value per se, but her ability to produce children for men and the nation more broadly. Therefore, her health was important in so far as it effects the health of her children. This period also marks an era where—when combined with the sexed and sexualized AIDS—women's biological and genetic differences from men were rendered so invisible that not even abnormalities in the once-privileged uterus or ovaries were under serious biomedical consideration. These conditions—the sexing of AIDS and decreasing prioritization of female sex organs—I suggest make the AIDS epidemic in the U.S. a particularly intriguing moment in the history of women's health.

Second, I have argued that the decade-long misdiagnosis and underdiagnosis of women in the AIDS epidemic has roots in the history of hysteria. While it is no longer a medical diagnosis, Americans still regularly use the term hysteria in a variety of ways to describe uncontrollable, perhaps even illogical, emotional responses. It remains a cultural touchstone with gendered nuances. Though the term itself became somewhat divorced from its medical context, hysteria's affective stickiness remained fixed to female patients and continued to characterize them as liars and hypochondriacs. Thus, doctors' assertions that physical symptoms were simply "all in her head" make much more sense when plotted along hysteria's history. Importantly, disbelief in women's accounts of their experiences does not occur only in biomedical contexts; it is instead part of a larger, cultural problem that we see most frequently appear during victim testimony. The medical complaint can be understood as a testimonial genre that shares remarkable similarities with legal testimony. However, where legal testimony is embedded in discourse of skepticism or doubt, the complaint falls into a discourse of objectivity. In both cases, women speak to an authority with the ability to render judgment about the truth of her embodied knowledge.

Though the response to women's healthcare in the AIDS epidemic in the U.S. was flawed, I close by suggesting that it is not a unique case in the history of women's health. What makes women in the AIDS crisis remarkable is the perfect storm of events that threw a combustible on the fire that is the extensive history of biomedical sexism. In this era, Ronald Reagan and the conservative party dominated the federal government, recent biomedical tragedies placed significant restrictions upon women and research, and the epidemic was first noticed in a marginalized community, ensuring limited public response. These factors among many more made the AIDS response in women less than what it might have been. Though the federal government eventually took steps to correct systemic issues preventing women from being recognized as having AIDS, the biomedical sexism problem exists. Recently, media has been flooded with accounts sexism and racism when it comes to such issues as maternal mortality,[138] chronic illness,[139] and women's pain.[140] In this chapter, I have made an intervention in the history of women's health by demonstrating how biomedical sexism influenced women's treatment in the AIDS epidemic, and this work can serve as a building block for other scholars addressing current problems.

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[138] Meaghan Winter, "A Matter of Life & Death: Why Are Black Women in the U.S. More Likely to Die During Childbirth?," *Essence*, 2017; P.R. Lockhart, "What Serena William's scary childbirth story says about medical treatment of black women," *Vox,* 2018, https://www.vox.com/identities/2018/1/11/16879984/serena-williams-childbirth-scare-black-women; Allyson Chiu, "Beyoncé, Serena Williams open up about potentially fatal childbirths, a problem especially for black mothers," *The Washington Post,* 2018, https://www.washingtonpost.com/news/morning-mix/wp/2018/08/07/beyonce-serena-williams-open-up-about-potentially-fatal-childbirths-a-problem-especially-for-black-mothers/.

[139] Nafissa Thompson-Spires, "On Telling Ugly Stories: Writing with a Chronic Illness," *The Paris Review*, 2018, https://www.theparisreview.org/blog/2018/04/09/on-telling-ugly-stories-writing-with-a-chronic-illness/; Jen Deerinwater, "Checkbox Colonization: The Erasure of Indigenous People In Chronic Illness," *bitchmedia*, 2018, https://www.bitchmedia.org/article/in-sickness/checkbox-colonization-erasure; Maya Dusenbery, "Doctors Told Her She Was Just Fat. She Actually Had Cancer.," *Cosmopolitan*, *Hearst Digital Media*, 2018.

[140] Tiana Clark, "PCOS. POC. Poetry. & Pilates: My body's alarm was going off, and I had to learn to listen to it.," *Lenny*, 2018, https://www.lennyletter.com/story/pcos-poc-poetry-and-pilates; Abby Norman, *Ask me About My Uterus: A Quest to Make Doctors Believe in Women's Pain* (New York, NY: Bold Type Books, 2018); Azmia Magane, "The Importance of Listening to Your Body—Even When Doctors Aren't Listening to You," *Allure*, 2019; Caroline Reilly, "It's All In Your Head: The Dangers of Disbelieving Female Pain," *bitchmedia,* 2018, https://www.bitchmedia.org/article/it's-all-your-head-dangers-disbelieving-female-pain-hearken; Joe Fassler, "How Doctors Take Women's Pain Less Seriously," *The Atlantic*, 2015, https://www.theatlantic.com/health/archive/2015/10/emergency-room-wait-times-sexism/410515/.

3.0 Rhetorical Legacies of "Gay Cancer": The Affective Influence of AIDS Media Coverage in Sexualizing an Epidemic

In December 1986, twenty-seven-year-old Penny Abernathy became a widow only eleven days after doctors diagnosed her husband with AIDS. Abernathy had seen AIDS specials on TV during her toddler's long hospital stay a few months prior and remembers thinking "Oh, those poor homosexuals."[1] At no point did these specials feature a woman. When she herself was diagnosed with AIDS that same December, Abernathy was shocked. She recalled: "If I had seen a woman on television like me saying, 'My husband died in eleven days because of something he did years before I married him and now I have the virus,' maybe I would have looked at Mark and said, 'Hey, bud, we need to get tested.'"[2] Abernathy's case illustrates the important role media can play about communicating risk in an epidemic. For Abernathy and women like her, the ability to identify oneself with a person in a newspaper or on nightly news coverage meant connecting oneself to a network of knowledge and acting upon this knowledge. However, the media had failed Abernathy in 1986. It was not that *no* information existed about women and AIDS at this time. Biomedical authorities consistently reminded the public that the AIDS virus did not discriminate along social groups.[3] Despite these expert warnings and despite changing epidemiological numbers, in both the media and American consciousness, AIDS continued to be framed as a gay man's disease.

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[1] Corea, *The Invisible Epidemic*, 75.

[2] Corea, *The Invisible Epidemic*, 75.

[3] Treichler and Warren, "Maybe Next Year," 111.

While no media has ever existed apart from others, the newsprint media in the early AIDS crisis was particularly interconnected across all media sizes—from small gay presses to the behemoth *New York Times* (*NYT*)—in ways that influenced how AIDS was reported to the American public. Though one could look at multiple kinds of print media to understand how the AIDS epidemic, this chapter focuses on major daily newspapers and wire services in the U.S. to understand how the media framed AIDS as a gay disease. I have chosen to emphasize these media for several reasons. First, newspapers and wire services first reported on what would become AIDS prior to any broadcast media. Second, newspapers and wire services, especially *NYT* and Associated Press (AP), can heavily influence what broadcast media reports. Third, the newspapers' communications and reliance on other newsprint media across size, location, and specialization offers strong evidence as to how AIDS' narrative framing took place. Finally, the print news media—in conjunction with the CDC's *Morbidity and Mortality Weekly Report* (*MMWR*)—almost always mark the beginning of the AIDS epidemic in any discussion of AIDS histories even nearly thirty years after the fact. Rarely do U.S.-focused histories explore the probable, initial "spillover" event that occurred in Kinshasa, Democratic Republic of the Congo in the 1920s,[4] nor do they begin with the 1969 death of Robert Rayford from AIDS,[5] nor do these histories start with the suspicious "junkie pneumonia" ravaging injection drug users in the 1970s.[6] Thus, though other alternatives exist, the U.S. narrative of the AIDS epidemic continues to be consistently portrayed

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[4] Jacques Pepin, *The Origin of AIDS* (Cambridge: Cambridge University Press, 2011); Tamara Giles-Vernick, et al., "Social History, Biology, and the Emergence of HIV in Colonial Africa," *Journal of African History* 54, no. 1 (2013).

[5] Gina Kolata, "Boy's 1969 Death Suggests AIDS Invaded U.S. Several Times," *The New York Times* (New York), October 28 1987, National, A; Theodore Kerr, "AIDS 1969: HIV, History, and Race," *Drain* 13, no. 2 (2016).

[6] Cindy Patton, *Inventing AIDS* (New York: Routledge, 1990), 27; Betty Williams, "Interview of Betty Williams," interview by Sarah Schulman, *ACT UP Oral History Project*, August 23, 2008, http://www.actuporalhistory.org/interviews/images/bwilliams.pdf; Cohen, *The Boundaries of Blackness: AIDS and the Breakdown of Black Politics*, 134-35.

as starting with the June 5th 1981 *MMWR*, the July 3rd, 1981 *NYT* article, and U.S. news print media more generally.

Bringing together rhetorical and onomastic traditions with affect theory, this chapter interrogates how early names for AIDS—those that existed before the Fall 1982 official naming of AIDS—were taken up by newspapers and wire services in the U.S. Wire services, in particular, are an important and often overlooked source for AIDS media coverage. For the many small and medium-sized newspapers which did not have science reporters across the country, AP and United Press International's (UPI) science coverage often offered the only expert coverage to which they had access. Even those major newspapers who did have science and medical writers sometimes relied on the wire services for reports.[7] In my analysis, I specifically focus on wire services—AP and UPI—and major metropolitan daily newspapers to understand the lifespan of "gay cancer." I argue that, though it only served to name AIDS for a year, the regular, rhetorical circulation of this name has generated what Sara Ahmed has referred to as "affective stickiness" for the American public that makes male homosexuality "stick to" AIDS. I further propose that this stickiness played a pivotal role in the public's inability to see women as at risk for AIDS even when early reporting did mention them.

I start this chapter with an overview of the theoretical literature informing my analysis. I first explore the rhetorical function of naming before moving onto an explanation of Ahmed's notion of "affective stickiness" and "affective economies." Then, I tie in rhetorical circulation in an effort to show the influence networks have on names and their affective charge. In the next section, I provide a brief history of how the newsprint media covered the AIDS crisis in the 1980s and demonstrate how they worked with and against one another to report on the epidemic. The

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[7] James Kinsella, *Covering the Plague: AIDS and the American Media* (New Brunswick, N.J.: Rutgers University Press, 1989), 56.

types of newsprint in this section go beyond what I examine in my archive analysis; however, my archive faithfully represents what was the general trend across most newsprint media at the time. My analysis of "gay cancer" across major daily newspapers and wire services shows that the name had a long life in the 1980s, peaking at three different points and, in the process, maintaining its affective attachment to gay men. After examining articles featuring the name "gay cancer," I conclude by remarking on the afterlife of this name in present day.

3.1 Rhetorics of Naming, Affective Stickiness, and Circulation

Before addressing how early names for AIDS circulated in the media, one must first understand what names do. John Algeo and Katie Algeo wrote that "[t]o name something, as far as human attention goes, is to make it. The unnamed is the unnoticed, and the unnoticed is for cognitive and communicative purposes nonexistent."[8] To put it another way, naming "allows us to define reality through language by acting as a field through which we view the world."[9] Phenomena, objects, and subjects only come into existence or reality in a meaningful way once they have been named. Implicitly, the one who names communicates that something or someone is worthy of communal attention by drawing attention to it via utterance. It is only through the process of naming, according to famous taxonomist Carl Linnaeus in *Philosophia Botanica*, that one can have access to knowledge about the phenomenon in question.[10] The *unnamed*, then,

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[8] John Algeo and Katie Algeo, "Onomastics as an Interdisciplinary Study," *Names* 38, no. 3/4 (2000): 265.

[9] Wendy Atkins-Sayre, "Naming Women: The Emergence of 'Ms.' as a Liberatory Title," *Women and Language* 28, no. 1 (2005): 9.

[10] Carl Linnaeus, *Philosophia Botanica,* trans. Stephen Freer (Oxford: Oxford University Press, 2003), 169.

becomes un-remarkable and fades into the backdrop of unknowable phenomena.[11] Given that to name is to bring something into being, the act of naming *does* something; it is not only an expression, but an *action*.[12] Such an act is implicated in power relationships. Onomastic theorists have argued that "bestowing a name is an act that indicates power because the individual being named is placed in a subject position and is often perceived as being of an inferior status to the one bestowing the name."[13] Thus, those who can name—those "who are in the position to legitimate meaning"—have the authority "to define the real," reducing all else to the "unreal, or nonexistent."[14]

The selection of certain phenomena as worthy of being named means that those named phenomena shape the way we understand the world. In *Language as Symbolic Action*, Kenneth Burke wrote that

> Not only does the nature of our terms affect the nature of our observations, in the sense that the terms direct the attention to one field rather than to another. Also, *many of the 'observations' are but implications of the particular terminology in terms of which the observations are made*. In brief, much that we take as observations about 'reality' may be but the spinning out of possibilities implicit in our particular choice of terms.[15]

Both by selecting those phenomena to be named and by affixing a name to them, some knowledge is created while other knowledge is foreclosed. Building upon Burke's terministic screen,

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[11] Julia T. Wood, "Telling Our Stories: Narratives as a Basis for Theorizing Sexual Harassment," *Journal of Applied Communication* 20 (1992): 352.

[12] Candice Chovanec Melzow, "Identification, Naming, and Rhetoric in *The Sky, the Stars, the Wilderness* and *The Maine Woods*," *Interdisciplinary Studies in Literature and Environment* 19, no. 2 (2012): 356; John L. Austin, *How to Do Things with Words* (Cambridge: Havard University Press, 1962); John R. Searle, *Speech Acts: An Essay in the Philosophy of Language* (New York: Cambridge University Press, 1969).

[13] Frank Nussel, *A Study of Names: A Guide to the Principles and Topics* (Westport: Greenwood, 1992), 3.

[14] Dale Spender, "Defining Reality: A Powerful Tool," in *Language and Power*, ed. Cheris Kramerae, Muriel Schultz, and William M. O'Barr (Beverly Hills: Sage Publications, 1984), 199.

[15] Kenneth Burke, *Language as Symbolic Action: Essays on Life, Literature, and Method* (Berkeley: University of California Press, 1966).

Campbell and Burkholder explained that "[a]lthough each terminology reflects reality, inevitably it is selective, mirroring only parts of reality. Thus, each terminology also deflects reality, directing attention away from some elements of the world and directing attention toward other elements."[16] Per Burke, the orientation provided by a name "is not an absolute, but a relationship to other characteristics."[17] Those characteristics highlighted by the name may create complex entanglements via association. Due to naming's influence on "our orientation to an object," what a phenomenon is named has considerable consequences.[18]

One way we see naming's consequences manifest is through its role in language and culture. Hayakawa explained that "[w]hen we name something, then, we are classifying. *The individual object or event we are naming, of course, has no name and belongs to no class until we put it in one*."[19] Labeling, classifying, and imposing standards via names are natural results of humanity's need to linguistically understand the world through sorting schema.[20] Importantly, such name-based classifications can be neutral. When functioning as labels, for instance, names may both serve to separate people and collectives—otherizing and silencing them in the process—or unite people under a common cause.[21] However, naming has been especially tied since Biblical times to having power or dominion over that which is nameable, particularly because to name is to have knowledge over the subject.[22] As a result, naming may be more closely associated with

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[16] Karlyn Kohrs Campbell and Thomas R. Burkholder, *Critiques of Contemporary Rhetoric* (Belmont: Wadsworth Publishing Company, 1997), 92.

[17] Kenneth Burke, *Permanence and Change: An Anatomy of Purpose* (Indianapolis: Bobbs-Merrill, 1965), 12.

[18] Melzow, "Identification," 359.

[19] Samuel I. Hayakawa, *Language in Thought and Action* (New York: Harcourt Brace Javanovich, Inc., 1978), 201.

[20] Melzow, "Identification," 357.

[21] Atkins-Sayre, "Naming Women," 8; Wood, "Telling Our Stories."; Maurice Charland, "Constituative Rhetoric: the Case of the Peuple Quebecois," *Quarterly Journal of Speech* 73 (1987); Gordon Nakagawa, "'No Japs Allowed': Negation and Naming as Subject-Constituting Strategies Reflected in Contemporary Stories of Japanese American Internment," *Communication Reports* 3 (1990).

[22] Melzow, "Identification," 356, 60.

power for negative ends. Despite the immense influence names have, like all language, names are subject to shifts in culture and society.[23] For instance, labels such as “queer” have been re-appropriated by some members of the LGBTQ+ community.

3.1.1 Names and Affective Stickiness

Not only do names help us organize our world, but they also bring affective connections as they become attached to worldly phenomena. For this project, the relationship between names and affect is one particularly important dynamic to consider for this reason. In her work about affect and disgust, Sara Ahmed wrote, “To name something as disgusting is not to make something out of nothing. But to say something is disgusting is still to ‘make something’; it generates a set of effects, which *then adhere as a disgusting object*.”[24] Building on existing theories of names, Ahmed argued that a name calls upon a history—that is to say, not *nothing*—that then changes the name’s object. Later, Ahmed added: “To name something as disgusting is not only to transfer the stickiness of the word ‘disgust’ to an object that then comes to stick, but also to the subject…the disgusted subject is ‘itself’ one of the effects that is generated by the speech act.”[25] Unlike the name theorists cited above, Ahmed has suggested that the act of naming also has consequences for the subject performing the act as it becomes bound in the naming’s affective effect. Just as the object is affectively charged, so too is the subject.

Ahmed characterized this affective effect as, what she has called, “affective stickiness.” Affective stickiness is “an effect of surfacing…*an effect of the histories of contact between bodies,*

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[23] Algeo and Algeo, “Onomastics as an Interdisciplinary Study,” 272.

[24] Sara Ahmed, *The Cultural Politics of Emotion*, Second ed. (Edinburgh: Edinburgh University Press, 2014), 93.

[25] Ahmed, *Cultural Politics*, 94.

objects, and signs…[S]tickiness depends on histories of contact that have already impressed upon the surface of the object."[26] That is, bodies, objects, and signs come into contact across history and that contact leaves behind a sticky residue. Future contact always builds upon the object's or sign's residual history. The sign's or object's sticky surface "*tells us a history of the object that is not dependent on the endurance of the quality of stickiness*" and indicates where the object has been historically.[27] Ahmed further explained that the stickiness

> is not the property of an object… [but] what sticks 'shows us' where the object has travelled through what it has gathered onto its surface, gatherings that become a part of the object… Stickiness then is about what objects do to other objects—it involves the transference of affect—but it is a relation of 'doing' in which there is not a distinction between passive or active.[28]

An object or sign's stickiness can both bind things together or create blockages in its affective circulation.[29] With regards to the articulation of signs specifically, affectively-charged signs no longer have to be uttered once the sign itself becomes sticky. Moreover, the stickiness itself can be difficult to interrupt once it becomes an intrinsic part of the sign. Ahmed explained, "The resistance [of the sign's stickiness] is not in the sign, but a 'sign' of how signs are already associated with other signs through metonymic proximity (word-to-word) or metaphoric displacement (word-for-word)… this historicity… is linked to repetition, to the very fact that signs must be repeatable."[30]

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[26] Ahmed, *Cultural Politics*, 90.
[27] Ahmed, *Cultural Politics*, 91.
[28] Ahmed, *Cultural Politics*, 91.
[29] Ahmed, *Cultural Politics*, 91.
[30] Ahmed, *Cultural Politics*, 93.

The sign's need for repetition or repeatability in order for stickiness to develop has led Ahmed to a theory of "affective economies," which has since been taken up by other scholars.[31] For Ahmed, affect *circulates and accumulates*—or sticks to—objects over time. She suggested that "[a]ffect does not reside in an object or sign, but is an effect of the circulation between objects and signs (=the accumulation of affective value over time). Some signs… increase in affective value as an effect of the movement between signs: the more they circulate, the more affective they become, and the more they appear to 'contain' affect."[32] In this sense, affect functions as a kind of capital in the economic sense. Furthermore, affect is "transssituational [sic] and transhistorical," gathering "disparate actions, sensations, and events" that influence our movements, beliefs, and social experiences.[33] The affective "currents" connect nonlinear moments, signs, and subjects that are "sometimes isolated and often unrecognized," leading to the overdetermination of discourse.[34] In this sense, "trace[s]" of history remain in circulation as names "[reopen] past histories of naming," the affective stickiness tearing away parts of history to bring them into present day.[35]

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[31] For examples of scholarship on affective economies, see: Senthorun Raj, "Grindring Bodies: Racial and Affective Economies of Online Queer Desire," *Critical Race and Whiteness Studies* 7, no. 2 (2011); Shirley Anne Tate, "Racial Affective Economies, Disalienation and 'Race Made Ordinary'," *Ethnic and Racial Studies* 37, no. 13 (2013); Mara Buchbinder and Stefan Timmermans, "Affective Economies and the Politics of Saving Babies' Lives," *Public Culture* 26, no. 1 (2014); Cheryl Lousley, "'With Love from Band Aid': Sentimental Exchange, Affective Economies, and Popular Globalism," *Emotion, Space and Society* 10 (2014); Shui-yin Yam, "Affective Economies and Alienizing Discourse: Citizenship and Maternity Tourism in Hong Kong," *Rhetoric Society Quarterly* 46, no. 5 (2016).

[32] Sara Ahmed, "Affective Economies," *Social Text* 22, no. 2 (2004): 120.

[33] Catherine Chaput, "Rhetorical Circulation in Late Capitalism: Neoliberalism and the Overdetermination of Affective Energy," *Philosophy & Rhetoric* 43, no. 1 (2010): 8; Louis Althusser, "Contradiction and Overdetermination," in *For Marx* (London: Verso, 1990), 101.

[34] Chaput, "Rhetorical Circulation," 7.

[35] Ahmed, "Affective Economies," 126, 31.

3.1.2 Names and Rhetorical Circulation

Much as with the case of affective economies, rhetoricians have argued that rhetorics also circulate. Rivers and Weber wrote that "[r]hetorics move and evolve."[36] Public address scholars have long since taken up theoretical approaches to circulation.[37] In *Publics and Counterpublics*, Michael Warner explored the constitutive nature of circulation, writing that publics are a self-organized "body of strangers united through the circulation of their discourse."[38] Due to its constitutive nature, circulation's interpretive communities "provide their own ways to evaluate and live their public lives based on the circulated texts that mesh with their civic mythos."[39] Circulation is not only a "transportation of ideas," but may involve "substantive maneuverings, retrofits, and commodifications."[40] It is "a rhetorical process that is contingent, partial, and context-bound."[41] It may be viral or slow in its social impact, but an important component of circulation is its ability of *persist*.[42]

Unlike classic configurations of rhetoric that take a linear approach, such as the rhetorical situation, scholars like Chris Mays have suggested that a "rhetoric-systems" approach may be more aptly suited to describe the way rhetorics flow. The rhetoric-systems approach is based on the work

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[36] Nathaniel A. Rivers and Ryan P. Weber, "Ecological, Pedagogical, Public Rhetoric," *College Composition and Communication* 63, no. 2 (2011): 194.

[37] See: Michael Warner, *Publics and Counterpublics* (Brooklyn: Zone Books, 2005); Michael Calvin McGee, "Text, Context, and the Fragmentation of Contemporary Culture," *Western Journal of Speech Communication* 54 (1990); Lester Olson, "Pictorial Representations of British America Resisting Rape: Rhetorical Re-Circulation of a Print Series Portraying the Boston Port Bill of 1774," *Rhetoric & Public Affairs* 12 (2009); Benjamin Lee and Edward LiPuma, "Cultures of Circulation: The Imaginations of Modernity," *Public Culture* 14 (2002); Mary E. Stuckey, "On Rhetorical Circulation," *Rhetoric & Public Affairs* 15, no. 4 (2012).

[38] Warner, *Publics and Counterpublics*, 86.

[39] Jason Edward Black, "Native Authenticity, Rhetorical Circulation, and Neocolonial Decay: The Case of Chief Seattle's Controversial Speech," *Rhetoric & Public Affairs* 15, no. 4 (2012): 638.

[40] Black, "Native Authenticity," 637.

[41] Christina M. Smith, "Theorizing Circulation in Visual Rhetoric Through Dorothea Lange's Images of Japanese American Internment," *Journal of Visual Literacy* 31, no. 2 (2012): 73.

[42] Jonathan L. Bradshaw, "Slow Circulation: The Ethics of Speed and Rhetorical Persistence " *Rhetoric Society Quarterly* 48, no. 5 (2018): 481.

of Deleuze and Guattari and De Landa. Deleuze and Guattari argued that the world consists of networks made up of flows that "produce phenomena of relative slowness and viscosity, or, on the contrary, of acceleration and rupture."[43] De Landa added that "What truly defines the real world… are neither uniform strata nor variable meshworks but the unformed and unstructured flows from which these two derive."[44] Informed by this work, Mays explained that rhetoric-systems allows us to

> [conceive] our arguments about the world (as well as the meanings and texts that reflect these arguments) as an interconnected set of relations wherein no individual rhetorical element in the system exists independently wherein the stability of each element is determined by, and helps determine, the stability of every other element. In such a system every movement of one of these elements affects and is affected by all of the others, and each of these linkages contributes to the stability of the whole; thus, in a rhetoric system each of our arguments and beliefs is connected to and reinforces all of the others.[45]

Importantly, rhetoric-systems allowed for the absence of movement and rhetorical affect within the system. For the purposes of this project, it is important to linger further over what appears to be the absence of circulation, but that we have seen is, in fact, just a different way of perceiving movement. According to Ahmed, flow only feels like motion when one is going *with* the flow; if one is moving against the flow, that flow feels like a blockage.[46] For instance, trauma is a type of blockage that consists of the "inability to mourn, to move from repetition to working-through."[47] Such stability, "stubborn beliefs," or affective trauma are "*evidence* of movement and rhetorical

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[43] Gilles Deleuze and Félix Guattari, *A Thousand Plateaus: Capitalism and Schizophrenia*, trans. Brian Massumi (Minneapolis: University of Minnesota Press, 1987).

[44] Manuel De Landa, *A Thousand Years of Nonlinear History* (New York: Zone, 1997), 260.

[45] Chris Mays, "From 'Flows' to 'Excess': On Stability, Stubbornness, and Blockage in Rhetorical Ecologies," *enculturation: a journal of rhetoric, writing, and culture* 19 (2015).

[46] Ahmed, *Cultural Politics*, 186-87.

[47] Marc Redfield, "What's in a Name-Date? Reflections on 9/11," *The Review of Education, Pedagogy, and Cultural Studies* 30, no. 3-4 (2008): 221.

effects."[48] The "tenacity" of stubborn beliefs indicates *persistence* and is "integral and [a] complex part of the way knowledge is created, sustained, and circulated in a rhetorical ecology."[49]

Rhetorical circulation theorists argue that the flow and connectivity between relations can be further understood through Althusserian overdetermination. Chaput argues that "rhetoric is an overdetermined space because no one situation affects future outcomes by itself: each situation contributes to change by collaborating with past beliefs, current (though often unclearly linked) instantiations, and imagined possibilities."[50] Rhetorical circulation is a supplement for the rhetorical situation—where the world is conceived of "a collection of sites that adds up to some rational whole"—as it makes sense of the "social world as a living totality of events that flow, change, and cohere in both predictable and unpredictable ways."[51] That which circulates between speakers, audiences, and events may be thought of as the "persuasive power affectively sustaining the overdetermined ecology of our life worlds."[52] This persuasive power circulates—"always passing through…never located"—to produce rhetorical value, which is measured through affect.[53]

3.1.3 Understanding Naming's Affective, Circulatory Force

Together theories of naming, affect, and circulation allow for an understanding of why names like "gay cancer" continue to be circulated nearly thirty years after the official naming of AIDS. To reiterate key points from above, names, or signs, bring phenomena into reality. Not only

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[48] Mays, "From 'Flows' to 'Excess'."
[49] Mays, "From 'Flows' to 'Excess'."
[50] Chaput, "Rhetorical Circulation," 12.
[51] Chaput, "Rhetorical Circulation," 12, 21.
[52] Chaput, "Rhetorical Circulation," 13.
[53] Chaput, "Rhetorical Circulation," 14.

do they indicate how the namer views the world, but they are also caught up in power dynamics that could, in some instances, negatively affectively charge them. In the case of "gay cancer," not only does the name identify the risk population and type of disease, but it also becomes stuck with affects and beliefs about cancer and gay men, the latter of whom already suffered significant social stigma. Stigma can be denoted by physical characteristics or by social clues. In his scholarship on AIDS tattoos, Dan Brouwer noted that "the 'negative characteristic' [leading to stigmatization] is an individual attribute, [and] the 'global devaluation' points to the social nature of stigma, or what Goffman calls a 'language of relationships.'"[54] Normativity is culturally determined, and through various stigmatizing social practices, the non-normative are punished in various psychological, social, or even physical ways.[55] This stigma, or negative affect, permits certain beliefs and allows those in privileged positions to make judgments about those suffering from "gay cancer."

Even when "gay cancer" became AIDS the affective entanglements sticking to the surface of "gay cancer" transfer to AIDS because that name refers to the same phenomenon in the world. Rhetorical circulation and systems further strengthen the nature of affective circulation, but also adds that these sticky signs not only touch other signs, but also larger arguments at the systems' periphery. For instance, the "gay cancer" node within the system may be activated in larger conversations about religious conservatism and signs of society's collapse or divine punishment. Finally, affect and rhetorical systems help explain why a term that functioned as a primary name for perhaps a year persisted for three decades. "Gay cancer" is not stagnant. The persistent circulation, I suggest, marks a need to return to a very brief moment that has limited collective memory to articulate a moment of traumatic unknowing.

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[54] Brouwer, "The Precarious Visibility," 117.

[55] Brouwer, "The Precarious Visibility," 117.

3.2 AIDS and the Press

Having assessed what names do as they circulate and their affective consequences, I now offer a detailed account of *where* and *how* AIDS news—including early names—appeared in U.S. media. Given its global impact, AIDS has been a source of interest for many media scholars, who have written about AIDS in international news,[56] in documentaries,[57] in U.S. nightly news,[58] and in alternative presses.[59] However, in this section I focus specifically on demonstrating the interconnectedness of three U.S. news outlets: (1) wire services, (2) major dailies, and (3) gay presses. Understanding how these media establishments became entangled will support my claim that, though women were present in some capacity in reporting as early as 1981,[60] the persistent framing of Kaposi's sarcoma (KS) and *Pneumocystis carinii* pneumonia (PCP) as "gay" cancer and "gay" pneumonia and later AIDS as a "gay" disease or "gay" plague implicitly rendered women invisible in the epidemic. This section concludes with an overview of how women did

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[56] Sydney Bryn Austin, "AIDS and Africa: United States Media and Racist Fantasy," *Cultural Critique* 14, no. Winter, 1989-1990 (1990); Nilanjana Bardhan, "Transnational AIDS-HIV News Narratives: A Critical Exploration of Overarching Frames," *Mass Communication & Society* 4, no. 3 (2001); Paul D'Angelo et al., "Framing of AIDS in Africa: Press-state Relations, HIV/AIDS News, and Journalistic Advocacy in Four Sub-Saharan Anglophone Newspapers," *Politics and the Life Sciences* 32, no. 2 (2013); Rebecca de Souza, "The Construction of HIV/AIDS in Indian Newspapers: A Frame Analysis," *Health Communication* 21, no. 3 (2007); Junling Gao et al., "Newspaper Coverage of HIV/AIDS in China from 2000 to 2010," *AIDS Care* 25, no. 9 (2013); Maria Nengeh Mensah and Thomas Haig, "Becoming Visible, Being Heard? Community Interpretations of First-person Stories about Living with HIV/AIDS in Quebec Daily Newspapers," *International Journal of Cultural Studies* 15, no. 2 (2012); Onjefu Okidu, "HIV/AIDS Communication in Four Nigerian Mainstream Newspapers," *Pan African Medical Journal* 17, 1 (2014).

[57] Juhasz, "The Contained Threat: Women in Mainstream AIDS Documentary."

[58] Colby and Cook, "Epidemics and Agendas: The Politics of Nightly News Coverage of AIDS."

[59] Jennifer Brier, "Locating Lesbian and Feminist Responses to AIDS, 1982-1984," *Women's Studies Quarterly* 35, no. 1 (2007); Brouwer, "Counterpublicity and Corporeality in HIV/AIDS Zines."; Evelynn Hammonds, "Race, Sex, and AIDS: The Construction of the 'Other'," *Radical America* 20, no. 6 (1987); Pickle, Quinn, and Brown, "HIV/AIDS Coverage in Black Newspapers, 1991-1996: Implications for Health Communication and Health Education."; Robin Stevens and Robert C. Hornick, "AIDS in Black And White: The Influence of Newspaper Coverage of HIV/AIDS on HIV/AIDS Testing Among African Americans and White Americans, 1993-2007," *Journal of Health Communication* 19, no. 8 (2014); Robin Stevens and Shawnika J. Hull, "The Colour of AIDS: An Analysis of Newspaper Coverage of HIV/AIDS in the United States from 1992-2007," *Critical Arts: A South-North Journal of Cultural & Media Studies* 27, no. 3 (2013).

[60] Jan Ziegler, "New Syndrome Can be Deadly for Homosexuals," *United Press International* (Boston), December 9 1981.

appear in news media when they did. However, before addressing each type of newsprint, I first discuss overarching trends in U.S. AIDS reporting in the 1980s.

3.2.1 AIDS and Media Trends

Scholars have suggested that AIDS' presence in the media during the 1980s may be best understood as phases in reporting trends. In their analysis on AIDS reporting, Dearing and Rogers proposed four phases: (1) the early era from June 1981 through April 1983; (2) the science era from May 1983 to June 1985; (3) the human era from July 1985 to January 1987; and (4) the political era from February 1987 until December 1988.[61] The early era—sometimes cited as the "gay plague" era—consisted of limited AIDS reporting, particularly by major American press institutions. Of the stories published in this period, 83% (1981) and 50% (1982) were devoted to the CDC's reports of a rare pneumonia and rare cancer affecting gay men.[62] During this time period, media portrayed AIDS as affecting only a small group of deviant individuals, gay men especially, who were reaping the consequences of their immorality.[63]

The science era of AIDS reporting began in 1983 with a publication by Dr. James Oleske in the *Journal of the American Medical Association* (*JAMA*) that was subsequently circulated widely by the press. This study suggested that routine household contact could lead to AIDS transmission based on Oleske's observation that babies born to high-risk parents were contracting

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[61] James W. Dearing and Everett M. Rogers, "AIDS and the Media Agenda," in *AIDS: A Communication Perspective*, ed. Timothy Edgar, Mary Anne Fitzpatrick, and Vicki S. Freimuth (New York: Routledge, 1992), 182. For international reporting trends, see: Deborah Lupton, *Moral Threats and Dangerous Desires: AIDS in the News Media* (Bristol, PA: Taylor & Francis, 1994).

[62] Mollyann Brodie et al., "AIDS at 21: Media Coverage of the HIV Epidemic 1981-2002," *Columbia Journalism Review*, Supplement, no. March/April (2004): 2.

[63] Edward Albert, "Illness and Deviance: the Response of the Press to AIDS," in *The Social Dimensions of AIDS: Method and Theory*, ed. Douglas A. Feldman and Thomas Malcolm Johnson (New York: Praeger, 1986), 13-14; Lupton, *Moral Threats*.

AIDS. No journalists questioned Oleske's study—despite Dr. Arye Rubinstein's publication in the same issue refuting the causal contact theory—and the American public was besieged with panic.[64] In addition to the routine contact theory, the Reagan Administration's response to the epidemic—though not Reagan's own response—made up 6% of national AIDS coverage.[65] During this era, American media's AIDS coverage increased over 600 percent.[66]

In July 1985, the human era of AIDS reporting started with the news that actor Rock Hudson was dying from AIDS. Now, Americans heretofore untouched by the epidemic could finally put a face to AIDS and began to understand that AIDS could "affect even all-American types" like Hudson.[67] By the year's end, the first reports of newborns with AIDS and the controversy over whether Ryan White, a 13-year-old HIV-positive boy, should be allowed to attend school perpetuated human interest stories in mainstream news.[68] Perhaps driven by the White story, news coverage about the blood supply peaked in 1985 at 15% of all AIDS stories.[69]

Finally, the political era of AIDS coverage reflected the increased concern of widespread HIV testing and privacy, President Reagan's first public recognition of the epidemic (garnering 8% of AIDS news coverage), and interest in heterosexual transmission.[70] Testing and privacy dominated the news media along with the annual International AIDS Conference held in San Francisco in 1990 (7% of AIDS news coverage).[71] The introduction of AZT in 1989 also provided

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[64] Kinsella, *Covering the Plague*, 107.

[65] Brodie et al., "AIDS at 21: Media Coverage of the HIV Epidemic 1981-2002," 2.

[66] Kinsella, *Covering the Plague*, 73.

[67] Dearing and Rogers, "AIDS and the Media Agenda," 182, 85; Kinsella, *Covering the Plague,* 4; Lupton, *Moral Threats,* 14.

[68] Dearing and Rogers, "AIDS and the Media Agenda," 185.

[69] Brodie et al., "AIDS at 21: Media Coverage of the HIV Epidemic 1981-2002."

[70] Everett M. Rogers, James W. Dearing, and Soonbum Chang, "AIDS in the 1980s: the Agenda-Setting Process for a Public Issue," *Journalism Monographs* 126 (1991); Timothy E. Cook and David C. Colby, "The Mass-Mediated Epidemic: the Poltiics of AIDS on the Nightly Network News," in *AIDS: the Making of a Chronic Illness*, ed. Elizabeth Fee and Daniel M. Fox (Berkeley: University of California Press, 1992); Dearing and Rogers, "AIDS and the Media Agenda," 187.

[71] Lupton, *Moral Threats,* 14.

a minor peak of coverage (5% of coverage); however, Brodie et al. noted that between 1987 through 1990, there were no major topics in AIDS coverage that outranked others.[72]

It would be disingenuous to say that all the print media outlets discussed below followed the same media trends across the decade. For instance, the gay presses had easier access to patient-focused stories by virtue of having gay reporters on staff; this is how self-proclaimed "AIDS Poster Boy" Bobbi Campbell came to write "Gay Cancer Journal" in the San Francisco's *Sentinel* in 1982. Yet, the contacts between the wire services, gay presses, and major dailies influenced what—and importantly *whose*—stories were being told. Attending to these similarities even with some variation helps explain why the "homosexual" frame was used so widely throughout media reporting in the 1980s.

3.2.2 Wire Services

AP and UPI are the two wire services most pertinent to understanding how wire services influenced the U.S. AIDS epidemic. Typically, AP broke news first and established a story's importance for media outlets across the world. In the 1980s, AP had 7,500 American members and served 10,000 media outlets globally, including newspaper, magazines, and news stations.[73] UPI, AP's closest competitor at the time, offered some reporting competition in the early 1980s, but the organization had limited subscribers—only 2,500—and had struggled economically since its start.[74]

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[72] Brodie et al., "AIDS at 21: Media Coverage of the HIV Epidemic 1981-2002," 2.

[73] Kinsella, *Covering the Plague*, 50.

[74] Kinsella, *Covering the Plague*, 49-50.

During the early years of the epidemic, AP and UPI took similar approaches their sources' origins and locations. Though AP began covering the epidemic months prior to UPI, both followed the epidemic's progression through the pages of the *MMWR, JAMA,* and the *New England Journal of Medicine* (*NEJM*).[75] However, correspondents from the wire services did not necessarily cover the same stories from these publications. For instance, stories that the AP's primary AIDS correspondent dismissed as not worth reporting would appear in UPI's wire service.[76] Like many other journalists, AP's correspondents and editors also followed various gay publications, including the *New York Native*.[77] However, neither AP nor UPI covered the epidemic from its epicenters—Los Angeles, San Francisco, and New York. Most of AP's early AIDS coverage was filed from offices in Atlanta, Boston, Washington D.C., and Daytona Beach.[78] These cities were home to major health organizations, medical research institutions, and medical conference centers, which, as James Kinsella suggested, accounted for the wire services' medically-influenced approach to AIDS coverage.

AP and UPI's ability to cover the epidemic was tied to both their personal approach to coverage and the rate of article publication in medical journals. Neither AP nor UPI showed much interest in the epidemic's earliest years. By the end of 1982, AP had filed nineteen stories and UPI only ten.[79] AP relied on CDC reports and medical journals as their sources, the latter of which were notoriously strict about authors' silence prior to publication and suffered from a year or longer publishing timeline. Where AP published more accurate and complete coverage—if a bit conservative in its approach—UPI was frequently behind on reporting and inaccurate when it did

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[75] Kinsella, *Covering the Plague*, 17-18, 49.
[76] Kinsella, *Covering the Plague*, 49.
[77] Kinsella, *Covering the Plague*, 45.
[78] Kinsella, *Covering the Plague*, 52.
[79] Kinsella, *Covering the Plague*, 55.

file an AIDS story.[80] For instance, UPI reported the epidemic began in San Francisco when in fact the first reports came out of Los Angeles followed by New York. UPI also referred to AIDS as the "gay plague" during a period when other risk groups began to emerge.[81]

Understanding AP and UPI's coverage is important given the pivotal wire services played in the media at this time. As I mentioned in the introduction to this chapter, most small and medium-sized newspapers relied on AP and UPI for expert coverage on science and health issues. Given their widespread influence, it is little wonder, then, why so many newspapers and media outlets failed to cover the AIDS epidemic closely. And when the media had begun reporting, they often relied on AP in particular to set the nature and tone of the coverage; thus, many stories about the infamous Patient Zero or the causal contact theory of spread came straight from AP.[82]

3.2.3 Major Dailies

The story of AIDS coverage in the U.S. major dailies is one mired in complications and unexpected reporting. While it is challenging to make broad statements about how each major daily handled the epidemic in the 1980s, Dennis Altman, in his 1987 *AIDS in the Mind of America*, suggested that

> the most extensive coverage has come in the *San Francisco Chronicle*; that other papers with good coverage have included the *Philadelphia Inquirer* and the *Los Angeles Herald*; that it has been largely neglected in the 'journals of opinion' such as *The Nation* or *The Public Interest*; and that the New York print media, which has a major impact on the rest of the country, has been uniformly disappointing in coming to terms with the epidemic.[83]

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[80] Kinsella, *Covering the Plague*, 54.

[81] Kinsella, *Covering the Plague*, 54.

[82] Kinsella, *Covering the Plague*, 58.

[83] Dennis Altman, *AIDS in the Mind of America: The Social, Political, and Psychological Impact of a New Epidemic* (New York: Anchor Books, 1987), 18-19.

Though he wrote his book only half a decade into the epidemic, Altman's assessment generally reflects the consensus of later scholarship. In their study of three major dailies—*NYT*, the *Washington Post* (*WaPo*), and the *Los Angeles Times* (*LAT*)—Rogers et al. argued that the NYT played a limited role in agenda-setting until 1987. In periods of relatively little media interest in the epidemic, such as pre-1983, *LAT* published more and gave greater visibility to AIDS stories than did *NYT*, making *LAT* and *WaPo* the primary agenda-setting[84] papers among the major dailies.[85] However, during major events like the announcement of Rock Hudson's death, *NYT* coverage outpaced other major dailies, and, by 1987, it would finally begin its extensive coverage of the epidemic and set the national agenda.[86] While not necessarily major agenda-setters, several less prominent publications offered early, cutting-edge reporting on the epidemic. In New York, Long Island's *Newsday* reported on the epidemic, but was ignored by *NYT*. Don Drake's AIDS reporting at the *Philadelphia Inquirer* did catch the attention of one *NYT* editor; however, the *Inquirer* did not make a significant difference in the *NYT* coverage.[87] In San Francisco, major dailies like the *Examiner* and the *Chronicle* wrote about AIDS prior to many of the gay presses, which Kinsella attributed to the unique "political clout" the gay community had in the city.[88] This reporting was summarily ignored by nationally recognized dailies.

As the closest publication America has to a paper of record, *NYT* warrants a more in-depth look in the context of AIDS coverage. In the early 1980s, *NYT* had a reach beyond any other American newspaper with 900,000 papers circulating daily, 1.5 million papers circulating on

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[84] Agenda-setting refers to the media's influence on which topics are deemed of national importance.
[85] Rogers, Dearing, and Chang, "AIDS in the 1980s: the Agenda-Setting Process for a Public Issue," 9-11.
[86] Rogers, Dearing, and Chang, "AIDS in the 1980s: the Agenda-Setting Process for a Public Issue," 9-10.
[87] Kinsella, *Covering the Plague*, 65.
[88] Kinsella, *Covering the Plague*, 35.

Sundays, and a staff of 7,300 people.[89] As I have previously addressed, *NYT* sets the agenda for many national publications and broadcast news outlets. However, that does not necessarily refer to the content these other outlets choose to cover so much as "the salience and credibility that other media decision makers attribute to the issues."[90] *NYT*'s reputation is further solidified due to its history of conservatism—or, its general disinterest in "breaking new ground"—and trustworthiness, which has resulted in media outlets viewing reports in *NYT* as fact.[91]

NYT had little interest in AIDS early in the epidemic as the editor at that time did not think news about gay men was appropriate for the publication.[92] In fact, reporters were not allowed to use the word gay in their articles unless they used it in quotations.[93] Due to this de-prioritization of "gay" issues, reporters would not follow up on leads about the gay community, including those about a deadly new disease, since it would do little for their careers at the paper.[94] Former CDC employee and *NYT* science writer Laurence Altman was the exception. Altman wrote several of the early AIDS reports at the *NYT* and had the medical knowledge to speak knowledgably about the CDC's reports. He may have covered the story in even more detail; however, Altman became distracted first by covering the medical angle of the Reagan assassination attempt and then was sent abroad to cover the Pope John Paul II assassination attempt where Altman broke both elbows.[95] These events ultimately prevented him from reporting in depth in 1981 on what would become AIDS. Though it demonstrate little interest in AIDS during its time as a "gay story" and "scientific story," *NYT*'s coverage increased when it became a governmental matter, and AIDS

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[89] Rodger Streitmatter, *Unspeakable: The Rise of the Gay and Lesbian Press in America* (Boston: Faber and Faber, 1995), 248.

[90] Dearing and Rogers, "AIDS and the Media Agenda," 183.

[91] Kinsella, *Covering the Plague*, 71, 82.

[92] Dearing and Rogers, "AIDS and the Media Agenda," 184.

[93] Dearing and Rogers, "AIDS and the Media Agenda," 184.

[94] Dearing and Rogers, "AIDS and the Media Agenda," 184.

[95] Dearing and Rogers, "AIDS and the Media Agenda," 184.

secured a spot on the front page on May 25, 1983 when the Assistant Secretary for Health and Human Services named AIDS the nation's number one health priority.[96]

While it lacks the clout of the *NYT*, San Francisco's *Chronicle* also requires further attention because it employed Randy Shilts, the most prolific AIDS journalist of his time and writer of *And the Band Played On*. In the early 1980s, the *Chronicle* was the "only major metropolitan daily in America with a reporter assigned to a 'gay beat.'"[97] This coverage had little to do with the paper's political leanings—it in fact often took a conservative stance on issues—and more to do with the political authority San Francisco's gay community earned in the 1970s.[98] The *Chronicle*'s initial AIDS reporting came via science writer David Perlman, who read the June 5 *MMWR* about a rare pneumonia killing gay men in Los Angeles and knew that San Francisco's gay population would be at risk; in response he penned "A Pneumonia That Strikes Gay Males."[99] Though early AIDS reports were limited, Perlman stayed abreast of the situation and attended meetings held by Dr. Marcus Conant, co-founder of San Francisco's first AIDS clinic.[100] When he arrived at the *Chronicle,* Randy Shilts saw an absence in Perlman's coverage thus far: it lacked the personal stories of those who were affected by the disease. For Shilts, this was an area in which he excelled. While not his first AIDS story in the *Chronicle,* Shilts wrote in the May 23rd, 1983 issue "Startling Finding on 'Gay Disease'," which was picked up by the wire services as well as some newspapers.[101] Such widespread coverage was odd at the time as the *Chronicle* was "perennially discounted by the Northeastern press establishment, and has long been considered a sensationalist

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[96] Kinsella, *Covering the Plague*, 71, 85.

[97] Kinsella, *Covering the Plague*, 164.

[98] Kinsella, *Covering the Plague*, 164.

[99] Richard A. McKay, *Patient Zero and the Making of the AIDS Epidemic* (Chicago: University of Chicago Press, 2017), 157; Kinsella, *Covering the Plague*, 164-65.

[100] Kinsella, *Covering the Plague*, 165.

[101] Kinsella, *Covering the Plague*, 169.

rag."[102] Throughout 1983 and 1984, Shilts became a controversial figure for his coverage of the bathhouse closures, and his journalistic ethics and flair for sensationalism called his reporting into question. Nevertheless, in 1987 Shilts published a narrativized account of the AIDS crisis, *And the Band Played On*, which enjoyed immense commercial success and made Shilts a celebrity.

Band did little to suggest that AIDS was anything but a gay disease and was the text that brought the cultural figure of "Patient Zero," a Canadian man named Gaetan Dugas, to life. Though only featured in a small portion of *Band*, Shilts' coverage of the man who allegedly brought AIDS to the U.S. became one of the most prolific stories to come from his journalistic account. Shilts portrayed Dugas as someone angry about his "gay cancer" diagnosis and who knowingly spread it to dozens of men in cities across the U.S. that he met through his work as a flight attendant. While criticism of Shilts and *Band* existed, it was not until recently that scholars began to put Shilts and *Band* in a different perspective and undo Dugas' misrepresentation in Shilts' "Patient Zero" story.[103] In his book-length project on Dugas, Richard McKay found that the identification of Dugas as "Patient Zero" had less to do with his prolific sex life than his amenability to helping authorities with contact tracing by offering his address book.[104] McKay also included accounts of Shilts distorting the AIDS timeline to make Dugas appear as if he knew his "cancer" was contagious; however, in reality, AIDS' cause had not yet been discovered and Dugas could not have known the harm he—and thousands of people like him—was doing by having unprotected sex.[105]

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[102] Kinsella, *Covering the Plague*, 181.

[103] For further publications on Shilts and Patient Zero, see: Priscilla Wald, *Contagious: Cultures, Carriers, and the Outbreak Narrative* (Durham, N.C.: Duke University Press, 2008); McKay, *Patient Zero and the Making of the AIDS Epidemic*.

[104] McKay, *Patient Zero and the Making of the AIDS Epidemic*, 267.

[105] McKay, *Patient Zero and the Making of the AIDS Epidemic*, 75, 239.

3.2.4 Gay Presses

Much like the major dailies, the gay press in the 1980s covered the epidemic with a wide array of approaches. Typically, in this era, the gay press functioned to bring tales of sex and humor to their neighborhoods with politics and news coverage a secondary priority for many papers.[106] On the east coast, New York was home to *Christopher Street* and the newly minted *New York Native*. The former took a sophisticated, literary-driven approach to documenting gay life where the latter was described as *Christopher Street*'s "sassy kid brother."[107] The *Washington Blade* in Washington D.C. was one of the few gay publications to focus more on politics and criticism than gay culture. Boston's leftist-aligned *Gay Community News* (*GCN*) was also one such politically minded publication and was the only major gay newspaper to privilege gay men and lesbians' voices equally.[108] The west coast was home to Los Angeles' *The Advocate*, the most successful and widely distributed of gay publications, and San Francisco's *Sentinel* and *Bay Area Reporter* (*BAR*), whose once cooperative approach to journalism turned into a bitter rivalry in the early 1980s.[109] While the combined circulation of gay and lesbian presses doubled to 800,000 from 1975 to 1985, most presses were only just beginning to achieve financial stability.[110] This led to many publications only being able to cover specific aspects of the epidemic. For instance, the *Native* covered medical developments, the *Blade* policy issues, and *GCN* legal and rights-based policy issues.[111] However, despite the limitations placed on the gay presses themselves, many gay

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[106] Kinsella, *Covering the Plague*, 25.
[107] Streitmatter, *Unspeakable*, 246.
[108] Streitmatter, *Unspeakable*, 247.
[109] Streitmatter, *Unspeakable*, 246.
[110] Streitmatter, *Unspeakable*, 247.
[111] Streitmatter, *Unspeakable*, 247.

journalists became sources for mainstream media journalists, particularly during the early years, because they often knew people directly involved in the stories.[112]

Among the most historically significant gay newspapers during the epidemic, the *Native*[113] had been in print for only half a year before the CDC first reported on what would become AIDS. Established in December 1980, the bi-weekly *Native* got its start reporting on gay news, entertainment, and erotica.[114] The *Native* had hired Dr. Lawrence Mass as a part-time reporter for the publication, and it was through a friend that Mass first heard about gay men hospitalized in intensive care with cases of *Pneumocystis* pneumonia.[115] On May 18th 1981, Mass published the first report on the epidemic in the United States in the *Native*, beating the CDC's *MMWR* article by two weeks.[116] Several months later in July, the *Native* would feature "gay cancer" as headline news for the small paper. Soon the *Native* became known as "The AIDS Paper" due to its extensive coverage of risk-behavior, social support organizations, and dangers of the potentially viral disease. Moreover, Mass became an important source for mainstream press journalists, including *NYT*'s Dr. Lawrence Mass, and was widely recognized as an authority on the epidemic by people such as Dr. James Curran at the CDC.[117] Mass' reporting boosted the *Native*'s readership, which resulted in some of the doctors at the forefront of the epidemic reading the nascent newspaper.[118] Unfortunately by mid-1983, Mass began to suffer from extreme exhaustion, anxiety, and depression; he stopped writing for the *Native* altogether and refused calls. The epidemic had taken

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[112] Kinsella, *Covering the Plague*, 45.

[113] The *Native* also published some of the early articles by prolific AIDS activist Larry Kramer that would later be included in his collected works *Reports from the Holocaust*. Kramer initially reached out to the *Native*'s Lawrence Mass in an effort to inform the public about KS. Kramer would also push the *Native*'s editor, Charles Ortleb, to speak out against government inaction. However, Ortleb's turn to conspiracy theories would ultimately fracture the relationship between Ortleb and Kramer. Kinsella, *Covering the Plague*, 29-32.

[114] Streitmatter, *Unspeakable*, 248.

[115] Streitmatter, *Unspeakable*, 248.

[116] Kinsella, *Covering the Plague*, 28.

[117] Kinsella, *Covering the Plague*, 33.

[118] Kinsella, *Covering the Plague*, 33.

its toll. Around this time, the *Native*'s reporting took a turn away from medical fact. *Native* editor Charles Ortleb grew fixated on an article published in *The Lancet* about a possible connection between AIDS and African Swine Fever Virus (ASFV). However, *The Lancet* was known to publish "more letters of far-flung theories" than its peer journals; the ASFV article was published in the "hypothesis" section of the journal where untested theories go and was written by someone with no experience researching AIDS.[119] Not even a visit from the conservative director of the CDC, offering an olive branch in the form of news of the AIDS' virus' discovery, could sway Ortleb from his ASFV origin theory.[120] The *Native's* reputation never recovered.

On the west coast, the three major gay presses had both the benefit of proximity to epicenters and being more established compared to the *Native*. Despite its associated editor having been one of the first men who died of AIDS and an immense circulation reach compared to other gay presses, the *Advocate* had limited interest in covering the epidemic, frequently reporting with skepticism and burying stories in the earliest years.[121] It would later feature a regular column, "The Helquist Report," that covered breaking medical news; however, the *Advocate* generally remained focused on reporting about gay culture and politics.[122] San Francisco-based *BAR*'s new editor imagined the paper as a "gay *National Enquirer*," resulting in little responsible journalism.[123] The second San Francisco newspaper, the *Sentinel*, achieved financial stability in 1981.[124] The paper featured one of the earliest columns written by someone with AIDS, Bobbi Campbell. The twenty-nine-year-old nurse's column on the *Sentinel*'s first page began: "I'm Bobbi Campbell and I have 'gay cancer.'"[125] Campbell's "Gay Cancer Journal" made him one of the most famous AIDS

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[119] Kinsella, *Covering the Plague*, 37.
[120] Kinsella, *Covering the Plague*, 40-41.
[121] Streitmatter, *Unspeakable*, 251.
[122] Streitmatter, *Unspeakable*, 250-51; Kinsella, *Covering the Plague*, 44.
[123] Streitmatter, *Unspeakable*, 251.
[124] Streitmatter, *Unspeakable*, 251.
[125] Streitmatter, *Unspeakable*, 263.

patients in the early epidemic, securing him public speeches, Congressional testimonies, and nightly news appearances.[126]

Despite their diverging practices, these West Coast publications ran into various issues with ad revenue, which influenced how it could cover the epidemic. As the leading gay publication in the U.S., the *Advocate* was not beholden to any single industry for its financial support; however, *BAR* and the *Sentinel* relied heavily on San Francisco bathhouses for advertisements. For this reason, *BAR* and the *Sentinel* had to tread carefully on how much blame to place on the bathhouses for AIDS' spread. Reporters such as Randy Shilts felt that *BAR*'s and the *Sentinel*'s unwillingness to challenge the bathhouses showed their cowardice; however, *BAR* reporter George Mendenhall framed the controversy differently: "We saw banning sex in the tubs as, with one stroke, losing everything Stonewall did for us. It meant, at the same time, pushing the gay press back twenty years to the time when we were operating hand-to-mouth. No way we'd let that happen. No way in Hell."[127] Mendenhall understood that San Francisco's gay press could not survive without the support of the bathhouses. His worst fears came to fruition during the lead up to the 1984 bathhouse closure controversy. With fewer men attending "the tubs," the bathhouses' revenues plummeted, which had a direct effect on the papers. The *Sentinel* was forced to cut its size from sixteen broadsheet pages to ten by the summer of 1983, and *BAR* fared no better.[128]

The final two publications worth addressing—Boston's *GCN* and D.C.'s *Washington Blade*—produced astute reporting for their specialized topics. The journalists at the *Blade* were particularly apt at "scooping" stories before mainstream or gay press could report due to its Washington insider connections. For instance, the *Blade* reported on the gay blood ban[129] weeks

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[126] Streitmatter, *Unspeakable*, 263-64.

[127] Streitmatter, *Unspeakable*, 253.

[128] Streitmatter, *Unspeakable*, 257.

[129] For a book-length account of the gay blood ban, see Bennett, *Banning Queer Blood*.

before major Washington newspapers or *NYT* even knew it was under consideration.[130] The *Blade* also took a skeptical approach to any promises of scientific advancement, especially with regards to the promised AIDS vaccine, unlike many of its peers.[131] In Boston, *GCN* offered in-depth coverage of AIDS discrimination cases. They also published weekly safe-sex guidelines, featured weekly stories by people living with AIDS, and circulated information about informational newsletters produced by people with AIDS.[132] Cindy Patton, who served as a *GCN* editor during this time, would write seven books on AIDS, including sex-focused texts such as *Women and AIDS* and *Last Served: Gendering the HIV Pandemic*.

3.2.5 Women, AIDS, and the News

This overview of three types of print media in the 1980s demonstrates what sort of media framing was possible in the early AIDS crisis due to the way each media was linked to the other. For instance, gay presses or dailies in usually less prominent cities such as Philadelphia and San Francisco led AIDS coverage over their more prestigious peers. Due to this earlier and better coverage, major metropolitan dailies relied on contacts at papers like the *Native* for tips or advice. This necessarily meant that, while the same story might be presented differently, nonetheless the same story was told. During this early era, there was also a trend by wire services and major dailies to focus their coverage on reports from medical journals and the CDC. While more “official” than human interest stories more prevalent in the gay presses, medical and CDC publications limited wire services and major dailies to a narrow set of publications with a very long time to press and

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[130] Streitmatter, *Unspeakable*, 259.
[131] Streitmatter, *Unspeakable*, 260.
[132] Streitmatter, *Unspeakable*, 293.

strict confidentiality rules. Lastly, publishing companies, whether great or small, are all in the business of *selling* news. Many papers, such as *NYT* and the *Chronicle*, were conservative leaning, which influenced both the stories and language they used in reporting. Beyond this tendency towards conservatism, however, is the reality that sensational stories grab the public's attention and sells newspapers. A mysterious cancer appearing in a derided, formerly pathologized community was intriguing. Therefore, it made sense for a variety of reasons *why* AIDS continued to be framed as a gay disease long after other it was seen in other groups of people.

As I argued in Chapter Two, women's absence from the AIDS epidemic aligns with much of women's health history. Those female scholars researching the AIDS epidemic and women have commented similarly on women's absence and why such absence may have occurred. Cindy Patton argued that gay men were a group who were able to became "hyper-visible in the grid of research, politics, and policy because their multiple designations align, cohere, and create a sense of a continuous body across institutional and community spaces."[133] Women disappeared because "there was no way to link up their fragmentary definitions into something that can hold a place in political representation."[134] Patton continues:

> 'Women' is too many things in the epidemic: epidemiology's 'partners of,' communities' 'other half,' and 'the general public's' move vulnerable part, the dangerous sexual outlaws who prey on wayward men. They are either a demographic exception (not gay men) or the idealized case where we can see the unbiased (by sexuality) 'truth' of the pathos of the epidemic. Simultaneously passive, innocent victim and monstrous, infectious sex organ, women do not yet have a voice that gives them purchase on the representational and medical systems that engulf them.[135]

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[133] Cindy Patton, "Women, Write, AIDS," in *Gendered Epidemic: Representations of Women in the Age of AIDS*, ed. Nancy L. Roth and Katie Hogan (New York: Routledge, 1998), xii-xiii.

[134] Patton, "Women, Write, AIDS," xii-xiii.

[135] Patton, "Women, Write, AIDS," xiii.

Effectively, women, according to Patton, were rhetorically positioned in too many roles, which led to fragmentation and the inability to cohere in the same way gay men could. While it offers a rationale for *why* women were absent, what remains is a question of why that absence was not noticed by the CDC and other federal agencies. Researchers have suggested that "Too often women are thought of as dispensable…and [their] dispensability as merely the natural order of things."[136] While harsh, there is some truth to the belief that women's lives are dispensable, particularly as those most affected by AIDS among women were women of color, poor women, and intravenous drug users—or, those at the greatest margins of society.

Patton's vital point about women and AIDS is that they were not entirely *absent* from all discussions and appearances in the media, but they existed in only fragmented capacities. This fragmentation may appear as absence; however, one should note that it does not mean absence altogether. In 1982, women were first reported as having AIDS-like symptoms, and in September—in the very update that first named the disease as "AIDS"—the *MMWR* included women in their assessment of AIDS cases for the first time.[137] Therefore, the media utilizing the *MMWR* as a reporting source would have been aware that women with AIDS existed. Moreover, the media did cover groups other than gay men even in the early years. For instance, though 100% of all stories about what would become AIDS 1981 were about gay men, this decreased the following year and would continue to do so throughout the 1980s.[138] While this does not mean that media was covering women in any greater percentage—and indeed they were not—what Brodie et al.'s study does suggest is that the American public had enough variety of story subjects that AIDS' gay male framing ought to have been challenged.

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[136] Treichler and Warren, "Maybe Next Year," 112.

[137] Treichler and Warren, "Maybe Next Year," 109, 15.

[138] Brodie et al., "AIDS at 21: Media Coverage of the HIV Epidemic 1981-2002," 5.

In their study on how women *were* portrayed by media across three media types, Treichler and Warren discovered that (1) women were present in early media, even if ambiguously; (2) mainstream media did not significantly cover AIDS and women; and (3) feminist publications did little to challenge mainstream media on their lack of coverage, to articulate their own understanding of why women ought to be concerned about AIDS, or to reframe the epidemic beyond the conservatism already characterizing it.[139] In those few instances when they were featured in the news, the media typically separated women into two categories. Women with AIDS who were white, married, and middle-class were shown as "safe" women, and all other women—sex workers, women of color, poor women, single mothers—were depicted as dangerous sources of infection.[140]

To summarize, information about women and AIDS existed in both medical and epidemiological data as well as in various types of media in the 1980s. Therefore, the reason for women's absence from media AIDS framing cannot be explained by a lack of information from those sources most cited by mainstream media and wire services. Though present in expert and news print media, the media's coverage of women and AIDS was remarkably limited. When represented, the media drew upon the virgin/whore binary trope to portray women with AIDS. Those women most at risk for AIDS were the very women who society often thinks of as disposable. If women were present in early media sources and if AIDS reporting increasingly focused on groups other than gay men as the 1980s progressed, the question remains as to how AIDS continued to be associated with gay men. By incorporating theories of affect and circulation, it becomes clear that this association may have persisted—and I argue that indeed it did—through the affective stickiness attached to AIDS in those early years. Within the rhetorical system, that

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[139] Treichler and Warren, "Maybe Next Year," 135.

[140] Juhasz, "The Contained Threat: Women in Mainstream AIDS Documentary," 27.

affect and framing was engaged even after the public's ideas about AIDS began to be called into question as media coverage expanded to show people with AIDS in different communities.

3.3 The Media Lifecycle of Gay Cancer: From Metonymy to Historical Marker

One can turn to a variety of primary source documents from this early period of AIDS reporting to begin to understand how the media unintentionally built affective networks within the rhetorical system surrounding AIDS. However, my case study focuses specifically on early names for AIDS, or "pre-AIDS names"[141] as vital components to building the dominant frame of AIDS as a homosexual disease. Because names function to bring a phenomenon into being, such rhetorical force is potent in the formation of framing. Even though that framing may be brought into question and old names fall into disuse, affect theorists have argued that the association still sticks to the surface of AIDS. As I will demonstrate in this section, the persistent use of early AIDS names to mark a point in time helps revitalize or strengthen the stickiness in public memory so that even in disuse these early names retain their rhetorical framing force.

3.3.1 Methodology

With no shortage of media sources to turn to in order to examine AIDS' names, this analysis focuses only on a small selection of possible primary sources for qualitative analysis. I began my research by searching in five online media databases: UPI's archive, Gale One, Gale

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[141] "Pre-AIDS names" refers to the period from 1981 to fall 1982 prior to the CDC's official naming of AIDS up until September 1982.

Primary Sources, National Newspapers, and Nexus Uni. These databases gave me access to papers and wire services such as the AP, UPI, *NYT*, *WaPo*, and *LAT* as well as various other national newspapers. In each database, I limited my date range to 1980 through 1992[142] and searched—both with and without quotations—the following well-documented early names for AIDS: gay cancer, gay plague, GRID, gay related immune deficiency. I also searched terms like "Kaposi's sarcoma" and "homosexual" together in order to collect those sources that may have not used early names or that may have referred to AIDS by another name that was less well known.

After amassing an archive of newspapers and wire service reports within these search limiters, I read the articles and collected data on the following: (1) date; (2) source; (3) location published (i.e. Boston, Atlanta); and (4) article title. I then added columns to my spreadsheet for the various names, opportunistic infections, and related descriptions of AIDS. Furthermore, I tracked any mention of women or women-specific diseases in these articles. Table 1 contains the results of my findings.[143] Based on these results, I selected one name—"gay cancer"—for closer analysis. I chose this name after excluding language found in the "common opportunistic infections" and "related diseases" column as this language did not quite speak to the pre-AIDS names themselves, but descriptions around and possible related conditions to AIDS. From the "early names" list, I chose to examine "gay cancer" more closely due to its long afterlife. For the sake of space, I did not select a "scientized name" for analysis.

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[142] As I mentioned in my introduction, the scope of this project ranges from 1981 to early 1993. Because I wanted to limit my results to the time period before gynecological abnormalities were included in the AIDS surveillance definition, I selected 1992 as my end year for newspaper coverage.

[143] In gathering this data, I never intended to present quantitative findings about early names for AIDS. While such a study would be interesting and should be done, I do not believe my data set contains the most complete set of sources required for such a task. My data instead lends itself to close textual analysis and general commentary on apparent trends.

Table 1. Results for AIDS Names and Related Language

Early Names	Common Opportunistic Infections	Scientific or Scientized Names	Related Diseases
Gay cancer Gay plague Gay pneumonia	Kaposi's Sarcoma Rare (Skin) Cancer *Pneumocystis carinii* pneumonia	Gay-related Immune Deficiency (GRID) AIDS-Related Complex (ARC) Kaposi's sarcoma and opportunistic infection syndrome (KSOI Syndrome) Immune Deficiency Syndrome (IDS)	Gay Bowel Syndrome (GBS) African Swine Fever Virus (ASFV)

3.3.2 Gay Cancer

One of the most prevalent names that appears in expert and non-expert coverage of AIDS' histories even into our contemporary moment is "gay cancer." Gay cancer is a misnomer for the cancerous lesion Kaposi's sarcoma, which prior to 1981 was typically seen in older men of Jewish and Mediterranean descent and not associated with homosexuality. However, the visibility of KS lesions along with posters featuring the cancer's images that circulated among the gay community in 1981 lead to gay cancer becoming a stand in for what would later be called AIDS. However prevalent the term many have been and continues to be, the history of gay cancer is a complex one with unexpected periods of media favor. In this section, I discuss gay cancer across three periods—1981-1986, 1987-1989, and 1990-1992—which correspond to moments when the term peaked in use in daily newspapers and wire services.

3.3.2.1 1981-1986

Though the scope of this chapter only includes major dailies and wire services, it is impossible to exclude gay presses when talking about gay cancer the earliest years of the epidemic. As early as July 18, 1981, Boston's *GCN* covered gay cancer in their section "News Notes." Under the heading "gay cancer," the unnamed author discusses Kaposi's sarcoma and shared characteristics among those with the cancer.[144] Importantly, this article, like several of those initial appearances of gay cancer in gay presses, only contains gay cancer in the headline.[145] The content of the articles themselves specifically talk about the appearance of Kaposi's sarcoma in gay men. Based upon this archive, evidence suggests that the name "gay cancer" originated as a shorthand in media publications for the much longer, more specific "rare forms of cancer found in gay men" or "Kaposi's in gay men" found within the articles.[146] While useful for print media that must be mindful of article length, the shift between shorthand and article content changes the meaning of the phenomenon significantly. In the latter case, a particular form of cancer is appearing for the first time in young, gay men. In the former case, the cancer itself becomes a possession of gay men, obscuring all other communities in which it might be found. Not long after gay cancer appeared in headlines, authors began to incorporate it into the article's body. Examples include "Bobbi Campbell, R.N., is writing a series for San Francisco's *Sentinel* on his struggle to overcome Kaposi's Sarcoma, commonly known as 'gay cancer'" and "The so-called Gay cancer in the news lately may be caused by a genetic flaw, said Dr. Fred S. Kantor, professor of medicine at Yale

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[144] "News Notes," in *Gay Community News* (July 18, Boston, MA, 1981).

[145] For further examples, see: Bill Stevenson, "The Gay Diseae Scare: Researchers Theorize on Causes of "Gay" Cancer, Pneumonia," in *Gaze* (September, Memphis, 1981); "Update on "Gay" Cancer and Pneumonia," in *Mom Guess What* (October, Sacramento, 1981); "Gay Radio Log KSAN Looks at 'Gay Cancer,'" in *Lambda News* (January 8, San Jose, 1982).

[146] "Gay Radio Log KSAN Looks at 'Gay Cancer.'"; Stevenson, "The Gay Diseae Scare: Researchers Theorize on Causes of "Gay" Cancer, Pneumonia."

University School of Medicine."[147] Prior to AIDS being named in September 1982, the Gale Primary Sources database lists forty-four gay periodicals across the U.S. in its collection that use the phrase gay cancer either in headlines or texts.

Though widespread in the gay community between 1981 and September 1982, gay cancer appeared far less frequently in major dailies and wire services. On March 31st, 1982, AP published the first article to mention gay cancer. AP science writer Warren Leary wrote, "There also are suggestions that recreational drug use may be a factor among gay cancer victims, [Dr. John L.] Ziegler said."[148] However, this was the only article to mention gay cancer prior to the CDC announcing the name "AIDS." Just after AIDS' naming, the *LAT* released the article "Gays Trying to Deal with Fear of Cancer." In it, author Japenga explained that "Dr. Michael Gottlieb, the UCLA physician who identified the original cases and has since become an authority on 'the gay cancer' (he objects to the term, 'It's unfair,' he says. 'It's also maudlin.') said the people who are most fearful are not those who already have the disease, but those who are desperately trying to avoid it."[149] This quote indicates that doctors like Gottlieb did not use "gay cancer" as a diagnosis or term, though later anecdotes and obituaries about people with AIDS sometimes suggested that they were given a diagnosis of "gay cancer."[150]

Between 1983 and 1986, uses of gay cancer were limited in mainstream press. On June 26th 1983, for instance, AP released an article that included the term, but otherwise it fell out of favor. However, this does not mean that the association between gay men and cancer stopped

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[147] "Cancer Blamed on Genetic Flaw," in *Update* (February 26, San Diego, 1982); Randy Alfred, "Dateline: San Francisco," in *Gazette* (December 24, Altanta, 1981).

[148] Warren Leary, "Doctors Link More Rare Cancers to Homosexuals," *Associated Press* (Daytona Beach, FL), March 31 1982.

[149] Ann Japenga, "Gays Trying to Deal with Fear of Cancer," *Los Angeles Times* (Los Angeles), September 29 1982.

[150] Burt A. Folkart, "Dan Turner; Offered Hope to Those with AIDS," *Los Angeles Times* (Los Angeles), June 6 1990.

circulating in the media; it had not. Nor does it mean that no other terms were used. Around this time, “gay plague” gained visibility in the press, helped along by Jerry Falwell’s assertion that AIDS was “a gay plague in this country.”[151] Gay plague also had more international appeal and appeared in several English-speaking newspapers globally. Thus, gay plague continued to do affective labor similar to gay cancer as did the appearance of gay men alongside reports of Kaposi’s sarcoma.

3.3.2.2 1987-1989

The 1987 through 1989 period marks the most significant shift in the history of gay cancer. During this time, gay cancer began to not only function as a description of KS, but also as a chronological marker in the narrative of AIDS’ history. That is, the name marks a time before AIDS was AIDS and instead known as gay cancer. The reemergence of gay cancer in the national media can be attributed to the publication of Randy Shilts’ *And the Band Played On*, which received national acclaim, and the creation of Patient Zero. To illustrate the temporal usage of gay cancer in discussing Shilts’ popular journalistic account of the epidemic, one can examine two national news reports. One *LAT* article described Shilts’ early career: “But by the early '80s, word of a new ‘gay cancer’ becoming a topic of nervous discussion. In May of 1982, Shilts wrote his first piece on the still mysterious illness. Later he became the first reporter in the country to be assigned to AIDS full time.”[152] An *NYT* report stated: “[Shilts] started to write stories about a mysterious ‘gay cancer.’ And when, in 1983, it became clear that it was a sexually transmitted disease of the immune system, Mr. Shilts, who could talk from personal experience about the

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[151] Sue Cross, “Falwell Wants Attack on “Gay Plague”,” *Associated Press* (Cincinnati), July 5 1983.

[152] Bob Sipchen, “The AIDS Chronicles: Randy Shilts Writes the Biography of an Epidemic and Finds More Bunglers Than Heroes,” *Los Angeles Times* (Los Angeles), October 9 1987.

promiscuous sexual behavior of gay men in San Francisco, concluded that 'clearly a disaster' was in the making."[153] Notably, in neither of these examples do the articles' writers challenge the name gay cancer or put it into a historical context to correct the idea that it solely affected gay men. The uptake of gay cancer as a historical marker further solidifies the association between AIDS and the gay community and obscures those who were also dying from it. This uptake adheres another layer of stickiness to the affective objects "AIDS" and "gay cancer," objects whose stickiness may have otherwise worn thin.

In addition to marking a moment in time, coverage of *Band* restored gay cancer as an alternative name for AIDS in the public conscious. In several articles by the AP, journalists recounted one of the most sensational pieces of the book—the introduction of Gaetan Dugas, Patient Zero, who Shilts claimed brought AIDS to the U.S. In one October article, AP reported that "Dugas would have sex with various partners in a San Francisco bathhouse and then turn up the lights to reveal purple lesions caused by the onset of Kaposi's sarcoma, a cancer associated with AIDS, Shilts writes. In one instance, [Dugas] said: 'Gay cancer. Maybe you'll get it too.'"[154] In this example, the term is juxtaposed with the scientific name for the cancer, perhaps indicating a lack of knowledge on Dugas' part. Another AP review of Shilts' Dugas subplot highlighted Dugas' supposed cavalier attitude towards his condition: "Dugas refused to believe that his 'gay cancer,' as he called it, could be spread sexually, telling a doctor, 'It's my right to do what I want with my body,' according to the book."[155] In both examples, the author portrayed "gay cancer" as a term that *Dugas* used specifically—"as he called it"—rather than contextualizing the name in its

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[153] Robert Reinhold, "AIDS Book Brings Fame to a Gay San Franciscan," *The New York Times* (New York), October 31 1987, 1.

[154] Rich Cartiere, "Book Says Inaction by Government and Gay Community Helped AIDS Spread," *Associated Press* (San Francisco), October 6 1987.

[155] Rich Cartiere, "Portrait of the Man who May Have Brought AIDS to North America," *Associated Press* (San Francisco), October 6 1987.

historical moment. Archival research suggests that many in the gay communities across the English-speaking world referred to KS as gay cancer. In these instances, it appears that gay cancer may serve to symbolically divide the scientifically knowledgeable Americans versus the uneducated foreigners entering the country and bringing disease. Here, foreigners like Dugas served as scapegoats.[156] Scapegoating is real or symbolic violence enacted on an individual to relieve a community of guilt by affixing blame. Anxiety over "the Other" entering the country to infect U.S. citizens contributed to such legislation as the 1987 ban on HIV-positive people traveling to the U.S.

Beyond the media coverage of Shilts' book, most references to gay cancer were used in the historical capacity to mark time. As I argued above, this returning—the circulation back to that very narrow period of time before AIDS has its official name—helped maintain the momentum and stickiness of the stick object "gay cancer." For example, 1988 *WaPo* article on AIDS survivors featured a story about Dan Turner: "When he was diagnosed Feb. 12, 1982, he was told he had 'gay cancer,' a mysterious new disease that seemed to single out homosexual men… the disease that would be known as acquired immune deficiency syndrome had not been named."[157] Though Turner's account suggested that he was told he had gay cancer and not Kaposi's sarcoma, my archival research into San Francisco Ward 5A's documents, specifically their necrology logbook,

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[156] For further exploration of scapegoating, see: Diane E. Goldstein, *Once Upon a Virus: AIDS Legends and Vernacular Risk Perception* (Logan: Utah State University Press, 2004); Barry Brummett, "Burkean Scapegoating, Mortification, and Transcendence in Presidential Campaign Rhetoric," *Central States Speech Journal* 32, no. 4 (1981); Theodore F. Sheckels, "The Rhetoric of Thabo Mbeki on HIV/AIDS: Strategic Scapegoating," *Howard Journal of Communication* 15, no. 2 (2004); René Girard, *The Scapegoat* (Baltimore: The Johns Hopkins University Press, 1986); Margaret Denike, "Scapegoat Racism and the Sacrificial Politics of 'Security'," *Journal of International Political Theory* 11, no. 1 (2015); Charlie Campbell, *Scapegoat: A History of Blaming Other People* (New York: Duckworth Overlook, 2011); Kenneth Burke, *Attitudes Toward History* (Berkeley: University of California Press, 1984); Burke, *Permanence and Change: An Anatomy of Purpose*; Kenneth Burke, *A Rhetoric of Motives* (Berkeley: University of California Press, 1969).

[157] Sandra G. Boodman, "AIDS Survivors: Beating the Odds; Unusual Longevity Inspires Optimism, Baffles Doctors," *The Washington Post*, February 8 1988, First.

suggests that medical professionals did not diagnose in such lay terms. More likely, Turner was told he had Kaposi's sarcoma, which he then translates for his audience (the reporter from *WaPo*) as gay cancer, the only word they had for AIDS back in 1982. In another example, author David Leavitt wrote in an *NYT* column about the moment AIDS entered his consciousness. Leavitt stated

> I was standing near the newsstand at the Oakland airport [in 1981], waiting for the plane…when I noticed a newspaper headline - something about 'gay cancer.' For a few seconds, anxiety buzzed around me, like a fly; then I brushed it away and got on the plane…. During the next several years, I was always able to recall it exactly, the way that people of my parents' generation could remember exactly what they were doing the moment they heard Kennedy had been shot.[158]

It is unclear what papers would have been on display in the airport in 1981 that might have been covering the emerging epidemic. Leavitt may have seen "gay cancer" specifically on the headline, though his phrase "something about" indicates that maybe the term was not so specific and that perhaps had read about a rare cancer in homosexuals. Regardless, the moment stuck in his memory: where he was, in which year, and what he was looking at—a newspaper with the headline "gay cancer."

3.3.2.3 1990-1992

Much like 1987, public events contributed to a sharp increase in the use of gay cancer in mainstream media in 1990. By far the most significant story was the release of *Longtime Companion*, an early film about AIDS that tracks the story of a group of friends from the day they read the July 3rd, 1981 *NYT* article about Kaposi's sarcoma. Media outlets reviewed the film, which is where some of the gay cancer appearances originate. For example, a *WaPo* review states that "[the film] starts with the innocuous 1981 New York Times article that spoke of a 'gay cancer,'

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[158] David Leavitt, "The Way I Live Now," *The New York Times* (New York), July 9 1989, 2.

and continues to the present, where friends and lovers have long since passed on."[159] The four other reviews present in the archive all offered a similar set-up where they situate the film's opening on Fire Island as the lead characters read the *Times* article about "gay cancer" to one another over the phone and in person. The issue with these reviews, however, is that at no point in the *Times* article in real life or in the fictional *Longtime Companion* does "gay cancer" as a term appear. The term's presence in these 1990 newspapers augments the language used in reality at worse and at best is a careless, sensational use of a term that might resonate better with readers than Kaposi's sarcoma may have. In either case, however, the historical rewriting of a momentous point in AIDS history brings back an outdated frame that perpetuates the connection between gay men and AIDS.

The second event that triggered the use of gay cancer was Dianne Feinstein's election campaign for governor of California. As mayor of San Francisco, Feinstein's political history is inextricably tied to the AIDS crisis. In some media framing, AIDS becomes part of Feinstein's legacy. *The San Diego Union-Tribune* wrote that "[Feinstein] inherited a city with a soaring crime rate, a $130 million budget shortfall, an increasing homeless population, and decreasing federal and state funds to provide housing and support mental hospitals. Most notably, she inherited a city that would soon learn of a deadly 'gay cancer.'"[160] However, gay cancer was also mentioned along with Feinstein due to her visit to an AIDS hospice center. The *LAT* coverage read: "Feinstein said she first heard of AIDS when, as mayor, leaders of the gay community 'came to me and told me about the terrifying and strange rumors of a so-called gay cancer.' Her administration quickly came up with $187,000 to investigate the reports, she said, the first public health funding for AIDS in

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[159] Desson Howe, "Capsule Reivews," *The Washington Post*, July 13 1990.

[160] Sharon Spivak, "A Political Parallel: Two Ex-Mayors who Would be Governer..and Feinstein's Days in San Francisco," *The San Diego Union-Tribute* (San Diego), September 21 1990.

the world."[161] A similar move was made in the two other articles about the hospice visit in the archive. However, one *San Diego Union-Tribune* report described Feinstein using the term in the present: "In the quiet of a hospice devoted to AIDS victims, Dianne Feinstein comforted the weak and underscored her commitment to turn the governor's office into a caring lobbyist for money to treat and research what she called 'gay cancer.'"[162] Juxtaposed with this language was a comment from one of the AIDS patients who told Feinstein "I have AIDS bad." It remains unclear in this example whether Feinstein actually said "gay cancer" or if that was another instance of journalistic shorthand that appears to have been somewhat prevalent in 1990s reporting.

From 1990 to 1992, gay cancer's usage appears most frequently in human interest stories to once again mark a point in the epidemic's time—the "before" AIDS period where the disease existed only as a collection of opportunistic infections. In 1991, the *LAT* featured a piece on how lives have changed since AIDS. The article recounts the summer of 1981 where "[Larry] Kramer and several friends went to Fire Island that 1981 Labor Day weekend to distribute articles about the mysterious new 'gay cancer' in gay neighborhoods and to collect money to support a fledgling new organization, Gay Men's Health Crisis."[163] An *NYT* article from 1992 features a story about a new immune disease like AIDS and those people who have it, including Alberto T. Alberto explained: "'I'm at a disadvantage because there have been 10 years of AIDS research and that has led to treatments and a whole infrastructure to confront AIDS,' he said. 'I may have to wait many years for any positive advances. It's like the first days of AIDS, when the first cases were believed

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[161] Bill Stall, "California Elections/Governer: Rivals Outline Proposals on AIDS, Drug Abuse; Feinstein: Democrat Vows to Accelerate Campaign Against Acquired Immune Deficiency Syndrome and to Seek More Help for Victims," *Los Angeles Times* (Los Angeles), September 7 1990, A.

[162] Sharon Spivak, "Feinstein Visits AIDS Hospice, Pledges to Lobby for Afflicted," *The San Diego Union-Tribune* (San Diego), September 7 1990.

[163] Marlene Cimons, "AIDS: 'It's Changed Us Forever'; Over a Decade, the Crisis has Brought Out Society's Best and Its Worst. It Also has Galvanized Gays, Energized Researchers and Made Scentists More Accountable," *Los Angeles Times* (Los Angeles), May 31 1991, A.

to be cancer, a gay cancer."[164] Alberto's use of gay cancer in this instance compared his present moment with a new immune disorder to that of the early years of AIDS when it was only a mysterious gay cancer. For Alberto, gay cancer marked a point in time that resurfaces with new medical mysteries. Like Patient Zero has transcended the AIDS epidemic, so too does gay cancer mark the first days of an epidemic.

3.4 Conclusion

The legacy of gay cancer exists in the present day, nearly forty years after the beginning of the AIDS epidemic. In a *WaPo* article from April 3, 2020, reporters Morgan and Yuan spoke to Ofole Mgbako, an infectious disease specialist at Columbia University, about the role inequality plays in getting people access to healthcare in the Covid-19 pandemic. They explain that Mgbako "noted that even today, decades after antiretroviral remedies, HIV infection is disproportionately prominent in the South and nationwide among black and Latino populations. Trump and others on the political right have labeled Covid-19 a 'Chinese virus.' Mgbako sees a parallel to the early designation of AIDS as a 'gay cancer.'"[165] The time period when AIDS was known as gay cancer was incredibly short—less than two years—before the CDC gave the syndrome its official name. Instead, more common phrases such as "rare cancer seen in homosexuals"—similar in wording, but vastly different in meaning—circulated more widely. While the name was widely used among gay presses, sources suggest that it had limited use in mainstream daily newspapers and wire

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[164] Mireya Navarro, "Immune Disease Mystery Leaves Patients in Limbo," *The New York Times* (New York), October 21 1992, A.

[165] Richard Morgan and Jada Yuan, "They Survived the HIV Crisis. Now New York's Aging Gay Population is Confronting Another Plague," *Washington Post* (New York), April 3 2020.

services up until the publication of Shilts' *And the Band Played On*. After *Band*, "gay cancer" took on a new role as a term that denoted a point in time where very little was known about the disease and people were dying quickly and without answers. The problem is, however, "gay cancer" was not always used in ways that reporters and media describe; the *NYT* article "Rare Cancer Seen in 41 Homosexuals" never used the name gay cancer like articles seven years later would imply.

I have argued in this chapter that the rhetorical afterlife of "gay cancer" in the late 1980s functioned to make the name "gay cancer" affectively sticky once again. Within the rhetoric-system of AIDS, myriad ways of sticking or identifying AIDS with homosexuality existed, and gay cancer was only one such way. The name revitalized the association between disease and community at a point in time when it was becoming more apparent that gay men were not the only people affected by AIDS. Women, communities of color, the poor, and intravenous drug users also suffered, often disproportionately, from AIDS. However, public action depends in large part on visibility, and the media is one such way of making something visible as is the language used by the media. Names *create* phenomena, and through associations become known to people. Though old associations stick and may sometimes even go unuttered, new associations can form within the system.

Despite the fact that women were present in early AIDS reporting and were never officially excluded from risk assessments, the news print media did not draw attention to AIDS in other vulnerable marginalized communities. For reasons associated with visibility and sensationalism, no strong affective ties could be built between women and AIDS in this period; AIDS would not "stick to" women in such a way as to make them appear as a community worthy of care. Moreover, the circulation of gay cancer as well as other gay-related AIDS for names increased the affective potency between AIDS and homosexuality. This is how in 1986 Penny Abernathy—the woman in this chapter’s opening anecdote—could see an AIDS special on TV and pity “those poor homosexuals.” This is also how Abernathy, five years into an epidemic, could be shocked to discover her husband had AIDS and so did she. There were no women on the TV specials, after all, and the women’s magazines made no mention of AIDS as a concern for women. It was a gay cancer, and surely that meant she was protected.

4.0 Women Who Do Not Count as Women: The CDC's AIDS Surveillance Definition and the Exclusionary Criteria that Defined an Epidemic

In January 1989, a twenty-one-year-old Latina woman known only as S.P. tested positive for HIV.[1] By mid-summer of that year, S.P.'s condition had declined rapidly. Her personal accounts and medical records indicate that she suffered from: pelvic inflammatory disease (PID), weight loss, headaches, shortness of breath, vomiting, chronic pelvic pain, constant burning in her uterus and vagina, recurring fever, nausea, severe anemia, cervical lesions, and a T-cell count[2] in the 200-300 range.[3] S.P. could not walk, sit, or stand for long periods of time due to the pain she experienced, and her doctor confirmed that she would not be able to work when her PID became symptomatic. In August 1989, S.P. filed for Supplemental Security Income (SSI) to support herself and her family; the SSA denied her application. Though S.P. was HIV-positive, she was *asymptomatic* according to SSA criteria and, as an administrative law judge stated upon her appeal, "her allegations of disabling pain lacked credibility."[4] Before her death in January 1994, S.P. would become the lead plaintiff in the class action lawsuit *S.P. v. Sullivan* that sued to expand the SSA's working definition of AIDS; however, her eventual victory would be too little, too late. In

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[1] Theresa M. McGovern, "S.P. v. Sullivan: The Effort to Broaden the Social Security Administration's Definition of AIDS," *Fordham Urban Law Journal* 21, no. 4 (1994): 1090.

[2] T-lymphocytes—also known as T-helper lymphocytes or "T-cells"—are vital to cellular immunity and protect against infections and cancers. HIV invades and kills T-helper cells, resulting in decreased immunity. Upon the development of a test, T-cell count became incorporated into the AIDS surveillance definition first in 1987 and revised later in 1992. Centers for Disease Control, "Revision of the CDC Surveillance Case Definition for Acquired Immunodeficiency Syndrome for National Reporting--United States," *Morbidity and Mortality Weekly Report* 36, Supplement (1987): 6S; Hung Y. Fan, Ross F. Conner, and Luis R. Villarreal, *AIDS: Science and Society*, Seventh ed. (Burlington, MA: Jones & Bartlett Learning, 2014), 39.

[3] McGovern, "S.P. v. Sullivan," 1090.

[4] McGovern, "S.P. v. Sullivan."

the interim, S.P. would lose custody of her children due to financial instability and inappropriate housing and would never be reunited with them before her death.[5]

S.P.'s case and the countless cases like hers illustrates a key issue for people with AIDS (PWAs) and activist allies in the late 1980s and early 1990s: the flawed CDC AIDS surveillance definition and its inappropriate appropriation by many government agencies and institutions. As S.P.'s case illustrates in this early era of AIDS, a person could test positive for HIV, but not meet the criteria to be considered an AIDS case.[6] Established by the CDC, AIDS criteria were based on the manifestations of AIDS in the first identified "risk group"[7]—gay men. These criteria included KS and PCP among other, more broadly termed, "opportunistic infections."[8] Once they were officially established in the CDC's first AIDS surveillance definition, revisions to AIDS disease manifestations changed in ways most benefited those who were already included.[9] However, as health professionals and activists would later observe, AIDS frequently manifested as different OIs in other populations in the form of tuberculosis, bacterial pneumonia, PID, and a range of gynecological and sexually transmitted diseases.[10] With epidemiologists' and clinicians' attention

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[5] McGovern, "S.P. v. Sullivan," 1095.

[6] I use "AIDS case" rather than "AIDS diagnosis" because I am talking specifically about how individuals were tracked by the CDC to develop statistics about the epidemic. As I will discuss extensively in this chapter, AIDS surveillance data represents who is seen by the CDC—for better or worse—and was coopted by varying institutions. Thus, AIDS diagnosis implies a clinical setting where the CDC AIDS definition was frequently used to determine if a patient had AIDS, but was not the exclusive determiner of diagnosis.

[7] The epidemic was first framed as occurring in four risk groups, the 4Hs: homosexuals, hemophiliacs, Haitians, and heroin (or intravenous drug users). Later, AIDS would be re-framed to be associated with certain risk *behaviors*, which more accurately reflected transmission routes.

[8] Centers for Disease Control, "Update on Acquired Immune Deficiency Syndrome (AIDS) -- United States," *Morbidity and Mortality Weekly Report* 31, no. 37 (1982).

[9] Centers for Disease Control, "Revision of the Case Definition of Acquired Immunodefiency Syndrome for National Reporting -- United States," *Morbidity and Mortality Weekly Report* 34, no. 25 (1985); Centers for Disease Control, "Update (1982)."

[10] McGovern, "S.P. v. Sullivan," 1087-88; Corea, *The Invisible Epidemic,* 76-78; Michelle Murrain, "Caught in the Crossfire: Women and the Search for the Magic Bullet," in *The Gender Politics of HIV/AIDS in Women: Perspectives on the Pandemic in the United States*, ed. Nancy Goldstein, and Jennifer L. Manlowe (New York: New York University Press, 1997), 64; Denenberg, "Unique Aspects of HIV Infection in Women," 32-35.

drawn to AIDS manifestations in gay men, those with other manifestations were more likely to be overlooked.

A core issue present in the development of AIDS definitions and their criteria is the nature of surveillance definitions and how the AIDS definitions specifically were taken up. As the arguments in *S.P. v. Sullivan* suggest, AIDS definitions were frequently charged with being too restrictive and exclusionary by the late 1980s; however, as epidemiologists would explain, case definitions were designed to be specific at the expense of "sensitivity."[11] The diseases appearing within the definition are those that are "rare in persons with normal immune systems" in order to avoid those diseases "found in large numbers of people who are not HIV-infected." [12] While not exclusively the case, often AIDS manifests as more common diseases in groups such as women and intravenous drug users as illustrated in the opening anecdote, which would result in those with more common disease manifestations unable to meet the criteria established by the CDC and the Council of State and Territorial Epidemiologists (CSTE).[13]

Additionally, upon the discovery of HIV and the development of an antibody test, a further surveillance complication arose. HIV surveillance and AIDS surveillance occurred separately until 2008 when AIDS became incorporated into HIV surveillance and classification.[14] In the United States, "the authority to require disease reporting is decentralized—states, territories, and

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[11] Carol Levine and Gary L. Stein, "What's in a Name - The Policy Implications of the CDC Definition of AIDS," *Law, Medicine & Health Care* 19 (1991): 279-80.

[12] Levine and Stein, "What's in a Name," 279-80.

[13] The Council of State and Territorial Epidemiologists is "an organization representing public health epidemiologists [that] establishes and periodically updates case definitions used in surveillance for nationally notifiable infectious disease." Nkuchia M. M'ikanatha et al., "Infectious Disease Surveillance: A Cornerstone for Prevention and Control," in *Infectious Disease Surveillance,* ed. Nkuchia M. M'ikanatha et al. (Hoboken, N.J.: Blackwell Publishing, 2013), 10.

[14] Eve D. Mokotoff and R. Luke Shouse, "Surveillance for human immunodeficiency virus infection in the USA," in *Infectious Disease Surveillance*, ed. Nkuchia M. M'ikanatha et al. (Hoboken, NJ: Blackwell Publishing, 2013), 305.

independent local authorities legislate reportable disease, and these vary by jurisdiction."[15] While some states diligently employed HIV *and* AIDS surveillance, other states[16] were resistant to HIV surveillance due to a lack of treatment and services and associated stigma and economic hardship due to job loss.[17] The surveillance inconsistencies across local and state jurisdictions created barriers to understanding both the scope of the HIV and AIDS epidemics, particularly across certain demographics. Despite efforts to ease privacy concerns by implementing a system of codes instead of using names in HIV reporting, the CDC would not accept coded cases for fear of duplication, adding a further challenge to capturing accurate epidemiological data.[18] The combination of restrictive definitions that did not include more commonplace diseases, separate tracking systems for HIV and AIDS, and uneven implementation of surveillance across state and territories led to a perfect storm of surveillance challenges that for many communities meant they were not being included in national data.

The problem of inaccurate data leads to a larger issue of who does and does not count in moments of public health crises and what it means to be excluded from definitions informing institutional response and intervention. While numerous ethical questions arise in discourse about the surveillance of vulnerable populations and opportunities for misuse, the AIDS epidemic in certain populations demonstrates a tangible example of the dangers and politics of *exclusion* from surveillance, a topic I address in greater detail in Chapter Five.[19] These dangers became clearer

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[15] M'ikanatha et al., "Infectious disease surveillance," 10.

[16] As an example of decentralization of disease reporting to the state-level during the crisis, New York—the state with the highest number of AIDS cases—did not collect data on HIV infections through at least 1991. Levine and Stein, "What's in a Name," 279.

[17] Mokotoff and Shouse, "Surveillance for human immunodeficiency virus infection in the USA," 305.

[18] It was not until April 2008 that all U.S. states and territories were equipped with confidential, name-based surveillance reporting. Mokotoff and Shouse, "Surveillance for human immunodeficiency virus infection in the USA," 305.

[19] For further discussion of public health surveillance and ethics and HIV/AIDS and ethics, please see: Amy L. Fairchild, "Dealing with Humpty Dumpty: Research, Practice, and the Ethics of Public Health Surveillance," *Journal of Law, Medicine & Ethics* 31 (2003); James F. Keenan, "Developments in Bioethics from the Perspective of

through the definitional misappropriation of the CDC surveillance definition by other government and medical institutions charged with intervening in the epidemic.

When they revised the AIDS definition in 1987, the CSTE and CDC described the definition's intended use: "The definition is intended only to provide consistent statistical data for public health purposes. Clinicians will not rely on this definition alone to diagnose serious disease caused by HIV infection… The diagnostic criteria accepted by the AIDS surveillance case definition should not be interpreted as the standard of good medical practice."[20] Despite this explicit statement, the CDC surveillance definition for AIDS would be used by "researchers, clinicians, hospital administrators, disability specialists, insurance administrators, health economists, legislators, social workers, policy makers, and the media," which would impact "entitlements and benefits, funding formulas, clinical research, medical care, and calculations of the costs of health care and social services."[21] Thus, diagnosis, disability benefits, and research relied upon the accuracy of a surveillance definition to capture the scope of an epidemic that was never meant to be relied upon for these services in the first place.

While there are several frames that can be employed to understand how the AIDS epidemic impacted women in the United States in its early years, these opening remarks offer definition as one such frame. In this chapter, I take seriously AIDS activist claims from the late 1980s and early 1990s that "[w]omen don't get AIDS[;] they just die from it" due to the CDC and CSTE's repeated

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HIV/AIDS," *Cambridge Quarterly of Healthcare Ethics* 14 (2005); Charles S. Bryan, "HIV/AIDS and Bioethics: Historical Perspective, Personal Retrospective," *Health Care Analysis* 10 (2002); Michael J. Selgelid, and Christian Enemark, "Infectious Diseases, Security and Ethics: The Case of HIV/AIDS," *Bioethics* 22, no. 9 (2008); Amy L. et al. Fairchild, "Privacy, Democracy and the Politics of Disease Surveillance," *Public Health Ethics* 1, no. 1 (2008); Lisa M. Lee, "Public Health Ethics Theory: Review and Path to Convergence," *Journal of Law, Medicine & Ethics* 40, no. 1 (2012); Angus Dawson, *Public Health Ethics: Key Concepts and Issues in Policy and Practice* (Cambridge: Cambridge University Press, 2012); S. Declich and A.O. Carter, "Public health surveillance: historical origins, methods and evaluation," *Bulletin of the World Health Organization* 72, no. 2 (1994).

[20] Centers for Disease Control, "Revision (1987)," S7.

[21] Levine and Stein, "What's in a Name," 278.

failure to include those diseases most frequently occurring in women in AIDS surveillance definitions.[22] In what follows, I suggest that definitions failed women in two ways. First, I argue AIDS definitions were exclusionary and unstable not only in the way they were used by the CDC for surveillance, but also in their creation. Second, I argue that despite the privileging of specificity over sensitivity, the definition contained rhetorical space to resolve some of these exclusionary practices. While the number of women who succumbed to AIDS in the United States is lost forever to history, understanding the importance of definitions in times of public health crises may offer a corrective in future epidemics.

To build these arguments, I proceed with the following structure. I begin by explaining what definitions are and what they do as theorized by rhetoricians. I then discuss activists concerns about and actions to repair AIDS definitions prior to 1993. Next, I perform a close textual analysis[23] of the 1982, 1985, and 1987 surveillance definitions of AIDS, which have been coded according to rhetorical topoi.[24] Here I argue for the flawed nature and instability of the definitions as they pertain to AIDS in women. Then, I briefly examine the appropriation of the AIDS definition, addressing the role of expertise and the issues with removing a definition from its context. Finally, I conclude by exploring the consequences of women's exclusion.

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[22] Women Don't Get AIDS (poster), undated. ACT UP Chicago. Records, [Box 15, Folder 5], Special Collections Research Center, University of Chicago Library.

[23] Close textual analysis is a methodological approach where scholars describe the form, content, and structure of a text and then interpret it, frequently through a theoretical lens.

[24] While I will address this more fully later in the chapter, *topoi* are common schemes or forms found in an argument's structure rather than its content. Examples of Aristotelian *topoi* include similarity/difference, degree, and cause/effect. For further description, see "topics of invention," Silva Rhetoricae, Birgham Young University, accessed January 5, 2019.

4.1 Definitions and Their Rhetoricity

Humans rely on definition to create and make sense of the world around them. To quote James E. Chesebro, "definitions size up situations, name the outstanding and structural ingredients of a situation, and label them in such a way that others perceive the attitudes which influence the definition of the situation."[25] Definitions consist of those situational characteristics that the definer deems worthy of distinction and frames the situation in a particular way for those experiencing it. This frame, then, is a strategy for understanding a situation, created by the definer intentionally or unintentionally.[26] As a tool to direct attention to certain aspects of a situation, definitions should not be understood as trivial, as static descriptions to be referenced, or as explanations in service of a particular argument.[27] Instead, definitions ought to be treated as arguments of their own and evaluated dialectically as such.[28] Importantly, when evaluating a definition as an argument, one must always attend to their situation and intended purpose.[29]

Due to their situatedness, definitions are bound by the circumstances from which they arise, meaning that they are often incomplete and only designed to deal with the context at hand.[30] In order to understand a definition, one must also understand its purpose within the context of an exchange and evaluate the definition accordingly.[31] In order to illustrate the importance of context, Douglas Walton drew on the examples of scientific, legal, and political definitions. Walton wrote, "a scientific definition should be seen as different from a legal definition, and both should be seen

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[25] James E. Chesebro, "Definition as a Rhetorical Strategy," *The Pennsylvania Speech Communication Annual* 41 (1985): 10.

[26] Chesebro, "Definition as a Rhetorical Strategy."

[27] Douglas Walton, "Persuasive Definitions and Public Policy Arguments," *Argumentation and Advocacy* 37 (2001): 120, 25-26.

[28] Walton, "Persuasive Definitions and Public Policy Arguments," 125.

[29] Walton, "Persuasive Definitions and Public Policy Arguments," 127.

[30] Chesebro, "Definition as a Rhetorical Strategy," 10.

[31] Walton, "Persuasive Definitions and Public Policy Arguments," 117, 25.

as different from a political definition… because it has a different purpose, and because the standards for evaluating it are, and should be, quite different."[32] Walton called the transfer of a definition between contexts "disturbing" as the important differences arising from context become obfuscated and the purposes for which the definition was developed—and, by extension, its consequences—have changed.[33]

As a result of their situatedness and inventive and framing capacities, definitions are inherently rhetorical. They "represent claims about how certain portions of the world *are*" through language, which, David Zarefsky has emphasized, is "not a neutral instrument."[34] Zarefsky further explained:

> [O]ur understanding of reality is not a given; it is something that we construct. The referents of any given situation are not clear and univocal; rather, they are constituted by the participants in an interaction. This process of construal is a central aspect of rhetorical invention. Since situations always can be construed in more than one way, the choice among points of reference is not neutral. Any definition is, in Kenneth Burke's phrase, both a selection and deflection of reality. Frame refers to the process of selecting one definition or perspective rather than another.[35]

The importance of selectivity to definition cannot be overstated; definers frequently have options in how they characterize a given situation, which necessarily means other characterizations may have been possible.[36] Through selection, those who define reveal what they deem to be important or significant in a certain time and place, revealing their attitudes about a phenomenon.[37] By

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[32] Walton, "Persuasive Definitions and Public Policy Arguments," 123.

[33] Walton, "Persuasive Definitions and Public Policy Arguments," 122.

[34] David Zarefsky, "Reagan's Safety Net for the Truly Needy: the Rhetorical Uses of Definition," *Central States Speech Journal* 35, no. 2 (1984): 113; Edward Schiappa, "Arguing About Definitions," *Argumentation* 7 (1993): 406, emphasis original.

[35] David Zarefsky, "Definitions" (paper presented at the Argument in a Time of Change: Definitions, Frameworks, and Critiques, University of Utah, 1997), 5.

[36] David Zarefsky, "Presidential Rhetoric and the Power of Definition," *Presidential Studies Quarterly* 34, no. 3 (2004): 611.

[37] Chesebro, "Definition as a Rhetorical Strategy," 10.

making the invisible visible or by bringing what was already visible into relief, definitions "[affect] the way we think, talk, and act about the realities for which they stand."[38]

As they have the ability to direct thoughts about reality, the consequences for defining are steep. To define a phenomenon means that the "severity of the condition is assessed, causality and blame are determined, and solutions are considered."[39] These results impact public opinion and allows those with the power to define to respond in particular ways.[40] Definition also "affects what counts as data for or against a proposal, highlights certain elements of the situation for use in arguments and obscures others, influences whether people will notice the situation and how they will handle it, describes causes and identifies remedies, and invites moral judgments about circumstances or individuals."[41] As they become established, definitions can empower and disempower and can be used in "a larger battle about values, politics, and often about money."[42] Importantly, once in use, altering or removing definitions becomes challenging and expensive.[43]

Among an array of disciplines and scholarly projects, definition has been theorized as serving a variety of functions across social, political, and scientific issues. In a review of the case study literature on definition generally and rhetoric of definition more specifically, five trends arise as important theoretical functions of definition: (1) marking boundaries, (2) rendering new concepts visible, (3) determining the ethics of a situation, (4) structuring and classifying in clinical settings, and (5) offering ways to understand social and political concepts. First, researchers have demonstrated that definitions function to mark boundaries in difficult social situations.[44] For

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[38] Zarefsky, "Definitions," 2,4.

[39] Zarefsky, "Definitions," 6.

[40] Zarefsky, "Definitions," 6.

[41] Zarefsky, "Presidential Rhetoric and the Power of Definition," 612.

[42] Walton, "Persuasive Definitions and Public Policy Arguments," 122.

[43] Walton, "Persuasive Definitions and Public Policy Arguments."

[44] Stuart J. Youngner, Robert M. Arnold, and Renie Schapiro, *The Definition of Death: Contemporary Controversies* (Baltimore: Johns Hopkins University Press, 1993).

instance, the distinction between when one biologically is or is not dead has become more complex with the rise of technoscientific intervention, but death might mean something different within legal jurisdiction. Second, defining renders new concepts visible such as hysteria or, more recently, homosexuality.[45] Third, definition serves a pivotal role in debates around ethics, including contemporary cases of stem cell research and the use of torture in the wake of 9/11.[46] Fourth, definition has close ties to medical professions where it is used to structure and classify in the service of health.[47] Lastly, definition is not only entrenched in the clinical, but has deep roots within political and social issues.[48] History is ripe with instances where identities that never existed before suddenly become not only socially significant, but entrenched in government policy, such as the construction of race and blackness.

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[45] Sabine Arnaud, *On Hysteria: The Invention of a Medical Category between 1670 and 1820* (Carbondale: The University of Chicago Press, 2015).

[46] John Lynch, *What are Stem Cells?: Definitions at the Intersection of Science and Politics* (Tuscaloosa: The University of Alabama Press, 2011); Michael Vicaro, “'A Liberal Use of Torture': Pain, Personhood, and Precedent in the U.S. Federal Definition of Torture,” *Rhetoric & Public Affairs* 14, no. 3 (2011); Jinee Lokaneeta, “A Rose by Another Name: Legal Definitions, Sanitized Terms, and Imagery of Torture in *24*,” *Law, Culture, and the Humanities* 6, no. 2 (2010).

[47] Sophia W. Chang, Mitchell H Katz, and Sandra R. Hernandez, “The New AIDS Case Definition: Implications for San Francisco,” *Journal of the American Medical Association* 267, no. 7 (1992); Alan E. Greenberg, et al., “Impact of the 1994 Expanded World Health Organization AIDS Case Definition on AIDS Surveillance in Unversity Hospitals and Tuberculosis Centers in Cote d'Ivoire,” *AIDS Care* 11, no. 1867-1872 (1997); Deepti Gurdasani, et al., “A Systematic Review of Extreme Phenotypes of HIV Control and Progression,” *AIDS* 28 (2014); Katie D. Schenk, et al., “Supporting Orphans and Vulnerable Children Affected by AIDS: Using Community-Generated Definitions to Explore Patterns of Children's Vulnerability in Zambia,” *AIDS Care* 20, no. 8 (2008); Aileen Clarke, “What is a Chronic Disease? The Effects of a Re-Definition in HIV and AIDS,” *Social Science and Medicine* 39, no. 4 (1994); Peter McTigue, “From Navas to Kaltoft: The European Court of Justice's Evolving Definition of Disability and the Implications for HIV-Positive Individuals,” *International Journal of Discrimination and the Law* 15, no. 4 (2015).

[48] F. James Davis, *Who is Black? One Nation's Definition* (University Park: Penn State Press, 2001); Lynn Clarke, “Contesting Definitional Authority in the Collective,” *Quarterly Journal of Speech* 91, no. 1 (2005); Shotwell, “‘Women Don’t Get AIDS’.”

4.2 Definitional Controversy: AIDS Activists and the Fight to Redefine an Epidemic

As Levine and Stein remind us in their 1991 article on the policy implications for AIDS definitions, "[d]isease classification systems and surveillance definitions are ordinarily tools for medical professionals, not matters for political debate and patient advocacy."[49] Yet, AIDS surveillance definitions during the epidemic's early years garnered much attention from AIDS activists. The implicit and likely unintentional exclusion of many women—except for that narrow percentage who could meet the requirements—occurred through infrastructural means within the surveillance system. By the time AIDS activists took their concerns to the CDC in the late 1980s and early 1990s, information about the epidemic's impact in women had already been lost. Moreover, the means through which to remedy the exclusionary practices suffered from contradictory rules. In order to get more OIs included in the definition, activists had to show proof that AIDS caused the OIs in these underrepresented populations. However, research parameters—including subjects—were determined by the surveillance definition. As a result, researchers were not producing the evidence that activists needed to change the definition *because* the definition needed to be changed in order for the research to be produced. It was an exemplary Catch-22. In this section, I offer a brief overview of the AIDS crisis from 1982-1987—the years between which definitional changes were made—and then identify the problems that occurred for women.

In late September 1982, the CDC released the first surveillance definition for the national reporting of AIDS cases, a little more than a year after the first AIDS cases were announced. As a syndrome, AIDS consists of a variety of indicator diseases—or opportunistic infections—that, when present, suggest a problem with one's immune function. In the earliest years of the epidemic,

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[49] Levine and Stein, "What's in a Name," 278.

the most visible indicator diseases for AIDS were KS, PCP, cryptococcal meningitis, and certain lymphomas.[50] Thus, the first definition was based on these early symptoms and the population in which they were found: gay men.[51] In 1985, the AIDs definition would change for the first time due to the discovery of the AIDS virus.[52] In addition to the 1982 indicator diseases, the CDC included certain cancers to the list and differentiated between indicator diseases with and without laboratory evidence.

Prior to 1987, the CDC would again bring together experts on AIDS to discuss what OIs they were seeing in PWAs. These experts included physicians who treated AIDS in children. Perhaps as a result of pediatric physicians' inclusion in the conversation, the 1987 AIDS definition included conditions only appearing in children with AIDS for the first time.[53] In addition to these conditions, the CDC "added HIV wasting syndrome, HIV dementia, and certain lymphomas…to the definition. The 1987 definition change now allowed physicians to 'presumptively diagnose AIDS in HIV-infected people… [meaning] physicians no longer had to order the expensive laboratory tests" to prove such conditions existed.[54] With the 1987 definition's implementation, AIDS rates in certain populations and rates of those who only met the 1987 rose considerably; these groups included people who were intravenous drug users, people of color, and women.[55]

The most significant problem that arose from developing an AIDS definition based on the symptoms in gay men was that the definition could then not account for the ways AIDS might

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[50] Corea, *The Invisible Epidemic*, 16-17.

[51] Corea, *The Invisible Epidemic*, 16-17, 76.

[52] In my conversations and email exchanges with him in 2019 and 2020, Dr. Arthur Ammann expressed confusion and frustration over the decision to continue to define AIDS by OIs rather than shifting entirely to tracking the HIV epidemic after the virus' discovery and testing became available. Ammann explained that HIV was the only disease to be defined by its end-stage manifestations and likened it to the equivalent of waiting until a cancer had reached stage four before seriously attending to it. While the situation was no doubt complex due to anxiety about testing, I am indebted to him for making this astute observation.

[53] Corea, *The Invisible Epidemic*, 76.

[54] Corea, *The Invisible Epidemic*, 77.

[55] Corea, *The Invisible Epidemic*, 77.

appear in other bodies. It is not a question that women also suffered from symptoms gay men did, such as PCP, but that the CDC did not attend to the sex-specific indicator disease that would appear only in female bodies.[56] These indicator diseases included: invasive cervical cancer, recurrent PID, vaginal candidiasis, and uterine tumors.[57] These diseases did not appear in the surveillance definition until 1993. Thus, any woman who had these OIs as AIDS symptoms were not officially counted as a PWA. In many cases, women died of AIDS-related Complex (ARC),[58] and ARC was not tracked by the CDC.[59] Several barriers existed that made efforts to include these sex-specific criteria remarkably challenging. First, on an interpersonal level, doctors might not believe women who reported having AIDS-like symptoms. For instance, when women went to the emergency room with PCP, doctors frequently diagnosed them with "upper respiratory infections" and discharged them. This was less often the case for men, who were more likely to be admitted with pneumonia or PCP.[60] As a result, "many more…women than the men experienced respiratory failure, ended up in the intensive care unit, and died."[61]

One means by which doctors might have come to believe women more readily and to think of AIDS would have been AIDS definitional criteria. Yet, criteria cannot be added without research to connect a disease to AIDS, which demonstrates a second barrier to the process of making AIDS definitions more inclusive. For many of these sex-specific diseases, the CDC stated that "there was not enough scientific data to justify adding these conditions" to the AIDS definition, yet research

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[56] Corea, *The Invisible Epidemic*, 42; Shotwell, "'Women Don't Get AIDS'," 519; Risa Denenberg, "What the Numbers Mean," in *Women, AIDS & Activism*, ed. ACTUP/NY Women & AIDS Book Collective (Boston, MA: South End Press, 1990), 34.

[57] Denenberg, "Unique Aspects of HIV Infection in Women," 33; Laurence and Weinhouse, *Outrageous Practices*, 147.

[58] ARC refers to the period when a PWA is no longer symptomatic, but did not yet fit the definitional criteria for AIDS.

[59] Denenberg, "Unique Aspects of HIV Infection in Women," 32.

[60] Corea, *The Invisible Epidemic*, 78.

[61] Corea, *The Invisible Epidemic*, 78.

into these diseases was grossly underfunded.[62] Activist efforts finally came to fruition in 1993 when invasive cervical cancer was included as the *one* sex-specific criterion in the redefinition, yet activists "remember that anecdotally Pelvic Inflammatory Disease seemed to be more prevalent than cervical cancer in HIV-positive women dying of opportunistic infections."[63] The question then arises as to why PID would be overlooked in favor of cervical cancer. The theorized answer: "there was no data from the scientific community on PIDS and HIV at that point, but there was some data about cervical cancer."[64]

4.3 Defining and Tracking AIDS Patients: Early Surveillance Definitions and Their Internal Failings

Having discussed the AIDS surveillance case definition history and its controversies, I now turn to the case definitions themselves to demonstrate how women were left out and what opportunities existed rhetorically to remedy women's exclusion. Specifically, I examine the 1982, 1985, and 1987 definitions as they appeared in the *MMWR*, both the definitions themselves and the context established in the larger article in which the definitions appear. I coded each article according to sixteen rhetorical *topoi*, and the resulting numbers were tallied for the article as a whole and just for the definition.[65] I then performed a close textual analysis on the *topoi* featured most prominently or those *topoi* that had numbers shift significantly between each definition.

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[62] Laurence and Weinhouse, *Outrageous Practices*, 147.

[63] Shotwell, "'Women Don't Get AIDS'," 519.

[64] Shotwell, "'Women Don't Get AIDS'," 520.

[65] The sixteen *topoi* used are as follows: existence/nonexistence of things, degree or quantity of things, spatial attributes, temporal attributes, motion or activity, abstract or physical form, physical or abstract substance, capacity to change, potency, desirability, feasibility, causality, correlation, genus-species relationships, similarity/dissimilarity, and possibility/impossibility.

Based on this methodology, I identified four issues that appeared in the definition articles that either contributed to the exclusion of women from the CDC definition or that were in tension with CDC efforts to only include the most severe diseases. In my discussion of Issues One and Two, I argue that the surveillance definitions where exclusionary and unstable in their construction. In Issues Three and Four, I argue that, despite the privileging of specificity over sensitivity, the definition contained rhetorical space to resolve some of these exclusionary practices.

4.3.1 Issue One: Definitional Inertia and Scientific Progress

The definitions' first weakness can be characterized as one of scientific progress and definitional inertia. It is most apparent in 1982 and 1985 definitions, making the issue present for at least the first seven years of the epidemic. The 1987 definition shared some of these characteristics, but its change was so significant that it requires separate consideration. Beginning with the 1982 definition, the CDC described what was and was not yet known about AIDS. As I explore further below, the first definition is marked by relative uncertainty since AIDS had been discovered just over a year prior and AIDS' cause had yet to be identified. By 1985 when the AIDS definition underwent its first revision, the revised definition was surrounded by discourse of scientific progress. However, the unstable definition written in 1982 received limited revision in practice. To articulate this problem more fully, I will first describe the initial 1982 AIDS definition and analyze its characteristics before offering a comparison to the 1985 definition to demonstrate the limited ways the definition changed despite advancements. I will then more clearly define how this issue undermines practices of inclusion.

4.3.1.1 Definitional Instability: the 1982 Surveillance Definition

The first AIDS surveillance definition appeared in the September 24th, 1982 issue of the CDC's *MMWR*, a little over a year since the first stirrings of a mysterious new illness.[66] Even then, AIDS only received passing mention on the first page. It was not until the third page that AIDS arises—"Update on Acquired Immune Deficiency Syndrome (AIDS) – United States"—beneath the title "Current Trends." The article's focus was not the AIDS surveillance definition, but a description of AIDS' current morbidity and mortality rates. The definition appeared on the following page—now the fourth page of the issue—in an "Editorial Note." It occupied several lines before being cut-off mid-sentence by several pages of tables detailing unrelated "cases of specified notifiable diseases" and reported deaths by city for the week. Four pages later, the definition picked up again and ended after several more descriptive lines. A short passage followed where the editor drew attention to AIDS morbidity and mortality rates in addition to tables that contained information about AIDS cases according to location and risk group.

While short in comparison to the later definitions, the first AIDS definition was dense and best explained by dividing it into three parts: the central definition, manifestations, and predictability. The first part, the substantive definition, was comprised of three sentences that offered an explicit description of what the CDC knew to be true about AIDS. The second part, the manifestations, served to qualify the definition and situate AIDS on a spectrum. The final part, predictability, spoke to the uncertainty of AIDS diagnoses.

The substantive definition was featured prominently in the first three sentences of the editorial note. It read:

> CDC defines a case of AIDS as a disease, at least moderately predictive of a defect in cell-mediated immunity, occurring in a person with no known

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[66] Centers for Disease Control, "Update (1982)."

> cause for diminished resistance to that disease. Such diseases include KS, PCP, and serious OOI. Diagnoses are considered to fit the case definition only if based on sufficiently reliable methods (generally histology or culture).[67]

The first sentence offered a succinct explanation of AIDS, identifying it as a problem occurring with cell-based immunity where individuals not typically at risk for certain diseases become at risk for unknown reasons. The second sentence then gave examples of these diseases in shorthand: Kaposi's Sarcoma (KS), *Pneumocystis carinii* pneumonia (PCP), and other opportunistic infections (OOI). In a footnote, the CDC expanded upon what they meant by OOI, giving a list of twenty-four additional "serious OOI" that included diseases such as pneumonia due to cryptococcosis, esophagitis due to cytomegalovirus, and progressive multifocal leukoencephalopathy.[68] Finally, the last sentence in the central definition determined appropriate methods for AIDS diagnosis. The CDC stated that reliable methods include histology—identifying a disease through tissue sample—or culture—identifying a disease through bacterial growth.

While the first part of the AIDS definition reads clearly, the second part becomes more muddled. Borrowing the term from the CDC, this second part of the definition can best be understood as a description of "the full spectrum of AIDS" and appeared as follows:

> However, this case definition may not include the full spectrum of AIDS manifestations, which may range from absence of symptoms (despite laboratory evidence of immune deficiency) to non-specific symptoms (e.g., fever, weight loss, generalized, persistent lymphadenopathy) (4) to specific diseases that are insufficiently predictive of cellular immunodeficiency to be included in incidence monitoring (e.g., tuberculosis, oral candidiasis, herpes zoster) to malignant neoplasms that cause, as well as result from, immunodeficiency.[69]

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[67] Centers for Disease Control, "Update (1982)," 508.

[68] Centers for Disease Control, "Update (1982)," 508.

[69] Centers for Disease Control, "Update (1982)," 508, 13.

This single sentence contained a lot of information, making it challenging to understand clearly compared to the central definition before it. To aid in understanding this section, I have plotted the full spectrum of AIDS as determined by the CDC in 1982 in Table 2 below. This spectrum should be understood as an addition to AIDS manifestations as described in the substantive definition.

Table 2. Full Spectrum of AIDS Manifestations (1982)

Full Spectrum of AIDS Manifestations			
Absence of Symptoms (despite lab evidence)	Non-Specific Symptoms	Specific Diseases Insufficiently Predictive	Malignant Neoplasms
	Including:	Including:	Including:
	Fever	Tuberculosis	Rare lymphomas
	Weight loss	Oral Candidiasis	
	Generalized Persistent Lymphadenopathy	Herpes Zoster	

While the table assists in understanding this part of the definition, it must be emphasized that these four categories that appear in the table as discreet are, in fact, general descriptions on a *spectrum* of AIDS.

This second part of the definition functioned to broaden the substantive definition's understanding. The diseases that appeared within the central definition were the most commonly observed diseases found in people with AIDS at that time; however, the CDC left room for other possibilities. The first point on the spectrum indicated that a patient might show lab evidence of infection, yet not have experienced any symptoms. The second point on the spectrum suggested that symptoms indicative of many diseases might also be indicative of AIDS, including fever, weight loss, and chronically abnormal lymph nodes. The third point moved towards specific diseases that may or may not have indicated AIDS infection. The final point marked certain rare blood and lymphatic cancers as possible early indicators of AIDS, as they could have been either a result of immunodeficiency or its cause.

The third and final part of the case definition emphasized AIDS' predictability as it was understood in 1982. This part responded to the full spectrum of AIDs manifestations, stating:

> Conversely, some patients who are considered AIDS cases on the basis of diseases only moderately predictive of cellular immunodeficiency may not actually be immunodeficient and may not be part of the current epidemic. Absence of a reliable, inexpensive, widely available test for AIDS, however, may make the working case definition the best currently available for incidence monitoring.[70]

If the purpose of the definition's second part was to expand the reader's understanding of how AIDS might manifest by suggesting a wide range of possibilities, the final part functioned to temper the likelihood of an AIDS case. The first sentence in this section explained that, due to the nature of AIDS as a syndrome, the diseases present might be non-AIDS-related. For instance, a patient with shingles may simply have shingles, unrelated to AIDS infection. The final sentence in this part addressed the current challenges of surveilling AIDS in the U.S. Though it presented its spectrum of manifestations with caveat that some diseases may not be AIDS-related, the CDC also emphasized that the surveillance definition as described, despite uncertainties, was currently the best way to track AIDS.

Having described the 1982 surveillance case definition, I now offer an analysis of the ways in which the definition articulated uncertainty, beginning with the substantive definition. The

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[70] Centers for Disease Control, "Update (1982)," 513.

editorial note containing the 1982 definition spanned nearly two hundred words, but only thirty-three of those words made up the substantive definition itself. The remainder served to expand or qualify the definition that preceded it. The substantive definition appeared in the first sentence of the editorial note: "CDC defines a case of AIDS as a disease, at least moderately predictive of a defect in cell-mediated immunity, occurring in a person with no known cause for diminished resistance to that disease."[71] The definition identified AIDS as consisting of a disease appearing in immune-compromised individuals who had no known reason for immune deficiency. Or, to state it another way, AIDS marked the presence of an immunity-related disease in someone who should not have that disease. As a single sentence summarizing AIDS, the definition presented a clear description of the syndrome and suggested a degree of confidence in its description by avoiding any language of uncertainty. For instance, the CDC could have written that "CDC currently defines" with the temporal marker signaling the potential for change in the future. Or, the definition might have read "a probable case of AIDS" or "likely occurring in a person" to signal some uncertainty about AIDS in its early days. However, the only signal of uncertainty in this opening sentence—"at least moderately predictive"—referred not to AIDS itself, but the nature of the disease experienced by the patient. As in, the disease was one indicative of a probable immune deficiency. While the single-sentence definition of AIDS was presented in this manner, the words that followed the definition—the remaining 158—were infused with a great deal of uncertainty that recharacterized the substantive definition as one of instability.

The uncertainty that reframed the substantive definition occurred through the use of *topoi* like presence, absence, and causality. These *topoi* appeared most frequently in the editorial note's "spectrum of AIDS manifestations" section. One end of the manifestation spectrum included the

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[71] Centers for Disease Control, "Update (1982)," 508.

"absence of symptoms (despite laboratory evidence)" where there are no symptoms experienced by a patient in whom disease is present. Another location on the spectrum included those with "non-specific symptoms" with an unknown cause. For those patients falling within this area of the spectrum, their symptoms could have been, the in the case of fever, indicative of AIDS or the common cold. Another area of the spectrum included "specific diseases that are insufficiently predictive of cellular immunodeficiency to be included in incidence monitoring." Again, a symptom or disease was identified, but the cause was unknown. The CDC could not include "insufficiently predictive" diseases in the formal definition because of uncertainty about underlying causes. Consequently, absences necessarily appeared in AIDS surveillance data. Finally, "Malignant neoplasms that cause, as well as result from, immunodeficiency" indicated another problem area of causality. In some cases, it was unclear which occurred first: cancer or immunodeficiency relating to AIDS.

Though the Spectrum of AIDS Manifestations contained the most instances of presence, absence, and causality, the definition's final part—predictability—offered further examples of these *topoi*. Here, the editor notes that some people who were categorized as AIDS patients "may not actually be immunodeficient and may not be part of the current epidemic." The presence of individuals without AIDS within surveillance reporting skewed monitoring reports. An additional absence also made gathering accurate data a challenge: the "absence of a reliable, inexpensive, widely available test for AIDS."

Having described the ways presence, absence, and causality revealed gaps of knowledge, I now briefly summarize my findings. First, where the substantive definition offers a clear, succinct explanation of how AIDS was defined in public health, the spectrum and predictability sections of the definition created uncertainty. The Spectrum of AIDS Manifestations place the clear substantive definition among qualifiers of uncertainty, including cases who were asymptomatic or whose had no known cause. These absences cast doubt on the CDC's ability to appropriately track the epidemic. This issue of epidemiological monitoring was further complicated in the section on predictability where the editor emphasized the fact that no reliable, easily accessible methods existed to track the epidemic with more accuracy. The editor then conceded that some patients with AIDS-like symptoms were likely being counted within AIDS morbidity and mortality reports when they should not have been. As I will explain in more detail later, the issues with presence, absence, and causal *topoi* make it appear as if the CDC was certain about far fewer characteristics than it initially appeared.

The second and most pervasive characteristic of the definition was the immense reliance on degrees to frame AIDS. Noun modification by degrees occurred throughout the definition, even within the substantive definition itself. In part one, AIDS was characterized by "diminished resistance" to disease and identified "serious [other opportunistic infections]" as an indicator of AIDS infection. Additionally, the editor noted that currently cultures and histology— "sufficiently reliable" methods—could be used to determine an AIDS case. When discussing the Spectrum of AIDS Manifestations, the editor mentioned the "full spectrum of AIDS," and "disease that are insufficiently predictive" of AIDS. Also, throughout this section and the last, "immune deficient" and "immunodeficiency" were used, indicating an inadequacy of the immune system to fight the diseases presently in the body. In the third part, "some patients" were identified as PWAs because the diseases they were experiencing were "only moderately predictive" of immunodeficiency. Without a test for AIDS, the case definition was "the best currently available" for disease surveillance.

At least two observations can be made about the presence of degrees in the definition. First, most of the nouns being modified by degrees were being modified negatively. In cases such as "diminished resistance" and "serious OOI," the degrees functioned to create a sense of urgency about the epidemic. People's resistance was diminished, yet the infections they face were both serious and opportunistic. In the cases of "some patients" and "only moderately predictive," the degrees emphasized uncertainty; "some" unknown amount of people may have been mistakenly identified as having AIDS due to diseases that could "only moderately" predict an AIDS infection. The only moment of positive degree modification—"the best currently available"—had the temporal attribute "currently", which suggests the definition, despite its uncertainty, was the best the CDC had to work with *now*.

The second observation about the role of degrees in the definition is that they functioned to create a significant amount of uncertainty, especially along with the presence, absence, and causality issues presented above. It was not unreasonable to be uncertain about AIDS in 1982, so I do not mean to portray uncertainty necessarily negatively. Yet, it must be noted that the substantive definition spoke to the very narrow area of certainty the CDC could claim on the Spectrum of AIDS Manifestations. The information beyond the substantive definition indicated the vast amount of information the CDC did not currently have access to about AIDS in these early stages. Importantly, within this vast realm of uncertainty, the CDC admitted that the definition was currently structured in such a way to include people who should not have been included and to exclude people who should have been included but could not be due to the absence of reliable testing. The 1982 definition was the grounds from which later definitions were built, and these later definitions had the ability to revisit and reassess the issues of inclusion and exclusion as they appeared in this first definition.

4.3.1.2 Progress and Inertia: the 1985 Definition

Three years after the publication of the first AIDS definition, *MMWR* published the first of several revisions in its June 28th, 1985 issue. As is the case with all surveillance definitions, the CSTE approved the 1985 revised definition, which occurred during its annual meeting earlier that month (June 2-5, 1985).[72] Unlike its 1982 counterpart, the 1985 revised definition—hereafter, the 1985 definition—appeared on the *MMWR* issue's front page in its "Current Trends" section, titled "Revision of the Case Definition of Acquired Immunodeficiency Syndrome for National Reporting – United States."[73] The definition spanned two pages and structurally differed from its previous iteration through the use of bold text, numbered and lettered lists, and an absence of footnotes containing pertinent definitional information. Thus, the 1985 presented a far more organized definition for readers.

Though longer and better visually designed, the 1985 definition's content shared similarities with the 1982 definition. The June 28th 1985 issue of *MMWR* did *not* explicitly contain the new AIDS definition, but cited the 1982 definition and offered amendments to it. If the reader was unfamiliar with the initial AIDS definition, they must revisit the 1982 issue using the reference information provided. The two definitions were also both prefaced and followed by contextualizing information, though this information varied topically between the issues.

In addition to the definition itself, I offer accounts of this contextual information in the remainder of this section. I have divided the section into three parts: (1) the 1985 definition; (2) retrospective; and (3) justification for definitional preservation. In the first part, I describe the 1985 definition's revised content and compare it to the 1982 definition. In the second part, I examine

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[72] Centers for Disease Control, "Revision (1985)," 373.

[73] Centers for Disease Control, "Revision (1985)," 373.

the historical retrospective offered to create a narrative of scientific progress. In the final part, I explore the inclusion of a justification for the AIDS definition's remarkably restricted evolution.

Despite the *MMWR* report's title in its June 28th, 1985 issue, the case definition of AIDS was effectively absent, appearing only in citational form in the second sentence of the report. Throughout the report, the CDC frequently referenced the 1982 definition with phrases such as "the 1982 definition," "a case definition of AIDS," and "the current case definition of AIDS;" however, the CDC did not restate what the 1982 definition was for the sake of their audience.[74] Instead, as I will address in a moment, the CDC offered "refinements" to the 1982 case definition without quoting it for the readers' ease of reference.[75]

During its June 1985 meeting, the CSTE provided a list of resolutions and recommendations to the CDC of which definitional refinements was one. The CSTE prefaced the list of refinements with two important calls to the CDC. First, the CSTE resolved "to include only the more severe manifestations of HTLV-III/LAV infection."[76] Second, the CSTE suggested the CDC "develop more inclusive definitions and classifications of HTLV-III/LAV infection for diagnosis, treatment, and prevention" as well as studies and surveys.[77] In the former case, the CSTE presumably suggested that the initial manifestations from the 1982 definition as well as the additions made in this report count as those severe manifestations because they remain included in the revised definition. However, no rationale was offered as to what makes them uniquely *severe* in comparison to other, possible manifestations. In the latter, however, the CDC did not expand upon or the CSTE did not explain what inclusivity means generally or for the specific intervention areas of diagnosis, treatment, and prevention.

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[74] Centers for Disease Control, "Revision (1985)," 373.
[75] Centers for Disease Control, "Revision (1985)," 374.
[76] Centers for Disease Control, "Revision (1985)," 373.
[77] Centers for Disease Control, "Revision (1985)," 374.

Last on the CSTE's list of recommendations to the CDC was a comparatively lengthy list of refinements to the 1982 case definition. The refinements can be characterized as a list of inclusions and exclusions to the case definition. With the discovery of HTLV-III/LAV and subsequent development of tests for it, a significant portion of the refinement recommendations required virologic and serologic testing to confirm an AIDS case, particularly when opportunistic infections had not manifested. The CSTE recommended six diseases to "be considered indicative of AIDS" as long as the HTLV-III/LAV test result is positive and age or time requirements are met.[78] Additionally, the CSTE explicitly stated that those with negative test results for serum antibodies for HTLV-III/LAV and for any other HTLV-III/LAV test would be excluded from an AIDS diagnosis in addition to those who do not have low lymphocytic ratios.[79] Finally, the CSTE stated that in lieu of testing, patients who meet all other definitional criteria would still be considered AIDS cases.

Of the two themes present alongside the 1985 definition, the retrospective of AIDS' history and its scientific progress is most prevalent. The CDC opened with a reference to the first cases of AIDS and traced the progress made since then all within the first two paragraphs of the article, laying a foundation for the revised definition's introduction. The article begins:

> Patients with illnesses that, in retrospect, were manifestations of acquired immunodeficiency syndrome (AIDS) were first described in the summer of 1981. A case definition of AIDS for national reporting was first published in the *MMWR* in September 1982. Since then, the definition has undergone minor revisions in the list of diseases used as indicators of underlying cellular immunodeficiency.[80]

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[78] Centers for Disease Control, "Revision (1985)," 374.
[79] Centers for Disease Control, "Revision (1985)," 374.
[80] Centers for Disease Control, "Revision (1985)," 373.

This account retroactively identified cases of AIDS in a moment before "AIDS" as a disease was known and, thus, offered an expert interpretation of AIDS history as it was known then. The timeline was presented simply and succinctly before the CDC addressed the minor changes to the AIDS definition since the 1982 definition's publication. After recounting this information, the article then introduced the major point of progress to understanding AIDS: "Since the 1982 definition was published, human T-cell lymphotropic virus type III/lymphadenopathy-associated virus (HTLV-III/LAV) has been recognized as the cause of AIDS."[81] As the article later explained, the first definition of AIDS was created prior to the identification of the virus, which left ambiguity as to its nature and manifestations. With the discovery of HTLV-III/LAV/HIV and creation of antibody testing as a result, the CSTE were able "to include additional serious conditions in the syndrome, as well as to further improve the specificity of the definition used for reporting cases" whereas before the definition "encompassed only certain secondary conditions that reliably reflected the presence of a severe immune dysfunction."[82] The identification of a causal agent for AIDS was framed as a moment of breakthrough where seemingly meaningful changes could be made by the CSTE to the AIDS surveillance definition. Thus, the article initially commented on a moment when no one knew that people were dying from AIDS to a moment where AIDS could be tracked, however limited that initial definition might have been. The article then quickly emphasized the discovery of HTLV-III/LAV before identifying for the reader what the discovery meant for tracking AIDS cases: improved accuracy and specificity.

The second theme present in the contextual information surrounding the definition was one of justification for definitional preservation. Within this theme, the CDC emphasized the effectiveness of the 1982 definition and then offered that effectiveness as a rationale for making

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[81] Centers for Disease Control, "Revision (1985)," 373.

[82] Centers for Disease Control, "Revision (1985)," 373.

only minor changes to the 1985 definition. For instance, the move for justification occurred in early moments in the article, prior to the introduction of the revised definition: “The current case definition of AIDS has provided useful data on disease trends, because it is precise, consistently interpreted, and highly specific.”[83] While other claims within the article were supported with citations, the claim of the 1982 definition’s effectiveness due to precision, consistency, and specificity was not supported by any outside study. After introducing the 1985 definition, the CDC commented on the impact the 1985 definition would have on current and future cases. It stated, “The revision in the case definition will result in the reclassification of less than 1% of cases previously reported to the CDC. The number of additional new cases reportable as a result of the revision is expected to be small.”[84] Here, the CDC noted that under the 1985 definition nearly all those already diagnosed with AIDS would not experience any reclassification and, perhaps more importantly, those who did not meet the definitional criteria prior to the 1985 definition were unlikely to meet the criteria for the 1985 definition. Together, the statements about the 1982 definition’s effectiveness and the 1985 definition’s limited impact on people with AIDS suggested heavily restricted definitional movement despite breakthroughs such as etiological identification.

4.3.1.3 The Consequences of Instability Disguised as Certainty

Having argued that the 1982 AIDS definition is one characterized by uncertainty and the 1985 definition offering a revisionist account indicative of stability and efficacy for the first definition, I now briefly explain how uncertainty obfuscated by assertions of progress and effectiveness troubles claims that the surveillance definition was capable of capturing accurate

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[83] Centers for Disease Control, “Revision (1985),” 373.

[84] Centers for Disease Control, “Revision (1985).”

surveillance data. Specifically, three issues arise: (1) restricted possibilities for improvement; (2) limited attention to scientific progress; and (3) overreliance on HIV antibody testing.

First, uncritically examining the foundational AIDS definition limits opportunities for improvement. As I have argued, the 1982 definition is heavily marked by uncertainty about AIDS through the reliance of characteristics like absence/presence, degree, and causality. Since so little was known about AIDS only a year into the epidemic, including its cause, uncertainty naturally arises in the definition. The claims that could be made with a degree of confidence reflected information gathered from those most visible at the time: white, gay men. Thus, the limited understanding of AIDS and need for the Spectrum of AIDS Manifestations to articulate absent or tenuous knowledge is reasonable and in itself not a flaw. The design flaw appears when, in 1985, the CDC represented the definition with its proposed refinements as precise, specific, and consistently interpreted by public health officers. Certainly, the substantive definition did offer a succinct explanation of AIDS at the time. Yet, the substantive definition is only one of three parts of the 1982 definition. The other two components offer a far more complex picture of AIDS, which is not so easily characterized. By refusing to acknowledge these moments of uncertainty, the CDC missed an opportunity to think about AIDS more capaciously.

Second, the 1985 definition is coupled with a narrative of scientific progress, yet the definition is only refined to include a remarkably small percentage of people. Due to its effectiveness, the CDC claimed that those few refinements to the 1982 definition were all that was necessary to successfully continue to track the AIDS epidemic. Thus, few people could expect to see their case change when the 1985 definition went into effect. However, on the previous page the CDC took care to explain the progress made since 1981 and touts the discovery of the AIDS virus. If the discovery of the virus was considered as significant as it rightfully should have been, then the 1985 definition would have logically reflected the fruits of such an important discovery.

The virus' discovery was significant because a *virus* was transmissible across the species where the multifactorial theory of AIDS causation attributed it behavior among a portion of the gay community. This is to say that the knowledge that AIDS is caused by a virus and not by a combination of sexual and drug-using behaviors implies that populations other than the so-called 4Hs ought to also have been considered as at-risk. These other populations would have included women. If other groups beyond the 4Hs could contract the virus, then a significant reevaluation of the pre-virus criteria seems reasonable. Based on the tension between progress and limited revision, no evidence of a sweeping reevaluation existed in the 1985 definition to be communicated to public health experts nationwide. By not offering expanded criteria for AIDS in 1985, the CDC was likely to continue to surveil those populations who met the criteria because the criteria were based on disease manifestations in those populations.

Third, the incorporation of an antibody test as part a criteria of meeting definitional requirements may undermine the need for careful evaluation of future definitional criteria. One significant difference between these first two definitions was the inclusion of an antibody test for the AIDS virus as part of the 1985 definitional criteria. The incorporation of the test was not in itself a problem, yet important issues arose with its use. Somehow those relying on the test to communicate information about AIDS must account for social determinants of health and access that existed in the 1980s. For instance, many individuals may have refrained from being tested because of stigma or fear of surveillance or lack of treatment options post-diagnosis. Others might not have had access to a testing site, the means to take time to go to a site, or the money required to be tested. Thus, while an "objective" measurement like a blood test may have done a lot of labor necessary to define an AIDS case, it could not have been the only means to define an AIDS case for those outside the established definitional criteria of KS, PCP, and OOI.

4.3.2 Issue Two: The Presence and Absence of Sex

The second issue that contributes specifically to the exclusion of women from surveillance efforts centers on the presence and absence of sex in definitional criteria. Activists in the early years of the epidemic identified the failure to include gynecological abnormalities as one such means of exclusion. Through a closer analysis of the definitions, more issues appear that further bolster activists' claims that women were ignored. In this section, I discuss where and how sex appears in early AIDS definitions. I begin by analyzing the definitional criteria for AIDS as they appeared in the *MMWR*. Next, I examine the contextualizing information that appeared alongside each definition. Finally, I explain how the presence and absence of sex in AIDS definitional criteria harms populations such as women despite claims that sex differences do not need to be a consideration.

4.3.2.1 Sex Differences in Definitional Criteria

For the first six years of the AIDS crisis, AIDS surveillance definitions did not include sex differences in their criteria; it was as if sexual organs were free from AIDS-indicative diseases. This changed with the 1987 surveillance definition, but not in a way that addressed growing concerns about women's exclusion from surveillance criteria. Women were implicitly evoked when children are referenced in the definition's Appendix I under the subsection "Laboratory Evidence For or Against HIV Infection." When evidence supported a disease indicative of AIDS, "a serum specimen [is to be taken] from a patient >15 months of age, or from a child <15 months of age whose mother is not thought to have had HIV infection during the child's perinatal period" or "a serum specimen [is to be taken] from a child <15 months of age, whose mother is thought to have had HIV infection during the child's perinatal period."[85] When evidence was inconclusive, "a serum specimen [is to be taken] from a child <15 months of age, whose mother is thought to have had HIV infection during the child's perinatal period."[86] In these three instances, women appeared worthy of inclusion when their children met criteria for AIDS. At that point, women's statuses became important because these statuses could tell the CDC something about a *child's* risk. These few lines were the only indication until 1993 that male and female bodies contained different organs and performed different biological processes that might require consideration in surveillance gathering.

4.3.2.2 Sex Differences in the *MMWR*

While they were not attended to until 1993 in the AIDS surveillance definition, sex differences appeared alongside the definitions as early as 1982 in the article's contextualizing information. Of the three definitions analyzed in this chapter, the 1982 definition had the greatest number of references to sex. After the 1982 definition's publication, any mention of sex differences sharply decreased in the contextualizing information, appearing not once in 1985 and only once in 1987. The focus away from sex differences suggests a move away from anticipating AIDS in certain bodies officially, yet two points should be considered here. First, as I discussed in the previous issue, the 1982 definition was not included in the 1985 definition; therefore, *MMWR* readers had no reference for previous, still pertinent criteria and would conceivably have to return to the 1982 *MMWR* issue if they wanted to refresh themselves on how criteria changed. Second,

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[85] Centers for Disease Control, "Revision (1987)," 10S.
[86] Centers for Disease Control, "Revision (1987)," 10S.

the shift away from explicit discussions of sex difference in 1985 and 1987 in the contextualizing information does not mean that sex was not understood implicitly. Historically, the body upon which research is performed and medicine provides treatments has been male as I discussed at length in Chapter Two. Thus, we ought to understand the absence occurring in later definitions as already implying a particular sexed subject.

The 1982 AIDS definition's contextualizing information performed significant labor to establish the male AIDS subject. In the six times that sex appeared alongside the definition, only once were females mentioned. In this instance, the CDC wrote that females are included "[a]mong the 20% of known heterosexual cases (males and females)."[87] Otherwise, the CDC focused its attention on males, both homosexual and heterosexual. Early in the article, the CDC wrote prior to the 1982 definition that "[a]pproximately 75% of AIDS cases occurred [sic] among homosexual or bisexual males."[88] Later, they explained that "[a]mong the 14 AIDS cases involving males under 60 years old who were not homosexuals" and who did not fit into the other identified risk categories, two had hemophilia.[89] Finally, prior to introducing the definition in the editor's note, the CDC identified groups based on risk factors, listing "homosexual or bisexual males—75%, intravenous drug abusers with no history of male homosexual activity—13%" among others.[90] In the article's closing remarks, the CDC once again reiterated risk groups by writing that "[o]nly a small percentage of cases have none of the identified risk factors (male homosexuality, intravenous drug abuse, Haitian origin, and perhaps hemophilia A)."[91]

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[87] Centers for Disease Control, "Update (1982)," 507.
[88] Centers for Disease Control, "Update (1982)," 507.
[89] Centers for Disease Control, "Update (1982)," 507.
[90] Centers for Disease Control, "Update (1982)," 508.
[91] Centers for Disease Control, "Update (1982)," 514.

By 1985 and 1987, the language of risk groups—and by extension the sexed makeup of those groups—decreased. In the 1985 article, no explicit discussion of sex appeared in the contextualizing information. However, as I have mentioned previously, the appearance of sex in 1982 is evoked in 1985 implicitly by the 1985 definition's partial inclusion of definitional criteria and subsequent reference to the early 1982 definition. Similar to the implicit presence in the 1985 definition, the 1987 definition included only a brief word about sex as it addressed the issue of children. Here, the CDC informed the reader of HIV infection criteria in infants, writing:

> Second, for children <15 months of age whose mothers are thought to have had HIV infection during the child's perinatal period, the laboratory criteria for HIV infection are more stringent, since the presence of HIV antibody in the child is, by itself, insufficient evidence for HIV infection because of the persistence of passively acquired maternal antibodies <15 months after birth.[92]

In this point, the reader is directed to consider the relationship between a woman and her child, particularly the way that antibodies might pass between them during pregnancy. Worth noting once again is that the woman only appeared due to her relationship with the child, and the discussion is framed around *the child's* perinatal period rather than *the woman's* pregnancy. This is despite the fact that the woman in this scenario would certainly have HIV.

4.3.2.3 The Importance of Sex-Based Inclusion in AIDS Definitions

By exploring where and how sex appears in early AIDS definitions and in the *MMWR* articles in which they appear, it becomes clearer whose body is taken into consideration as surveillance criteria was established and evolved over time. In the first decade of the epidemic, this body was predominantly male despite sex differences and diseases of those organs. While arguing that biological difference matters in the health sciences can quickly devolve into biological

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[92] Centers for Disease Control, "Revision (1987)," 3S.

essentialist arguments, *not* attending to sex differences is equally as problematic. The inclusion of men more frequently in the material around the AIDS definitions suggested a particular sex that is at risk for AIDS. This directed the attention of individuals responsible for disease surveillance at all levels to more readily imagine the AIDS patient as male. Equally as important to remember is that as early as 1985, the CDC and CSTE *were* imagining bodily difference in discussions of AIDS definitions; after all, the patient's age was a consideration for AIDS disease indicators and what evidence counted for an AIDS diagnosis. Thus, it is not impossible to conceive that sex differences could have been included prior to 1993, and history proves that it was, indeed, possible to include sex differences in some capacity

4.3.3 Issue Three: Spatial and Temporal Constraints to Indicator Diseases

The third issue appearing across all three definitions undermines claims that only the most severe diseases may be included in the AIDS definitions for surveillance purposes. Due to the CDC's inclusion of only *severe* or *rare* diseases in AIDS definitions to protect the accuracy of their surveillance numbers, women with AIDS, who frequently suffer from more commonplace diseases, were disadvantaged when it came to being included in definitional criteria. Yet, as I explain in this subsection, the nature of spatial and temporal constraints to definitional criteria suggests that parameters could have been established around more common diseases to ensure more accurate surveillance data. I first examine the way space and time appear in the 1982, 1985, and 1987 definitions before analyzing more closely how space and time could have offered a feasible solution to the longstanding concern of representing the true scope of the epidemic.

4.3.3.1 The Presence of Space and Time in AIDS Definitions

From the first AIDs definition, constraints such as time and space have been used by the CDC and CSTE to modify indicator diseases of AIDS. In 1982, the definition included five instances of time and space—and specifically bodily location—in its discussion of early criteria. The CDC wrote that the 1982

> case definition may not include the full spectrum of AIDS manifestations, which may range from absence of symptoms (despite laboratory evidence of immune deficiency) to non-specific symptoms (e.g., fever, weight loss, generalized, persistent lymphadenopathy) to specific diseases that are insufficiently predictive of cellular immunodeficiency to be included in incidence monitoring (e.g., tuberculosis, oral candidiasis, herpes zoster)[93]

This excerpt from the Spectrum of AIDS Manifestations placed constraints upon lymphadenopathy—*persistent*—and candidiasis—*oral*. At this point, however, what the CDC considered "persistent" lymphadenopathy remains undefined. On the same page located in a footnote that expanded upon what the CDC defined as serious OOI, the CDC included, among others: "progressive multifocal leukoencephalopathy; chronic enterocolitis (more than 4 weeks) due to cryptosporidiosis; or unusually extensive mucocutaneous herpes simplex of more than 5 weeks duration."[94] Once again, *progressive* remained undefined, but the CDC was clearer about the duration required of enterocolitis and herpes simplex. In this definition, temporal constraints were more heavily relied upon than spatial constraints, but by 1985 spatial constraints appeared more frequently.

In its refinements to the 1982 definition, the CDC incorporated more spatial and temporal markers on the list of additional diseases added to the 1985 definition. In this definition, the CDC

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[93] Centers for Disease Control, "Update (1982)," 508, 13.

[94] Centers for Disease Control, "Update (1982)," 508.

designated a separate list of diseases that did not appear in the surveillance definition, but that constituted an AIDS case as long as a test showed the presence of HTLV-III/LAV antibodies. These additional diseases included, among others: "disseminated histoplasmosis (not confined to lungs or lymph nodes," "isoporiasis, causing chronic diarrhea (over 1 month)," "bronchial or pulmonary candidiasis," and "Kaposi's sarcoma in patients who are 60 years old or older when diagnosed."[95] Shortly after this list, the CDC explained once more that the criteria in the current definition did not have to be met. The CDC wrote: "a histologically confirmed diagnosis of chronic lymphoid interstitial pneumonitis in a child (under 13 years of age) will be considered indicative of AIDS unless test(s) for HTLV-III/LAV are negative."[96] Finally, the CDC added that "[p]atients who have a lymphoreticular malignancy diagnosed more than 3 months after the diagnosis of an opportunistic disease used as a marker for AIDS will no longer be excluded as AIDS cases."[97] From these examples, it is apparent that the CDC made efforts to consider duration of disease and location of diseases as part of its revised criteria, making space for a few new diseases (as long as a test confirmed viral antibodies) and including a disease that had not previously been allowed.

While 1985 saw only a small increase in spatial and temporal criteria, 1987's definition included markedly more than the previous two definitions combined. Within the multiple page document for 1987, twenty-four uses of location and duration appeared to augment criteria. Given the large number of cases in the definition, a representative few have been gathered to demonstrate the form location and time take. In a list beneath the heading "without laboratory evidence of HIV infection" titled "indicator diseases diagnosed definitively" the following diseases appeared, among others: "candidiasis of the esophagus, trachea, bronchi, or lungs," "cryptosporidiosis with

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[95] Centers for Disease Control, "Revision (1985)," 374.
[96] Centers for Disease Control, "Revision (1985)," 374.
[97] Centers for Disease Control, "Revision (1985)," 374.

diarrhea persisting >1 month," "herpes simplex virus infection causing a mucocutaneous ulcer that persists longer than 1 month; or bronchitis, pneumonitis, or esophagitis for any duration affecting a patient >1 month of age."[98] In contrast to prior definitions, 1987 is remarkable in that most of the established criteria are constrained by either duration or location of disease. The specificity of disease and parameters for which a patient must adhere to be qualified as an AIDS case increased over time.

4.3.3.2 The Function of Space and Time in Surveillance Criteria

The rising emphasis on identifying location and duration of disease in the first three definitions of AIDS suggests an increased value on specificity. Indeed, public health officials like James Chin, the Chief of the World Health Organization's (WHO) Global Programme of AIDS' Surveillance Forecasting and Impact Assessment Unit during the 1990s, stated that "'these definitions were designed to be as *specific* as possible even if they sacrificed some sensitivity.'"[99] This statement meant that "the CDC wants to avoid expanding the case definition to include severe disease found in large numbers of people who are not HIV-infected. Its primary concern is with 'severe illnesses which are rare in persons with normal immune systems, i.e., conditions that are high specific to HIV disease.'"[100] As activists of the era pointed out, however, some of the most prevalent diseases found in women with AIDS—particularly those female-specific diseases—also occurred in women who are *not* immunosuppressed. The CDC's need to be selective in what it included as part of its definition and the reality of disease manifestation in women may at first seem incompatible, yet the turn to location and duration of disease beginning in the mid-1980s

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[98] Centers for Disease Control, "Revision (1987)," 4S.

[99] Levine and Stein, "What's in a Name," 279.

[100] Levine and Stein, "What's in a Name," 279-80.

also suggests a solution to the problem of incorporating commonplace diseases. This very solution was employed in 1993 with the inclusion of invasive cervical cancer in the updated AIDS definition; at that time, the CDC set location parameters around cervical cancer by stipulating that it had to be invasive—at another site in addition to the outer layers of the cervix. Thus, it is not inconceivable that location and duration could also have been employed to modify less severe, more commonplace diseases like vaginal yeast infections or unexplained vaginal bleeding as they had to other criteria like herpes simplex virus or cryptosporidiosis.

4.3.4 Issue Four: The Relationship between Correlation and Causation

The final issue appearing in all three definitions addresses the function of correlation and causation in establishing surveillance criteria. For my purposes, *causation* is used when there is evidence of cause and effect relationship between two or more phenomena, whereas *correlation* means two or more phenomena have been identified, but the source of the phenomena remains undetermined or ambiguous. In the surveillance case definitions for AIDS, both correlation and causation appeared throughout in roughly equal measure, though in the early definitions ebbs and flows exist for which *topos* takes precedence. In this section, I first describe how correlation and causation appear throughout the 1982, 1985, and 1987 definitions and then explore how these *topoi* reveal opportunities for inclusion that were not taken.

4.3.4.1 The Use of Correlation and Causation in AIDS Surveillance Definitions

As it was created prior to the discovery of HIV, the 1982 definition has more instances of correlation than causation. Only one instance of causation appeared in this first definition when the CDC established the definition for AIDS: "CDC defines a case of AIDS as a disease, at least moderately predictive of a defect in cell-mediated immunity, occurring in a person with no known cause for diminished resistance to that disease."[101] Despite the causation being undetermined, and therefore more in line with my working definition of correlation, I have categorized this instance as an example of causation. In this instance, AIDS was defined as the presence of a disease in a person where there should not be one; there was no ambiguity about the source of the disease, only that there was no logical cause for it. This differed from the four instances of correlation that appear in the definition. For instance, the CDC included malignant neoplasms on the Spectrum of AIDS Manifestations, stating that they might be the "cause, as well as result from, immunodeficiency."[102] In this example, malignant neoplasms might be the cause of immunodeficiency in a patient, or they could be the effect of AIDS. Thus, the symptom and the source remain in tension. Immunodeficiency and malignant neoplasms in this scenario were co-incidental, but the order—and therefore the cause—remained ambiguous.

The other instances of correlation were not so specific as the example of malignant neoplasms but address similar concerns. The CDC wrote that they excluded certain diseases from surveillance reporting because they were "insufficiently predictive of cellular immunodeficiency to be included."[103] The CDC then added that "some patients who are considered AIDS cases on the basis of diseases only moderately predictive of cellular immunodeficiency may not actually be immunodeficient and may not be part of the current epidemic."[104] In these cases, a patient lived in a gray area where they both could and could not have AIDS because they displayed or did not adequately display the diseases associated with AIDS. Thus, the CDC—without a test to confirm

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[101] Centers for Disease Control, "Update (1982)," 508.
[102] Centers for Disease Control, "Update (1982)," 513.
[103] Centers for Disease Control, "Update (1982)," 513.
[104] Centers for Disease Control, "Update (1982)," 513.

the presence of a virus in this moment—attributed certain disease correlations as causations for the sake of surveillance, despite uncertainties.

With the discovery of the AIDS virus, the CDC wrote the 1985 definition in a way that featured causation over correlation. In the definition itself, correlation did not appear at all. Causation, however, was present on three occasions, two of which are the same phrase used twice. Along with a short list of added criteria, the CDC wrote that particular diseases within set parameters "will be considered indicative of AIDS" twice.[105] As I will discuss in more detail in the 1987 example, the use of "indicative" or "indicator" suggested correlation as there was space for alternative explanations. However, the use of "indicative of AIDS" specifically suggested a desire to call a disease that met particular criteria—diseases and a positive antibody test—AIDS for surveillance purposes. The other instance of causation occurred when discussing a disease and its symptom: "isosporiasis, causing chronic diarrhea (over 1 month)."[106] This structure of cause, effect/cause, effect (or, AIDS, isosporiasis, chronic diarrhea) was used widely by 1987.

The 1987 definition was in many ways a reset on the definitions that came before, and much of the revision undertaken at this time focused on providing an extensive list of criteria, citing specific cause and effect relationships. Causation appeared ten times throughout the definition, suggesting the CDC's priority to name relationships between opportunistic infections and AIDS when possible. Most examples shared a formula like in the isosporiasis example above: "disease caused by *M. tuberculosis*, extrapulmonary" and "herpes simplex virus infection causing a mucocutaneous ulcer."[107] The other predominant appearances of causation occurred in moments where HIV was accepted or rejected as a cause for an indicator disease. Here, the CDC structured

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[105] Centers for Disease Control, "Revision (1985)," 374.
[106] Centers for Disease Control, "Revision (1985)," 374.
[107] Centers for Disease Control, "Revision (1987)," 4S-5S.

its subsections with titles such as “Causes of immunodeficiency that disqualify diseases as indicators of AIDS in the absence of laboratory evidence for HIV infection” and “With laboratory evidence against HIV infection.”[108] In these cases, laboratory evidence ruled out a causal relationship between a disease and HIV/AIDS.

Though outnumbered by causation, correlation appeared in six instances in the 1987 definition alongside causation as a means to structure criteria. In this case, the CDC employed titles such as “Indicator diseases diagnosed presumptively.”[109] The use of “indicator” and “presumptive” appeared throughout examples of correlation. For instance, the CDC explained that “[f]or national reporting, a case of AIDS is defined as an illness characterized by one or more of the following ‘indicator’ diseases, depending on the status of laboratory evidence of HIV infection.”[110] Later, the CDC stated that “[i]n other situations, accepted clinical practice may be to diagnose presumptively on the presence of characteristic clinical and laboratory abnormalities.”[111] When “indicator” and “presumptive” were used in these capacities, causation was not established definitively, but seemed the most likely of a myriad of other possible causes. Some diseases were more likely than not to indicate a likely AIDS case whereas other diseases required testing to establish cause because they could appear as a result of other medical complications. In these instances, correlation worked within a still strict set of parameters in 1987, but there was more give in the realm of possible causes before additional steps were taken to test or confirm in some capacity.

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[108] Centers for Disease Control, “Revision (1987),” 4S, 6S.
[109] Centers for Disease Control, “Revision (1987),” 5S.
[110] Centers for Disease Control, “Revision (1987),” 4S.
[111] Centers for Disease Control, “Revision (1987),” 4S.

4.3.4.2 Correlation's Rhetorical Benefits

As I have already established, one of the primary concerns the CDC had for its surveillance definition was that it be specific at the expense exclusion. This specificity meant that more common diseases, particularly those effecting women, could not be included in the AIDS definition because their cause could lay outside of HIV. Numbers could be skewed, and the surveillance data would not give the most accurate scope of the epidemic. However, the 1987 AIDS definition specifically allowed a space for diseases whose cause could not be determined definitively to be included still, despite some uncertainty. This is the rhetorical function of correlation in these definitions: to demonstrate a relationship between an effect and two or more causes and suggesting a likelihood in the absence of definitive proof. Many opportunistic infections associated with AIDS can be multi-causal and HIV must be diagnosed definitively in these instances, the same of which could have been done for female-specific diseases. Yet even without a reliance on testing, a combination of duration, location, and correlation together could come near the specificity the CDC required. After all, something like this appeared in the 1993 definition with the addition of invasive cervical cancer.

4.4 Conclusion

As Walton and Chesebro remind us, definitions are created from a particular context and bound to that context; they should not be used and evaluated beyond their intended purpose.[112] Despite clear instructions in 1987 not to use it beyond its surveillance context, the CDC's case

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[112] Walton, "Persuasive Definitions and Public Policy Arguments," 117, 25; Chesebro, "Definition as a Rhetorical Strategy," 6-7.

definition for AIDS was utilized in research, government funding, clinical contexts, and disability benefits. Every person with a disease deserves to be included in official numbers and in that capacity, the CDC and CSTE failed women. However, the widespread uptake of the definition beyond its intended purposes made the exclusion of women and others in marginalized positions from the CDC definition all the more egregious. Some of these consequences included the inability of those not meeting definitional criteria to access social assistance programs like Medicare, Medicaid, SSI, and Social Security Disability Income, leaving many of those with end-stage HIV without the means to care for themselves at the end of their lives.[113] The appeals process for disability claims was further complicated for women because "their disabling illnesses [were] often considered trivial by administrators and administrative law judges."[114] Federal funding for AIDS through the Ryan White Care Act was also highly dependent on the AIDS case definition, and without accurate numbers resources were likely to be under-allocated or misallocated.[115] In the case of AIDS research, funding that is not given to curative research is typically given to those opportunistic diseases in the CDC's case definition.[116] Research about women and drugs was already hindered by the 1977 FDA guidelines for drug trials that excluded women of childbearing potential for most trial stages, and the lack of research on those AIDS indicator diseases most commonly found in women due to their exclusion in the CDC definition meant that the dearth of information about women and AIDS only deepened.[117] Finally, activists expressed concern that the CDC definition's use in clinical care settings contributed to the underdiagnosis of AIDS in

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[113] Levine and Stein, "What's in a Name," 282.
[114] Levine and Stein, "What's in a Name," 282.
[115] Levine and Stein, "What's in a Name," 285.
[116] Levine and Stein, "What's in a Name," 285.
[117] Levine and Stein, "What's in a Name," 285.

women due to the doctor's inability to recognize AIDS symptoms beyond those listed in the surveillance criteria.[118]

Thus, the consequences of having an AIDS surveillance case definition that fails to include segments of the population are steep. Though the CDC only intended the definition to be used in one particular way, the reality is that several infrastructural facets relied on expertly determined definitions for an unknown emerging disease to complete their work. The AIDS definition's expanded use upped the stakes for having an inaccurate definition. As I have explored in this chapter, the surveillance case definition for AIDS was flawed. In the CDC's failure to reflect on scientific progress and alter the definition accordingly, in the manner in which it discussed (and did not discuss) sex differences and what that meant for visibility, in its resistance to including those diseases that effected women most despite have rhetorical room for it in the definition: for all these reasons, women suffered as a result of the CDC's failure by omission. Theresa McGovern—the lawyer for People with AIDS in *S.P. v. Sullivan*, the case mentioned at the start of this chapter—stated prior to 1992 that "the CDC's case definition was undercounting women by 40 to 50 percent."[119] With the inclusion of "T-cell counts under 200 as well as cervical cancer, [pulmonary] tuberculosis, and recurrent [bacterial] pneumonia" in the 1993 AIDS definition, the AIDS case number in women "increased 204 percent" in the first quarter in comparison with the same quarter the previous year.[120] McGovern, who was an advocate for women, had underestimated the impact the updated definition would have for women by *150 percent*.

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[118] Levine and Stein, "What's in a Name," 286.

[119] Laurence and Weinhouse, *Outrageous Practices*, 148.

[120] Laurence and Weinhouse, *Outrageous Practices*, 148-49.

5.0 Categorically Other: Case Report Forms, Surveillance Reports, and the Creation of (Non-)Knowledge about Women and AIDS Through Classification

In a November 1991 issue of the radical feminist periodical *off our backs*, beth elliot published a commentary titled "Does Lesbian Sex Transmit AIDS? GET REAL!" elliot's scathing article focused on AIDS activists who, she claimed, were motivated by sexism and sought to strengthen the association between AIDS and homosexuality by claiming lesbian risk. For elliot, this move suggested that "all those dental dams [were] keeping [lesbians'] mouths out of contact with their brains" as the CDC and health experts showed that lesbians had little to no AIDS risk.[1] In January 1992, *off our backs* reader Libby Smith sent a letter to the periodical to argue that elliot's view was irresponsible. Smith argued that, while elliot may have been correct to claim that IV drug use and heterosexual sex were higher risk activities, elliot also ignored "the fact that lesbian sexuality may involve blood (menstrual or otherwise) or anal penetration, both of which are more likely to transmit the virus."[2] Based on her experience as an AIDS and substance abuse researcher, Smith argued that lesbians were not treated equally in data collection. For instance, she claimed that a research questionnaire used at her facility was designed in such a way that "any woman who has not had sex with a man in the last five years will skip to the end of the survey and not answer any questions about her sexual behaviors."[3] By Smith's estimation, this research approach and the CDC's automatic dismissal of sex between woman leading to HIV transmission, as indicated by the CDC's lack of data collection, were just two more examples of "the old 'what

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[1] beth elliott, "Does Lesbian Sex Transmit AIDS? GET REAL," *Off Our Backs* 21, no. 10 (1991).

[2] Libby Smith, "does lesbian sex transmit aids? view irresponsible," *Off Our Backs* 22, no. 1 (1992).

[3] Smith, "does lesbian sex transmit aids? view irresponsible."

could two women do in bed?' question."[4] For Smith, perhaps elliot was right to say that lesbians never transmitted the virus to one another or perhaps "the male dominated government, medical establishment, and anti-AIDS movement don't know and don't care about lesbians."[5]

The controversy over how women who have sex with women (WSW) may or may not transmit HIV as illustrated here by the disagreement between elliot and Smith demonstrates how AIDS risk remained a topic of contention between WSW, a decade into the epidemic. At the time of these articles' writings, the CDC did not collect data about AIDS rates in WSW in their surveillance reports, nor did they regularly address the likelihood of such transmission. As such, WSW—like elliot and Smith—were left to speculate about necessary precautions to take with sexual partners and the motivation behind the dearth of data. However, the lack of information did not stop there. For most of the AIDS epidemic's first decade in the U.S., the CDC offered very little nuance to AIDS transmission rates in women *generally*. This lack of information, I argue, can be attributed to problems in two separate CDC documents. First, the CDC's "AIDS Case Report Form" offered fewer responses to questions about women's behavior than those about men and artificially narrowed the scope of AIDS transmission in women by asking only about behavior occurring after 1978. Second, upon receiving the "Case Report Form," the CDC gathered the data and published the *AIDS Weekly Surveillance Report*. In translating the data from the "Case Report Form" to the *Surveillance Report*, the CDC failed to include information about women that had been included in the Case Forms, such as data on AIDS cases in bisexual and homosexual women. Thus, we know far less historically about AIDS transmission in women because of how the CDC created epidemiological surveillance instruments.

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[4] Smith, "does lesbian sex transmit aids? view irresponsible."
[5] Smith, "does lesbian sex transmit aids? view irresponsible."

Central to these AIDS data collection issues are broader questions of how public health surveillance apparatuses work. During this era of the AIDS epidemic, designated disease reporters—such as local health department workers and physicians—would fill out a "Case Report Form" about their patient, listing crucial information about symptoms, testing, and demographic information. This "Case Report Form" was then sent to the CDC so that they could track AIDS morbidity and mortality across the U.S. After gathering this data, the CDC would publish their findings in, among other places, the *AIDS Weekly Surveillance Report*, which would be circulated to expert and non-expert publics. The use of categories and classifications within those categories in documents like the "Case Report Form" is a core feature of gathering surveillance information. Rather than the objective instrument that such documents tend to be popularly portrayed as, the "Case Report Form" has been shaped by its creators' biases, values, and politics. Thus, how questions were posed about the AIDS patient and how the reporter may have responded to those questions given available classificatory choices reveal the master narratives inherent in what scholars have jokingly characterized as "boring" infrastructural documents. Drawing on the work of scholars like Susan Leigh Star, Geoffrey Bowker, and Martha Lampland, in this chapter I explore classification's rhetorical nature and demonstrate its interconnectedness with questions of epidemiological surveillance. I use archival documents to forward two arguments about women and AIDS that pertain to classification. Building from my argument in Chapter Four about definitional exclusion, I first argue that the "Case Report Form"—the surveillance tool used for data collection—had the means to be more inclusive than the AIDS Surveillance Case Definition despite being built from the definition. This could have been achieved through the use of demographic information, which is why definition and classification ought to be analyzed as separate, interrelated phenomena. Second, I offer evidence to support AIDS activists' claims that the CDC’s surveillance infrastructure was both sexist and heterosexist. However, I complicate these claims by arguing that heterosexism was far more prevalent in the CDC’s *AIDS Weekly Surveillance Report*—the tool for data dissemination—rather than the CDC’s “Case Report Form” itself.

The chapter begins with a review of the literature on classification. Here, I explore how classifications can be understood as rhetorical—as techniques of persuasion—and thus beholden to the political and social values of their creators. After this overview, I move to discuss surveillance broadly as it has been theoretically constructed before addressing epidemiological surveillance specifically, including its function and history. I then turn to activists’ concerns about the CDC’s AIDS *Surveillance Reports* in the late 1980s and early 1990s. The next section delves into the primary source materials themselves where I perform close-textual analysis of both the “AIDS Case Report Forms” and the *AIDS Weekly Surveillance Report*, which span from 1982 to 1992. I then offer my conclusions.

5.1 An Approach to Classification and Rhetoric

As a key public health tool, the “AIDS Case Report Form” collected data about AIDS cases via classificatory options developed by CDC experts. Thus, understanding how classification systems function as rhetorical phenomena allows one to better grasp the subjective nature of surveillance data and the means by which women with AIDS were made invisible in the process of data gathering. If we take rhetoric to be the ability in any situation to observe the available means of persuasion, then we can understand classification as a technique of rhetoric because classification is a means of persuasion. Classification renders phenomena intelligible by establishing similarities and differences to those phenomena we already know or understand. Upon establishing that relationship, we then know how to interact with the phenomenon, and such interaction—the consequences of the process of classification—becomes political, socially, and ethically inflected. In *Sorting Things Out: Classification and Its Consequences*, Geoffrey Bowker and Susan Leigh Star defined classification as "*a spatial, temporal, or spatio-temporal segmentation of the world*."[6] In the process of segmenting the phenomenon in order for it to be rendered classifiable, nuance must be removed to a certain degree. Classification can only achieve its purpose "through the simultaneous maximization of similarities and difference within and between analytically determined groups."[7] Thus, some data are necessarily lost in the classification process in order for something to be classified.

Once formally or informally established, classification systems—if they have been naturalized and do not conflict with one's positionality—typically become invisible. They are then used, in part, to create knowledge about those things being classified.[8] Knowledge production is highly charged with cultural values, often replicating the master narratives to which the creators of classification systems adhere. For example, historical racial categories such as quadroon or octoroon reinforced the American belief of the one-drop rule where an individual with even one Black ancestor was classifiably not-white. In some instances, classification interpellates a subject's internal self-identification, but always implies the existence of naturalized categories.[9] Classification, thus, determines what a subject is, how that subject can be treated, and what rewards

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[6] Geoffrey C. Bowker and Susan Leigh Star, *Sorting Things Out: Classification and Its Consequences* (Cambridge, MA: MIT Press, 1999), 10. emphasis in original.

[7] Oscar H. Gandy Jr., "Statistical Surveillance: Remote Sensing in the Digital Age," in *Routledge Handbook of Surveillance Studies*, ed. Kirstie Ball, Kevin Haggerty, and David Lyon (New York: Routledge, 2014), 126.

[8] Bowker and Star, *Sorting Things Out*, 10-11.

[9] Richard Jenkins, "Identity, surveillance and modernity: Sorting out who's who," in *Routledge Handbook of Surveillance Studies*, ed. Kirstie Ball, Kevin Haggerty, and David Lyon (New York: Routledge, 2014), 160.

or punishments might be fitting as a result.[10] Jenkins argues that "penalties and benefits are, in fact, inseparable in practical processes of classification."[11]

Some classifications are so widely adopted that they become *standards*. The AIDS "Case Report Form" contained classifications that became standards at the state and federal level for disease reporting across the United States. As such, those facets of standardization that make it a unique form of classification ought to be highlighted. Stefan Timmermans and Marc Berg explained that "a standard refers to a measure established by authority, customs, or general consent to be used as a point of reference."[12] While some classifications are temporary and limited to specific discourse communities, standards are established classifications that are more widely used and for longer periods of time.[13] As unique classification types, standards have six characteristics:

> 1. A 'standard is any set of agreed-upon rules for the production of (textual and material) objects. 2. A standard spans more than one community of practice (or site of activity). It has temporal reach as well as that it persists over time. 3. Standards are deployed in making things work together over distance and heterogenous metrics…4. Legal bodies often enforce standards, be these mandated by professional organizations, manufacturers' organizations, or the state…5. There is no natural law that the best standard shall win…6. Standards have significant inertia and can be very difficult and expensive to change.[14]

In addition to these qualities, Susan Leigh Star and Martha Lampland argued that standards are nested, unevenly distributed, relative, incorporated globally across networks and systems, and enforce or reinscribe social values.[15] In her work on (in)visibility in the context of radiation health

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[10] Jenkins, "Identity, surveillance and modernity," 160; Gandy Jr., "Statistical Surveillance: Remote Sensing in the Digital Age," 126.

[11] Jenkins, "Identity, surveillance and modernity," 160.

[12] Stefan Timmermans and Marc Berg, *The Gold Standard: The Challenge of Evidence-Based Medicine and Standardization in Health Care* (Philadelphia: Temple University Press, 2003), 24.

[13] Bowker and Star, *Sorting Things Out*, 15.

[14] Bowker and Star, *Sorting Things Out*, 13-14.

[15] Lampland and Star, *Standards and Their Stories*, 4-5.

effects, Olga Kuchinskaya explained that the alignment between how something is formally represented and practiced alongside empirical, standardized measurement influences (in)visibility. Through realignment of formal representations and measurement of a phenomenon, one may have increased alignment—and therefore better, more visible and usable standards—or increased misalignment.[16]

As "a power vestige of modernism," the use of standards promotes the belief of predictability, objectivity and rationality and, by extension, social progress.[17] In these respects, standards convey a quality of being scientific. However, standards a mired in politics and subjectivity. They "reorder practices and change the position of different actors," reconfiguring and reprocessing subjects and objects.[18] To illustrate standards' historicity, arbitrariness, and political nature, Star and Lampland offer the example of the work-hour. They explain that the standard work-hour might appear differently depending on "political regime and class position."[19] For instance, the 40-hour work week, once standard decades ago in America, might be a luxury for the contemporary working poor, who are paid an unlivable wage with limited benefits for the same period of work that could sustain a family half a century ago.

Classifications'—and by extension standards'—always material and institutional social construction situates them well within the rhetorical realm in two explicit ways. First, as phenomena lose their nuance in the classification process, the classification schema's creator selects and deflects portions of reality. For example, classifying objects found in the home by color is an approach one might take, but important nuances such as toxicity are likely to be lost in such

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[16] Olga Kuchinskaya, *The Politics of Invisibility: Public Knowledge about Radiation Health Effects after Chernobyl* (Cambridge, MA: The MIT Press, 2014), 111-12.

[17] Timmermans and Berg, *The Gold Standard*, 8.

[18] Timmermans and Berg, *The Gold Standard*, 22-23.

[19] Lampland and Star, *Standards and Their Stories*, 6, 15.

a system. Standardizing necessarily means "screen[ing] out unlimited diversity," but may even require "screen[ing] out even limited diversity."[20] As Bowker and Star emphasize, selecting and defecting reality is "not inherently a bad thing—indeed it is inescapable. But it *is* an ethical choice."[21] The very process of classification *requires* a phenomenon to be (re)constructed in order to fit within the system; however, how the classifier *chooses* to reduce a phenomenon to classifiable parts is value-laden. As a result, selection and deflection produce (non-)knowledge and (in)visibility. When human actors make decisions based on their viewpoint—referred to as situated knowledge—knowledge and visibility become morally inflected.[22] Again, visibility can be negative in so far as it may lead to hyper-surveillance of already vulnerable communities; however, visibility may also be positive in surveillance as my case study in this chapter demonstrates. From a theoretical perspective then, all groups can benefit from or be harmed by the processes of classification. Though in practice, the systems—as politically and morally entrenched—frequently perpetuate privilege and symbolic violence.[23]

Second, classifications and, particularly, standardizations are rhetorical in nature as they are profoundly context-bound and have the rhetorical force of socially ratified conventions. Star and Lampland write that "standardization is a recursive practice, necessarily historical and embedded in a series of complex events and social structures."[24] They continue:

> The attempt to purify and simplify professes of standardization—through bureaucratic maneuvers or more contested legal procedures— contributes directly

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[20] Lampland and Star, *Standards and Their Stories*, 8.

[21] Bowker and Star, *Sorting Things Out*, 6. emphasis in original.

[22]Timmermans and Berg, *The Gold Standard*, 22; Lampland and Star, *Standards and Their Stories*, 8; Bowker and Star, *Sorting Things Out*, 44; Haraway, "Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective."

[23] Pierre Bordieu, *Distinction: A Social Critique of the Judgment of Taste* (New York: Routledge, 1984).

[24] Lampland and Star, *Standards and Their Stories*, 14.

> to the overdetermined or layered, socially and culturally embedded quality of standards. With time, this process can lead to what Callon (1998) calls 'irreversibility.'"[25]

Through the layering of social and cultural values, classifications and standardizations inherit those values embedded in the layers that came before. As a result, "[s]mall changes made early in the life of any developmental system will ramify throughout the growth of the system, becoming increasingly more difficult to eradicate."[26] Social values permeate the data that results from these standardizations. Lisa Gitelman explains that, while there is a cultural assumption that "data are transparent, that information is self-evidence, the fundamental stuff of truth itself," the reality is quite different.[27] Even data's supposed objectivity is "situated and historically specific; it comes from somewhere and is the result of ongoing changes to the conditions of inquiry, conditions that are at once material, social, and ethical."[28] Thus, the data produced in the process of standardization are always socially value-laden, yet perceived as or embedded in the discourse of objectivity/decontextualization.[29]

5.2 State Surveillance in the AIDS Epidemic

In an effort to produce easily accessible data, epidemiological bodies like the CDC create infrastructural documents that rely heavily on classifications to gather information quickly and efficiently about disease outbreaks. The "AIDS Case Report Form" I discuss later in this chapter

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[25] Lampland and Star, *Standards and Their Stories*, 14.

[26] Lampland and Star, *Standards and Their Stories*, 14.

[27] Lisa Gitelman and Virginia Jackson, "Introduction," in *"Raw Data" is an Oxymoron*, ed. Lisa Gitelman (Cambridge, MA: MIT Press, 2013), 2.

[28] Gitelman and Jackson, "Introduction," 4.

[29] Gitelman and Jackson, "Introduction," 5-6.

is one such document relied upon heavily to surveil the epidemic's scope in the U.S. since 1981. However, in order to better understand the role of classification in such documents, first it is vital to put such documents into context. As the "Case Report Form" was meant to surveil disease amongst the population, we must first understand the intricacies of surveillance, particularly when discussing marginalized communities and especially when such surveillance allows for access to important social needs such as healthcare and financial support. In this section, I offer a theoretical overview of surveillance before addressing the specificities of epidemiological surveillance and its history. I then briefly discuss common issues activists raised with AIDS epidemiological surveillance in order to demonstrate the awareness of the time.

5.2.1 The Modern Janus: State Surveillance and Its Complexities

In an increasingly globalized and technological world, surveillance permeates many facets of everyday life. Surveillance can be defined as "any collection and processing of personal data, whether identifiable or not, for the purposes of influencing or managing those whose data have been garnered."[30] Or, to state it another way, the two central reasons for surveillance are the protection and the management of people.[31] These rationales may appear simple and even necessary, but, as with any human-controlled process, become problematic in practice. State surveillance is also manifestation of Foucauldian governmentality, "the ensemble constituted by the institutions, procedures, analyses and reflections, calculations and tactics which can support

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[30] David Lyon, *Surveillance Society: Monitoring Everyday Life* (Buckingham: Open University Press, 2001), 8; Kevin Haggerty and Richard Victor Ericson, "The New Politics of Surveillance and Visibility," in *The New Politics of Surveillance and Visibility*, ed. Kevin Haggerty and Richard Victor Ericson (Toronto: University of Toronto Press, 2000), 8.

[31] Jenkins, "Identity, surveillance and modernity," 162.

'that very specific but very complex form of power whose main target is the population, major form of knowledge is the political economy and essential technical instrument are security apparatuses.'"[32]

Surveillance did not always take the form that it does in our contemporary moment. Initially, traditional surveillance utilized "the unaided senses and was characteristic of pre-industrial societies—information tended to stay local, compartmentalized, unshared and was often unrecorded, or if kept, difficult to retrieve and analyze in depth."[33] In the seventeenth and eighteenth centuries, for instance, security processes took the form of statistics—known as "the science of the state"—to study crime and disease.[34] With the rise of modernity, bodies became an ever increasing site of surveillance. Through surveillance and classification, "bodies could be rationally ordered…in order to socialize them within the emerging nation-state. Bodies were distrusted as sensual, irrational, and thus in need of taming, subject to disciplinary shaping towards new purposes."[35] With the proliferation of technology a new form of surveillance arose. This new surveillance had the "means to extract or create information…to go beyond…the unaided senses and minds or what is voluntarily reported."[36]

Surveillance is not a singular entity, but a vast assemblage of surveillance processes that join to produce information about the subjects under state surveillance.[37] As such, these

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[32] Michel Foucault, *Security, Territory, Populations: Lectures at the Collège de France 1977-1978*, ed. Michel Senellart, trans. Graham Burchell (New York: Palgrave Macmillan, 2007), 111; Ayse Ceyhan, "Surveillance as biopower," in *Routledge Handbook of Surveillance Studies*, ed. Kirstie Ball, Kevin Haggerty, and David Lyon (New York: Routledge, 2012), 42.

[33] Gary T. Marx, "Preface: "Your Papers please": personal and professional encounters with surveillance," in *Routledge Handbook of Surveillance Studies*, ed. Kirstie Ball, Kevin Haggerty, and David Lyon (New York: Routledge, 2012), xxv.

[34] Mathieu Deflem, "Surveillance and Criminal Statistics. Historical Foundations of Governmentality," *Statistics in Law, Politics and Society* 17 (1997): 155; Ceyhan, "Surveillance as biopower," 41.

[35] Lyon, *Surveillance Society*, 292.

[36] Marx, "Preface," xxv.

[37] Haggerty and Ericson, "The New Politics of Surveillance and Visibility," 8.

assemblages surveil indirectly. Governments, institutions, and citizens employ surveillance, the latter of which both submit to state surveillance and surveil other citizens on behalf of the state.[38] There are two primary roles within state and epidemiological surveillance apparatuses specifically. Within the institutional or governmental setting, the individual or technology observing others adopts the role of the surveillance agent. [39] The individual being observed is referred to as the surveillance subject.[40] Like all socially-embedded processes, those who may adopt the roles of agent and subject are not always interchangeable; some individuals are forced more often than not to remain subject *to* surveillance.[41]

Scholars of state surveillance link surveillance apparatuses to having power over the body, frequently citing Foucault's notion of biopower to explain the relationship. For Foucault, biopower is having "power over life" where "the species' body is not the exclusive attribute of the state, but can be achieved anywhere by any organization through information gathering and data-management processes and tools."[42] The connection between "physical security phenomenon" and probabilities rising out of statistical information allows "[state surveillance] apparatuses [to] calculate risks, but they also calculate their costs and foresee the reactions of power and set the optimal acceptability level by the population."[43] The combination of disciplinary power and biopower—or biopolitics—together "normalize individuals by coercing them, often by subtle mechanisms, to conform to standards and, in so doing, to create self-regulating pliant bodies and populations."[44] Part of this normalization process includes rendering the body visible. As Hille

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[38] Ceyhan, "Surveillance as biopower," 40.

[39] Marx, "Preface," xxv.

[40] Marx, "Preface," xxv.

[41] Marx, "Preface," xxvi.

[42] Ceyhan, "Surveillance as biopower," 38.

[43] Ceyhan, "Surveillance as biopower," 42.

[44] Monica J. Casper and Lisa Jean Moore, *Missing Bodies: The Politics of Visibility* (New York: New York University Press, 2009), 7; Jonathan Xavier Inda, *Targeting Immigrants: Government, Technology, and Ethics* (New

Koskela argues, "the connection between *bodies, space, power and knowledge* is recognized to be an essential feature in conducting surveillance and maintaining control. Making the body visible is a vital element of such dynamics."[45] In addition to who may be rendered hyper- or (in)visible, biopower and state surveillance also define whose lives are rendered disposable, sometimes referred to as the biopolitics of disposability.[46]

Two ethical considerations arise in state surveillance discourse. First, state surveillance practices are frequently and justifiably criticized for the ways in which they cause further harm to already vulnerable communities.[47] However, surveillance may not always be harmful. As Gary Marx explains, "surveillance was neither good nor bad, but context and comportment made it so."[48] Those who problematize state surveillance cite its role in disciplining certain populations into behaving in normative ways. John Fiske writes that "surveillance is a way of imposing norms where those who have been othered into the 'abnormal' have [surveillance] focused more intensely upon them."[49] Smith argues that, due to highly surveilled communities being seen as threats to the normal state, surveillance subjects are subject to "premature death in order to preserve the body of

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York: Wiley, 2005); Nikolas Rose, "Molecular Biopolitics, Somantic Ethics and the Spirit of Biocapital," *Social Theory and Health* 5 (2007).

[45] Hille Koskela, ""You shouldn't wear that body": The problematic of surveillance and gender," in *Routledge Handbook of Surveillance Studies*, ed. Kirstie Ball, Kevin Haggerty, and David Lyon (New York: Routledge, 2012), 51.

[46] Achille Mbembe, "Necropolitics," *Public Culture* 15, no. 1 (2003): 27; Henry A. Giroux, "Reading Hurricane Katrina: Race, Class, and the Biopolitics of Disposability," *College Literature* 33, no. 3 (2006).

[47] See: Shoshana Amielle Magnet and Corrine Mason, "Surveillance Studies and Violence Against Women," *Surveillance & Society* 10, no. 2 (2012); Corrine Mason and Shoshana Amielle Magnet, "Of Trojan Horses and Terroist Representations: Mom Bombs, Cross-Dressing Terrorists, and Queer Orientalisms," *Canadian Journal of Communication* 39, no. 2 (2014); Saher Selod, *Forever Suspect: Racialized Surveillance of Muslim Americans in the War on Terror* (New Brunswick: Rutgers University Press, 2018); Christine Quinan, "Gender (In)securities: Surveillance and Transgender Bodies in a Post-9/11 Era of Neoliberalism," in *Security/Mobility: Politics of Movement*, ed. Matthias Leese and Stef Wittendorp (Manchester: Manchester University Press, 2017).

[48] Marx, "Preface," xxi.

[49] John Fiske, "Surveilling the City: Whiteness, the Black Man and Democratic Totalitarianism," *Theory, Culture & Society* 15, no. 2 (1998): 81.

the whole."[50] As they are constantly reaffirming social norms, state surveillance infrastructures consist of master narratives about normalcy. Whereas "surveillance is a technology of whiteness" is most cases, for example, when whiteness becomes associated with social problems like drug use, certain types of whiteness then becomes "negatively racialized as contagion and polluting."[51]

In some cases, however, not surveilling could be as damaging as surveilling too extensively even though "obvious risk of government abuses [remain]."[52] For instance, as feminist scholars have long pointed out, privacy is not always "an unmediated good" because many women experience violence in sites of supposed privacy.[53] While surveillance is also a tool of patriarchal power, at times it still must be harnessed to address issues of gender violence because state-provided services are one of the limited (and sometimes still ineffective) means to stopping violence at home.[54] Though it does not absolve those who would use state surveillance to maintain power over vulnerable populations, such an example complicates the belief that surveillance is an always harmful practice.

A secondary ethical component of surveillance that must be emphasized is that surveillance, like classifications, is often embedded in discourse of objectivity. There is a widespread belief that "what are captured in surveillance processes are straightforward objective data."[55] Moreover, state surveillance practices tend to go unexamined because—like

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[50] Andrea Smith, "Not Seeing: State Surveillance, Settler Colonialism, and Gender Violence," in *Feminist Surveillance Studies*, ed. Rachel E. Dubrofsky and Shoshana Amielle Magnet (Durham: Duke University Press, 2015), 22.

[51] Simone Browne, "Race and surveillance," in *Routledge Handbook of Surveillance Studies*, ed. Kirstie Ball, Kevin Haggerty, and David Lyon (New York: Routledge, 2012), 75.

[52] Marx, "Preface," xxii.

[53] Smith, "Not Seeing," 31-32.

[54] Smith, "Not Seeing," 32-33.

[55] Koskela, ""You shouldn't wear that body"," 50.

classifications—good surveillance is “mundane and seamless.”[56] Yet, these are the very reasons that surveillance apparatuses need to be further examined. All scientific data is produced by people occupying different subject positions that necessarily influence the creation and reading of scientific knowledge.[57] The knowledge produced by state surveillance processes “are no less political or value laden than any other information.”[58] As such, how state surveillance apparatuses are deployed, by whom, against whom, and to what end become vital questions when weighing surveillance’s use.

The hidden nature of surveillance and the way in which surveillance is employed against some subjects more than others both serve to highlight one key feature of surveillance: its ability to render subjects (hyper-)visible. Susan Leigh Star writes that visibilities are everywhere, so it is necessary to “temper the clutter of the visibility by creating invisibles: abstractions that will stand quietly, cleanly, and docilely for the noisome actions and messy materials.”[59] Susan Leigh Star and Anselm Strauss warn that “the relation between invisible and visible work is a complex matrix, with an ecology of its own. It is relational, that is, there is no absolute visibility, and illuminating one corner may throw another into darkness.”[60] They continue, “On the one hand, visibility can mean legitimacy, rescue from obscurity or other aspects of exploitation. On the other, visibility can create reification of work, opportunities for surveillance.”[61] From a Foucaldian perspective,

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[56] Rachel E. Dubrofsky and Shoshana Amielle Magnet, “Feminist Surveillance Studies: Critical Interventions,” in *Feminst Surveillance Studies*, ed. Rachel E. Dubrofsky and Shoshana Amielle Magnet (Durham: Duke University Press, 2015), 3.

[57] Haraway, “Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective.”; Koskela, ““You shouldn’t wear that body”,” 50.

[58] Koskela, ““You shouldn’t wear that body”,” 50.

[59] Susan Leigh Star, “The Sociology of the Invisible: The Primacy of Work in the Writings of Anselm Strauss,” in *Social Organization and Social Process: Essays in Honor of Anselm Strauss*, ed. David Maines (Hawthorne, NY: Aldine de Gruyter, 1991), 265.

[60] Susan Leigh Star and Anselm Strauss, “Layers of Silence, Arenas of Voice: The Ecology of Visibile and Invisible Work,” *Computer Supported Cooperative Work* 8 (1999): 24.

[61] Star and Strauss, “Layers of Silence, Arenas of Voice: The Ecology of Visibile and Invisible Work,” 24.

state surveillance's disciplinary power "is exercised through [power's] invisibility while imposing a compulsory visibility on its targets."[62] When a subject is rendered invisible, they are legitimated and "taken for granted as an inherent part of the social fabric" whereas "power needs to be able to see what it has categorized as the abnormal."[63] This attention to visibility can render some subjects hyper-visible within surveillance apparatuses. Both visibility and invisibility have consequences for how a subject can make claims to citizenship.[64]

5.2.2 Epidemiological Surveillance

Surveillance apparatuses take many forms, the most important of which for this project is epidemiological surveillance. In the epidemiological context, surveillance is defined as "the systematic ongoing collection, collation and analysis of data for public health purposes and the timely dissemination of public health information for assessment and public health response as necessary."[65] Case reporters, such as health care providers and physicians, collect data about reportable disease cases via case report forms that are then forwarded to public health authorities and eventually to the CDC. Some diseases require reporters to notify authorities of suspected or confirmed cases; however, even reportable diseases are underreported.[66] In part, underreporting has been attributed to physicians not knowing which diseases are reportable.[67] The United States has no central authority for disease reporting. Instead, "states, territories and independent local

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[62] Browne, "Race and surveillance," 73.

[63] Fiske, "Surveilling the City," 82; Dubrofsky and Magnet, "Feminist Surveillance Studies," 11.

[64] Casper and Moore, *Missing Bodies*, 10.

[65] "WHA58.3: Revision of the International Health Regulations ", 2005, accessed February 26 2020, http://apps.who.int/gb/ebwha/pdf_files/WHA58-REC1/english/Resolutions.pdf.

[66] Timothy J. Doyle, M. Kathleen Glynn, and Samuel L. Groseclose, "Completeness of Notifiable Infectious Disease Reporting in the United States: An Analytical Literature Review," *American Journal of Epidemiology* 155, no. 9 (2002).

[67] M'ikanatha et al., "Infectious disease surveillance," 9.

authorities legislate reportable diseases, and these vary by jurisdiction."[68] Authorities determine whether epidemiological surveillance apparatuses will be passive or active, which indicates the degree to which public health agencies seek out and investigate diseases cases. Passive reporting occurs most frequently when disease reporting is governmentally mandated. In this situation, public health officials do not have to seek out case reports; physicians notify officials of cases, even if underreporting remains an issue.[69] In contrast, active disease surveillance demands public health officials make "intensive public health efforts to identify cases needed to determine incidences and epidemiologic characteristics of specific conditions within defined regions."[70]

Public health surveillance has a long history in the United States that first held modest power over the population before gaining a privileged position in the twentieth century. As early as 1741, family and public individuals—such as ship captains, lodging owners, and physicians—reported suspected disease cases to local authorities, who at the time served as public health officials.[71] In accordance with preindustrial values, Americans participated "in a kind of brotherly surveillance" in many aspects of life, and disease surveillance fell within these norms.[72] The rise of germ theory and bacteriology in the early twentieth century brought the professionalization of disease reporting vis a vis public health departments, reducing the role of the lay person in public health surveillance. In this era, public health officials in the U.S. had little to worry about in terms of respecting privacy; jurisprudence allowed them to convert homes into hospitals, seize and destroy private belongings if suspected of disease, and infringe upon personal liberty for the sake of the community's health.[73]

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[68] M'ikanatha et al., "Infectious disease surveillance," 10.

[69] M'ikanatha et al., "Infectious disease surveillance," 12.

[70] M'ikanatha et al., "Infectious disease surveillance," 12.

[71] Amy L. Fairchild, Ronald Bayer, and James Colgrove, *Searching Eyes: Privacy, the State, and Disease Surveillance in America* (Berkeley: University of California Press, 2007), 1-2.

[72] Fairchild, Bayer, and Colgrove, *Searching Eyes*, 2.

[73] Fairchild, Bayer, and Colgrove, *Searching Eyes*, 6.

Despite the privilege legally afforded to public health officers, the relationship between these officials and doctors was complicated. Doctors believed that the doctor-patient relationship was a sacred one and that it was their duty to shield patient information from public health officers.[74] Though public health officials had the law behind them and the courts determined physicians legally had to report disease cases, between 1887 and 1932 few cases were brought against doctors for failure to report.[75] Additionally, not until the late twentieth century did the Courts hear a privacy-related disease surveillance case brought forth by a citizen; such cases had exclusively been between physicians and public health officials determining the limits of surveillance's reach into patients' lives.[76] Even with the rise of the Cold War and anxiety about surveillance, disease surveillance and reporting "enjoy[ed] a privileged status" as there was a belief that "professional codes of medical ethics and their strong precedents for protecting intimate health information provided adequate sanctuary from broader assault[s] on privacy."[77] Not until *Whalen v. Roe* (1977) did citizens challenge the authority of public health officials to gather personal data for public health reporting. In this case, the U.S. Supreme Court upheld the public's interest in disease surveillance over citizens' privacy. However, in an era of "democratic privacy" where physicians no longer always serve as an intermediary between patients and public health officials like they had in previous centuries, citizens had the "desire and ability….to dictate the terms of privacy for themselves" in health policy, such as the case of confidential HIV testing. This entailed both resistance and "the right to be counted, rejecting privacy as a value that trumps all others."[78]

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[74] Fairchild, Bayer, and Colgrove, *Searching Eyes*, 6-7.
[75] Fairchild, Bayer, and Colgrove, *Searching Eyes*, 12.
[76] Fairchild, Bayer, and Colgrove, *Searching Eyes*, 14.
[77] Fairchild, Bayer, and Colgrove, *Searching Eyes*, 20.
[78] Fairchild, Bayer, and Colgrove, *Searching Eyes*, 28-29.

At the beginning of the AIDS epidemic, state and local public health officials implemented disease surveillance according to traditional procedures. Designated public health reporters created case reports that included patient identifiers, demographics, and risk factors for transmission.[79] After filling out the case forms, reporters implemented necessary patient care and sent de-identified reports to the CDC for national surveillance.[80] Due to the order in which epidemiologists discovered AIDS and HIV, AIDS surveillance existed prior to HIV surveillance and the latter more controversial than the former. Some politicians and people with HIV expressed concern "as no treatment or services were initially available and [they] had a real [concern] of job loss and stigmatization."[81] Since states and local governments determine disease surveillance, some states—in response to this anxiety—used codes instead of names to report HIV cases. However, concern over duplicating de-identified cases and subsequent accuracy led the CDC to reject de-identified case report forms for HIV surveillance.[82] Beginning in 2008, all 50 states and associated territories had implemented confidential, name-based reporting, allowing for the CDC to fully track national HIV morbidity and mortality rates.[83] As I discussed in chapter four with regards to the AIDS surveillance definition, HIV/AIDS is a unique disease in that epidemiological tools and data were used to determine things like access to funding and services. This remains the case. The Ryan White HIV/AIDS Program continues to use surveillance reports to determine how much the federal government distributes to states for the medical care of HIV-positive individuals.[84] As

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[79] Mokotoff and Shouse, "Surveillance for human immunodeficiency virus infection in the USA," 305.

[80] Mokotoff and Shouse, "Surveillance for human immunodeficiency virus infection in the USA," 305.

[81] Scott Burris, "Surveillance, social risk, and symbolism: framing the anaylsis for research and policy," *Journal of AIDS* 25 (2000).

[82] Mokotoff and Shouse, "Surveillance for human immunodeficiency virus infection in the USA," 305.

[83] "Surveillance Overview," (Web), Centers for Disease Control and Prevention, updated October 30, 2019, accessed February 28, 2020, https://www.cdc.gov/hiv/statistics/surveillance/index.html.

[84] Mokotoff and Shouse, "Surveillance for human immunodeficiency virus infection in the USA," 305.

such, the quality of surveillance data has remained a critical HIV/AIDS issue for the past four decades of the epidemic.

5.2.3 Activist Concerns with Women and AIDS Surveillance

In many respects, the AIDS epidemic drew public investment to areas that had historically been under the purview of experts. Interest in how the CDC gathered data about the epidemic was one such area of interest among AIDS activists. Beginning in the epidemic's first decade, some activists tried to make visible potential problems with how the CDC collected surveillance data beyond its basis in the flawed AIDS surveillance definition. Activist concerns about data collection specifically, especially with regards to data about women, fell into four primary categories: morbidity and mortality percentages, transmission routes, risk behaviors, and WSW.

5.2.3.1 Morbidity and Mortality Percentages Among Women

Morbidity and mortality percentages refers to the number of AIDS cases in women appearing in surveillance data. While many of the other identified issues contribute to this problem, activists drew attention to two overarching problems about the statistics as a whole. First, the CDC data separated AIDS cases by risk behavior categories. Divided amongst these categories, AIDS rates in women appear to be statistically small in number.[85] In the early 1980s, AIDS symptoms in women were not researched because the number of cases in women was "considered too small for quantitative analysis."[86] By the mid-1980s when the number of cases in women matched the number of cases in men at the start of the epidemic, public health officials claimed that "the

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[85] Patton, *Last Served*, 5-6.

[86] Patton, *Last Served*, 12.

percentage of women as a function of the total cases was too low" to justify research when other populations had higher incidences.[87]

5.2.3.2 Transmission Routes

Activists identified transmission routes as a second issue that obfuscated data about AIDS in women. In the early 1980s, the CDC developed the "AIDS Case Report Form." Subsequent surveillance data produced from information gathered on these forms functioned under the premise that male-to-male sex was the primary means of AIDS transmission. Part of the "Case Report Form" consisted of a hierarchy of likely modes of transmission with male-to-male sex at the top of the hierarchy as most likely to transmit the AIDS virus. During this period, the CDC did not allow for a case to have multiple modes of transmission. For instance, a man who had sex with other men (MSM) and who was also an IV drug user IVDU would *only* be classified as having gotten AIDS via sex with men as it was ranked first in the hierarchy. Cindy Patton noted that had IVDU been at the top of the exposure hierarchy, MSM would have *always* made up fifty percent of AIDS cases rather than their much higher percentages in the era of single-transmission data.[88] Because IVDU is a category in which women may be included, this hierarchy may have resulted in the CDC understanding women to be more at risk than the actual hierarchy allowed. Furthermore, women frequently appeared in categories such as "undetermined mode of exposure," "no identified risk," or simply "other" because the official categories of exposure were constructed in a way that privileged men's visibility.[89] As a result, historical work in this era has to account for the overrepresentation of women in "catch-all" categories.[90]

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[87] Patton, *Last Served*, 12.

[88] Patton, *Last Served*, 97.

[89] Paula A. Triechler, *How to Have Theory in an Epidemic: Cultural Chronicles of AIDS* (Durham: Duke University Press, 1999), 243.

[90] Triechler, *How to Have Theory*, 243.

By the late 1980s, the CDC introduced multiple exposure risks as part of their transmission categories. This meant that a man who had sex with other men (MSM) and who was also an IV drug user (IVDU) would be classified as an MSM/IVDU rather than MSM within the original hierarchy. Within the new system that allowed for multiple risks of exposure, those whose definitive exposure route was only male-to-male sex dropped to fifty percent of the total cases.[91] This suggests that the CDC's original classification hierarchy likely inflated numbers of AIDS in men who has supposedly received it via sex with other men; in reality, those with multiple risks of exposure were miscategorized at times.

In addition to the privileging of men's visibility, the CDC constructed risk exposure categories that defined women's risk according to their relationship to others. In cases such as IVDU, which accounted for roughly half of women's exposure risk, epidemiologists wondered if sex needed to be considered at all because it was not, in their view, a sexed behavior.[92] The other risk category viewed women as sexual partners of men with AIDS. This is problematic as it "reinforces the prevalent view that women's identities are not autonomous but established by the significant others to whom they are attached."[93] While it can be important to know, it also erases women *as women* from large parts of the data.[94] Both heterosexism and sexism obfuscated the reality that it was "receptive partners in intercourse," regardless of their sex, that put people at risk.[95] Since gay men were viewed as promiscuous with significant numbers of sexual contacts, they were rarely thought of in the context of their sexual roles with other men; that is, they were not conceived of as "partners of…" but rather as individuals with agency. Women, in comparison,

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[91] Patton, *Last Served*, 97.
[92] Patton, *Last Served*, 12.
[93] Triechler, *How to Have Theory*, 245.
[94] Triechler, *How to Have Theory*, 243.
[95] Patton, *Last Served*, 96-97.

were almost *only* thought of in the context of sexual partnership. Had the CDC taken this into account, Cindy Patton argues that the "clearest and most accurate ranking of probable routes of transmission would have placed needle sharers at highest risk, followed by receptive partners in intercourse, regardless of [sex]."[96]

5.2.3.3 Risk Behaviors

Related to transmission routes, activists showed concern about how risk categories were constructed and who appeared at risk. For the first two years of the epidemic, a column for women did not exist in surveillance summaries in the *MMWR* despite the CDC discussing cases in *MMWR* articles.[97] When sex later appeared and categories developed, women fell into the following risk exposure categories: intravenous drug users, partners of intravenous drug users, sexual partners of homosexual or bisexual men; transfusion recipients; sexual partners of persons with hemophilia; heterosexuals born in pattern II countries;[98] and mothers of pediatric AIDS patients.[99] These categories either "decontextualized" women's risk "as a partnership in a vast ill-defined general public" or her body was viewed as "ground zero of sexual danger" in cases such as sex work."[100] When women of color in particular were shown to be over-represented in AIDS surveillance, it further reinforced ideas that communities of color's sexualities were perverse or exotic "and

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[96] Patton, *Last Served*, 96-97.

[97] Patton, *Last Served*, 11.

[98] Globally, HIV has been conceived of in "pattern" clusters. Pattern I countries (the Americas, Western Europe, New Zealand, and Australia) are those countries where unprotected sex between men and unsterile needle use are the primary causes for HIV infection. In pattern II countries (sub-Saharan Africa and the Caribbean), unprotected sex between men and women, perinatal transmission, and blood transfusions are the most frequent causes of HIV infection. Finally, pattern III countries (North Africa, Middle East, eastern Europe, Asia, and the western Pacific) see the cases most frequently due to blood products and sex with people from pattern I and II countries. W. W. Darrow, "Assessing Targeted AIDS Prevention in Male and Female Prostitutes and their Clents," in *Assessing AIDS Prevention*, ed. F Paccaud, J.P. Vader, and F. Gutzwiller (Boston: Birkhäuser Verlag, 1992).

[99] Triechler, *How to Have Theory*, 244.

[100] Patton, *Last Served*, 5-6.

categorically different than ‘white’ (hetero)sexuality.”[101] Furthermore, the categories and identities used in surveillance do not “necessarily translate into recognizable identities or even recognized groups of women.”[102] Though they have some commonalities, the categories themselves were not well-representative.[103]

5.2.3.4 Women Who Have Sex With Women

If women in general were hard to see within the *Surveillance Reports,* WSW, as the opening of this chapter suggests, were virtually invisible due to the CDC’s construction of the “Case Report Form.” The CDC counted any woman who had sex with a man even once since 1978 as a partner of a man, leading to the heterosexualization or otherization of any woman who had sex with women.[104] In some instances, women might be assumed to be heterosexual based on assumptions made by her physician. According to Zoe Leonard, “Case Report Forms” “are often filled out in the patient’s absence…are often illegible or incomplete…the CDC found it impossible to categorize nearly 700 out of 5,000 women because they couldn’t determine their sexual behaviors from the report forms.”[105] Even if a WSW was noted somehow on the form, any other risk exposure would trump this “other” qualifying behavior. For instance, a WSW who used intravenous drugs would be classified as an IVDU automatically. Multiple means of exposure never existed for women with HIV/AIDS, only men.[106] Collecting data about WSW specifically was also informed by sexism and heterosexism. First, women who reported having sex with women were considered by AIDS researchers to be “lying” or that the data they were provided by

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[101] Patton, *Last Served*, 11.

[102] Triechler, *How to Have Theory,* 244.

[103] Triechler, *How to Have Theory,* 244.

[104] Patton, *Last Served*, 5-6.

[105] Zoe Leonard, “Lesbians in the AIDS Crisis,” in *Women, AIDS & Activism*, ed. The ACT UP/NY Women & AIDS Book Group (Boston, MA: South End Press, 1990), 115.

[106] Leonard, “Lesbians in the AIDS Crisis,” 115-16.

the patients was incomplete.[107] Second, WSW's exclusion was justified because they typically have a low sexually transmitted disease rate.[108] There is also a common cultural assumption that WSW have sex infrequently or that their sex is too "gentle or boring to transmit a virus."[109]

5.3 The CDC's "AIDS Case Report Form"

Having described epidemiological surveillance and common, sex-related issues identified by activists, I now offer a deconstructive reading of the AIDS Case Report Form. Star and Lampland write that deconstructive readings of infrastructural documents can illuminate master narratives saturated with cultural norms that may otherwise go unnoticed.[110] In this respect, I (1) demonstrate how the "Case Report Forms'" demographic information could have offered a corrective to *some* bias stemming from the AIDS definition out of which they were constructed, and (2) resituate many activists' concerns about non-inclusive data collection to the *Weekly Surveillance Report* rather than the "Case Report Form" itself. I do so by examining four versions of the "Case Report Forms" found during my archival research at the University of California San Francisco in their AIDS History Project Archive. As I will discuss in more detail as I analyze them below, each form was found in collections belonging to either doctors or researchers writing books during the era. Because they have been difficult to locate, I have selected these four forms due to their availability. However, archive filing and clues on the forms themselves suggest that the four forms I discuss in this section do span the timeframe of this project, giving some sense of how the

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[107] Patton, *Last Served*, 66.

[108] Triechler, *How to Have Theory*, 246.

[109] P. Clay Stephens, *U.S. Women and HIV Infection*, ed. Padraig O'Malley, The AIDS Epidemic: Private Rights and the Public Interest, (Boston: Beacon, 1988).

[110] Lampland and Star, *Standards and Their Stories*, 22.

forms may have changed over time. Additionally, while the forms contain space to gather information about opportunistic infections, the focus of this chapter is the social categories and related risk factors on which the CDC collected data. In many ways, the shifts in opportunistic infections and diseases associated with AIDS—as opposed to the social information—replicates the information I have already discussed via the AIDS surveillance case definition in chapter four. Absent in chapter four's discussion is that demographic data provided in the "Case Report Forms", and hence the forms' importance as infrastructural tools.

5.3.1 1982 KSOI Case Report Form111

The earliest version the form appears in the materials of Marcus Conant, who was a San Francisco dermatologist and one of the earliest physicians seeing patients with AIDS. The 1982 form is noteworthy among the four forms because it was updated in pen by an unknown author from an even earlier form titled "Phone Report Form" dated "August 14, 1981." Based on the typed information on the form, including those opportunistic infections and diseases indicative of the earliest AIDS cases, it is almost certainly a 1981 form for the then-unnamed syndrome. However, for the purposes of this chapter, I emphasize the handwritten additions in conjunction with the typed information rather than treating them as separate iterations of the same form. I made this decision because the handwritten update clearly defines the form's purpose as a "KSOI Provisional Revised Case Surveillance Report Form" revised "6/17/1982." My archival research suggests that public health officials and physicians referred to AIDS primarily as KSOI or KSOI

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[111] Centers for Disease Control, KSOI Provisional Revised Case Surveillance Report Form," 1982, AIDS History Project Special Collections, Conant (Marcus A.) Papers, Box 1: 1982, Folder 12: May, University of California San Francisco Archives and Special Collections."

Syndrome prior to the official naming in late 1982, making this form a particularly fascinating object for research into the epidemic's first year and a half.

Compared to latter forms, the 1982 form asked few questions about patient demographic information. The CDC gathered basic information such as patient name, age at diagnosis, date of birth/death, marital status, race, and residence. Except in two instances, this information remained unchanged from the base "Phone Report Form" to the later KSOI Provisional Form; the same information was requested, and the same options provided. The two exceptions occurred within the classificatory options for "Race." This section, which appeared between "marital status" and "residence," had three type written columns and one handwritten additional column. Positioned just below the category titled "race," the form's author wrote in the option "Haitian." Positioned in the white space next to the third column, the text read: "If immigrant, from what country?" The addition of Haitian and immigration indicated the development of Haitian as a risk category for AIDS, which occurred in the epidemic's first few years. Immigration could suggest concern about whether Haitian descent itself was a risk or if it was immigration from Haiti that indicated increased risk for AIDS. The optional space to write country of origin also might have helped identify other countries whose populations were at risk. Both additions, however, suggest rising concern with AIDS as a pandemic and anxiety over immigrants and "flexible citizens."[112]

In the final section of the form titled "Other pertinent information," two other, small additions were made to already existing questions that address what would come to be part of demographic data. First, the Phone Report Form asked the question "IV Drug usage?," gave boxes

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[112] Per Aihwa Ong, "flexible citizens" are those immigrants and international travelers who move across borders in search of better (often capitalistically motivated) opportunities. See Aihwa Ong, *Flexible Citizenship: The Cultural Logics of Transnationality* (Durham, N.C.: Duke University Press, 1999); Huiling Ding, "Transcultural Risk Communication and Viral Discourses: Grassroots Movements to Manage Global Risks of H1N1 Flu Pandemic," *Technical Communication Quarterly* 22, no. 2 (2013).

for “yes, no, unknown,” and beneath that “If yes, specify:” with an empty line for the reporter to fill in. In the 1982 form, the author underlined twice “IV” for emphasis. Beneath “If yes, specify:,” the author wrote “(e.g., heroin?).” Much like the case of Haitian and immigration, this small emphasis and clarification marks the increased concern over intravenous drug use as a possible mode of AIDS transmission. Second, the author added an entirely new question to the form beneath the “(e.g., heroin?)” clarification. The question asks: “Blood transfusion before this illness?:” with lines to note yes, no, or unknown. That this question did not exist on the prior version of this form suggests that transfusion-related transmission was just becoming a consideration for AIDS surveillance. Together, these few minor changes show the development of the “4H Club” or “4H disease”[113] literally being written into AIDS surveillance. The “sexual preference” and IV drug use questions were already present on the initial form; however, Haitians and blood recipients/hemophiliacs only just became part of surveillance efforts in June 1982.

5.3.2 1983 AIDS Case Report Form114

The second form was filed in the Don Francis papers. Francis, an epidemiologist, was one of the first researchers to discover AIDS was caused by an infectious agent. Based on the papers’ filing system and a likely indicator on the form itself, the “Acquired Immune Deficiency Syndrome (AIDS) Case Report” form can be dated at approximately 1983 and may have gone into effect in April 1983 specifically. Unlike the 1982 form, the 1983 form appears to be more similar in layout

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[113] “4H Club” or “4H Disease” were names that circulated in U.S. culture in the first years of the epidemic. The “4H” refers to the four risk groups identified by the CDC, whose names all began with H: homosexuals, heroin-users (intravenous-drug users), Haitians, and hemophiliacs. The name was implicitly referenced in jokes like: “What’s the worst part about having AIDS?” “Convincing your mother you’re Haitian.”

[114] Centers for Disease Control, Acquired Immune Deficiency Syndrome (AIDS) Case Report, “1983, AIDS History Project Collections, Francis (Don) Papers, Box 17, Folder 4: AIDS Protocols 1983, University of California San Francisco Archives and Special Collections.”

to later versions of the form and has no handwritten additions. The form also expanded from two pages to four pages in length in the span of less than a year. Based on the shift in titling from KSOI to AIDS, the form's expansion can most likely be attributed to the syndrome's official naming and the development of a clearly articulated AIDS surveillance definition in the *MMWR*.

The CDC continued to divide patient data in two categories—personal information and demographic information; however, important changes occurred between 1982 and 1983 within these categories. The 1982 section "Patient" was renamed "Basic Patient Information" in 1983 and contained information about name, date of birth, race/ethnic origin, and sex, among others. Where the KSOI form allowed space for either patient "name or initials," the 1983 form no longer accepted patient initials, suggesting a more serious surveillance effort. The 1982 section "status," which indicated whether a patient was alive or dead," expanded in 1983 under the title "Current Condition/Prognosis" to include four options. These options included "outpatient/ambulatory," hospitalization in critical or non-critical condition, and dead. Allowing for greater patient condition classifications may have aided in tracing AIDS' chronicity and severity in this early moment. 1982s section "Race" was renamed "Race/Ethnic Origin" in 1983 and no longer included questions specifically about immigration or individuals of Haitian descent. While the classifications remained functionally the same, if titled and organized differently, "not stated"—the option for uncertainty, other, or perhaps even multiracial identities—was removed entirely. By 1983, an AIDS patient had to be identified as: White, Black, Asian/Pacific Islander, American Indian/Alaskan Native, or "of Hispanic (Latin American)" origin.

The 1982 section "Other pertinent information" included much of the same questions as the 1983 section "Social and Risk Factors" with a few additions from 1982's "Patient" information. Twenty-four questions fell into the "Social and Risk Factors" category, which covered topics like:

occupation, marital status, living arrangements, country of birth, IV drug use, sexual orientation, and pregnancy/birth. In 1982, sexuality fell under “sexual preference” in the “Patient” section of the form. The options for sexual preference were male, female, both, and/or unknown. In 1983, the form asked “what is the sexual orientation of this patient?” followed by “heterosexual, homosexual, bisexual, none, unknown.” Notably, the earliest form asked questions only about the *sex* of the individuals with whom the patient had sex. However, beginning in 1983, the focus shifted from only the sexual partner(s)’ sex to both the partner(s)’ sex and the patient’s sexual *identity*. By privileging both identity and behavior, the 1983 form further strengthens the relationship between homosexual-identifying men and AIDS.[115]

When revising for the purposes of the KSOI form in 1982, other categories were expanded or limited. For instance, public health officials wanted to know broadly about immigration with the exception of a specific question about Haiti. The 1983 form expands upon these questions considerably. After asking if the patient was born in the U.S. and, if not, when they immigrated, the form then asks: “If patient or either parent were born outside the U.S., what was country/territory of birth/origin?” The options provided are: Canada, Cuba, Dominican Republic, Haiti, Mexico, Puerto Rico,[116] Cambodia/Vietnam/Laos,[117] Other (specify country/territory).” This increase further demonstrates concern over the U.S.’s borders and interest in identifying any

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[115] In Public Health, it is common to discuss sexuality in at least two ways: behavior and identity. Identity refers to how one socially orients themselves with their sexual identity, i.e. lesbian. Behavior refers to the types of sex that an individual engages with, i.e. a woman who has sex with men and women. For a variety of cultural reasons, sexual identity and sexual behavior do not always correspond, especially when a particular identity is socially stigmatized.

[116] I have found no clear reason why Puerto Rico, as a U.S. territory since the late nineteenth century, would have been classified as a country of origins for immigration-based questions. My suspicion is that Puerto Rico was coded as such to gather data about race/ethnicity as well as track cases that may have originated in the Caribbean, particularly as it neighborhood the “hot zone” Haiti.

[117] It is unclear why the CDC identified these southeast Asian countries of particular interest in 1983. The first cases of HIV/AIDS within the region did not occur until the early 1990s. Thailand, South Korea, and Japan all reported HIV/AIDS cases in the mid-1980s, which suggests that HIV/AIDS outbreaks had little to do with the rationale for including these nations. However, the U.S. government may have been motivated to preemptively track southeast Asian countries due to the Cambodian Humanitarian Crisis and influx of refugees.

correlations between country and AIDS risks. Despite this rather early expansion of named locales, Haiti continued to occupy a position of heightened visibility in the U.S. Where it expanded on immigration questions, the 1983 form asked a single question about intravenous drug use: "Has the patient ever used <u>needles</u> for <u>self-injection</u> of non-prescription drugs?" Unlike 1982 when public health officials requested specific information about the drugs used, 1983's form gave the options yes, no, or unknown. The change suggests that public health officials were more concerned about the mode of transmission than the substance being transmitted. Though the name "4H Disease" was not adopted by health professionals and served as a lay way to refer to AIDS, the name still referred to the common risk groups associated with AIDS. "Heroin users" stood as the H in this name for intravenous drug use, suggesting that health officers may have been looking at heroin specifically as an indicator for AIDS. The removal of the shortly lived "If so, specify" in the 1983 form implies that the drug used was no longer important and that "heroin users" served a particular purpose in a popular moniker that no longer reflected health officials' actual interests.

5.3.3 1985 AIDS Confidential Case Report118

Located in the Nancy Stoller papers, the "Acquired Immunodeficiency Syndrome (AIDS) Confidential Case Report" went into effect in early 1985. Where the 1983 form expanded considerably on its earlier iterations, the CDC reduced the 1985 form to two pages. The reduction in length is largely the result of fewer questions about the patient's symptoms, diseases, and extensive contact information for healthcare personnel responsible for the patient. The 1985 form

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[118] Centers for Disease Control, "Acquired Immunodeficiency Syndrome (AIDS) Confidential Case Report," 1985, AIDS History Project Collections, Nancy Stoller Papers, 1981-1995, Box 1, Folder 23: CDC Surveillance Forms [blank] undated, University of California San Francisco Archives and Special Collections.

marks the first time that patient confidentially was emphasized and built into the form via sections for the Soundex Name Code[119] and lengthy passages on the back of the form ensuring confidentiality measures. The heightened vigilance surrounding confidentiality—and perhaps even the reduction in space allotted to symptoms—can be attributable to the isolation of the as-yet-unnamed AIDS virus and development of a test for the virus.

In 1985, the “Basic Patient Information” remained largely identical to the 1983 form. The two changes that occurred involve the question about race and the data about the patient’s current condition. Where the 1983 form asked a separate question regarding ethnicity, the 1985 form collapsed the two questions into one. Under the section “Race/Ethnicity,” the classifications “White (not Hispanic)” and “Black (not Hispanic)” were added in addition to the new Race/Ethnicity classification “Hispanic.” Unlike the previous form, the 1985 form once again incorporated a functionally “other” category with the option for “Not specified,” which had not been included since the 1982 version. With regards to the patient’s current medical condition, the 1985 form no longer asked about whether the patient was hospitalized and whether they were in critical or non-critical condition. Instead, the question “Current Status” only asked whether the patient was “Alive,” “Dead,” or whether their condition was “Unknown.”

The “Social and Risk Factors” section incorporated more changes by virtue of containing many questions that once were considered part of basic patient information in the earliest years. The immigration questions were worded the same with the exception of the CDC no longer having an interest in the patient’s *parents*’ country of origin. However, the CDC dropped several classification options, only asking if the patient immigrated from Canada, Dominican Republic, Haiti, Mexico, Puerto Rico, or Other. The case reporter continued to be asked to identify the

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[119] The Soundex Name Code was a tool employed in the U.S. for confidential disease reporting to the CDC.

country of origin if not listed among those classification options given. After the immigration question, the form asked questions regarding “sexual orientation” and IV drug use. Both questions were worded nearly identically to the 1983 form with the same classificatory options offered. The CDC chose to reduce the number of questions related to sexual behavior from 1983 to 1985. Both forms asked whether or not an individual, regardless of their sex, had sex with a male partner or with a female partner. The CDC removed questions about whether the patient had been in non-sexual contact with a person with AIDS or sexual contact with someone who came to have AIDS. Instead, the CDC asked whether the patient had “heterosexual relations with a person with a risk factor for AIDS.” This was the first time that sexual orientation appeared within this category of questions, and it suggests that all homosexual relations were coded as being risky and all homosexuals as already at risk for AIDS. Otherwise, the specification of heterosexual would not have been needed. The shift away from previous questions also indicates that the CDC no longer viewed casual, non-sexual contact with a person with AIDS as a possible risk factor. Yet, the CDC deemed it important to know whether or not the patient had been sexually involved with anyone *at risk* for AIDS as opposed to just someone who “now [had] AIDS.”

Despite the relatively minor changes to the “Social and Risk Factors” section, the CDC included a clear temporal constraint upon the form in 1985. In the 1983 form, the reporting agent was asked “During the five years preceding diagnosis of possible AIDS, did this patient:” followed by a list of questions. In 1985, this question was updated to read “Since 1978 and preceding the diagnosis of AIDS, did this patient.” Though the time period referenced in both forms is about the same given the forms’ publication dates, the identification of 1978 created temporal rigidity for which all patients had to account; the time span (five years) was no longer flexible dependent up on the patient’s diagnosis. This meant that greater periods of time and behaviors performed within that time period had to be accounted for in ways that the 1983 form did not request. While in practice this may have helped patients with only one risk factor identify probable transmission route, the extended time period may have expanded possible transmission routes for individuals with multiple risk factors and therefore obscured the most likely route. As activists noted, a woman who only had sex with women within five years of diagnosis in 1983, for example, would have likely been classified as "other/unknown." However, within the 1985 system, if that same woman had sex with a male partner once in 1979, she would automatically be counted as heterosexual risk.

5.3.4 1992 HIV/AIDS Confidential Case Report Form120

Also located in the Nancy Stoller papers, the final "Case Report Form" discussed in this chapter is the "Draft Proposed Adult HIV/AIDS Confidential Case Report Form" that adhered to the AIDS case definition proposed in November 1991. The form explicitly includes an expiration date of November 1992, making the draft far easier to situate within the "Case Report Form" timeline. While categories have been restructured and renamed, the content within in the form itself and its length remains roughly the same between 1985 and 1992. The most significant language and categorical shift can be attributed to the widespread use of the HIV antibody test. For instance, the 1992 form asked for the patient's diagnostic status at the time of reporting: HIV (not AIDS) or AIDS.

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[120] Centers for Disease Control, Draft Proposed Adult HIV/AIDS Confidental Case Report Form, "1992, AIDS History Project Collections, Nancy Stoller papers, 1981-1995, Box 6, Folder 38: Meeting Minutes 1992, University of California San Francisco Archives and Special Collections."

The form's two sections that have been the primary focus of this chapter were renamed by 1992. The "Basic Patient Information" section became "Demographic Information" and "Social and Risk Factors" became "Patient History." The only notable change in Basic/Demographic information was the removal of all countries listed as classificatory options in the immigration question. Instead, the 1992 form asked if the patient was (1) born in the U.S., (2) U.S. dependencies and possessions, with a request to specify the territory, (3) Other (specify), and (4) Unknown. 1992 marked the first time that the CDC offered the "unknown" classification, though technically a case reporter could have written it on the line included with "other" on the previous forms.

The Risk Factors/Patient History section, however, posed more questions about sexual behavior than previous forms. The case reporter would have asked all patients, regardless of sex, whether or not they had sex with a male or female "after 1977." In the 1985 form, these questions were followed with a question as to whether or not the patient had "heterosexual relations with a person with a risk factor for AIDS." By 1992, the single question about "heterosexual relations" expanded to include seven specific risk factor questions. Identified risks included: intravenous drug use, bisexual male, hemophilia, transfusion or transplant recipient, a person with HIV or AIDS with an unspecified risk, or born in a country with predominate heterosexual risk. After finishing the list of "heterosexual relations" questions and posing a few others, the CDC asked a single, remarkable question that is entirely new to any of these report forms: had the patient ever "exchanged sex for money or drugs."

The sexual exchange question is worth lingering over for two reasons. First, the behavior at the center of the question replicated previous questions as the CDC wanted to know whether or not the patient engaged in sex. Exchanging anything for money or drugs does not put a person at risk for HIV; otherwise, a pharmacy technician would be at risk within this framework. The actual *risk* is the sex act itself, which has already been asked about in previous questions. In that regard, the question is superfluous. Effectively, the CDC wanted to know whether or not the patient performed sex work in the previous fourteen years.

Second, sex work is a highly gendered form of work most often associated with women. The 1992 report form may have marked the first time that the CDC recognized sex work as a possible risk category despite that risk only being articulated through spatial association with other known risk categories. Activists and female researchers had tried beginning in the early 1980s to bring attention to sex work as one prominent way *women* acquired AIDS, remarking that if a prolific number of sexual partners—as gay men were often accused of having—put one at risk for AIDS then certainly public health officials should turn their attention to women in this industry.[121] Despite the logic of these claims, public health officials and the media largely focused on sex workers only through their concern for the men with whom they might have sex and infect.[122] As this 1992 form was only a draft, it remains to be seen whether or not the question was ultimately included in the final form and whether the information gathered by the CDC about sex work circulated and to what extent.

5.3.5 Discussion

The early "AIDS Case Report Forms" reveal three important findings about early AIDS disease surveillance and activist response. First, the "Case Report Form" was only meant to collect new surveillance data about the epidemic in a very limited way. That is, the CDC constructed a form to answer the questions they knew to ask; there appeared to be little room for discovery within

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[121] Corea, *The Invisible Epidemic*, 9.
[122] Patton, *Last Served*, 67; Corea, *The Invisible Epidemic*, 14.

the apparatus itself. This can be most readily seen in those instances where the 4Hs are written into and out of the Report Form. For instance, asking questions about sexual *identity* and placing homosexuality highest among the hierarchy of risk will create data that will skew towards sexual identity rather than sexual practices as a critical factor for AIDS. However, a question about whether a patient was penetrated during sex regardless of their sex would have created a different set of risk behaviors. The Report Form did not seek to necessarily offer new data so much as reflect then existing knowledge. In that respect, AIDS activists claims that the CDC ignored AIDS in women by pointing to surveillance data was technically true, particularly as the CDC did nothing to discover why so many women were categorized as "other" in transmission route.

Second, the forms show that activists claims that the definition was too narrow and that it negatively impacted surveillance data were not entirely accurate. It is true that sections of the form that relied on the definition—such as symptoms and opportunistic diseases—would have had a bias against women's inclusion as I have already discussed in the previous chapter. However, other question categories present within the forms that did *not* rely on the definition could have, at least theoretically, compensated for the bias. Every iteration of the form included separate questions about the patient's sex and their sexuality or sexual history. It was *possible* for a WSW to appear on the form; the case reporter simply had to check the classification "female" and "homosexual" or "had sexual relations with a female partner." Thus, it would be possible, with particular caveats, to reconstruct portions of the AIDS epidemic from these forms to show the impact on WSW, for example. However, the most significant caveat is that case reporters filled these forms out in ways informed by their own biases. For instance, the assumption that any woman with AIDS was heterosexual, as reports suggested, may have led a case reporter not to ask whether a female patient had ever had sex with a woman or if she was any identity other than heterosexual. Smith's account in the opening anecdote to this chapter offers a similar scenario occurring in her own research experience. Therefore, it is not beyond reason to assume that case reporters may have responded similarly. In this regard, activists' concerns were slightly misplaced though not unwarranted. The distinction is important as the solution would have required different efforts: infrastructural change versus bias education.

Finally, though the "Case Report Form" itself *could* have offset some gender bias, the CDC's collection and the surveillance reports based on this data ultimately replicated and furthered sex- and sexuality-based biases. In the metaphorical black box between data input and output, what surveillance statistics were made visible and what statistics were thrown out or which combinations never examined became lost. At some point at the CDC, someone made the decision that the classifications male and homosexual/bisexual were important and female and homosexual/bisexual were not. We know this because prior to 1982, as I will demonstrate below, female and bisexual *was* for a brief moment in time of interest to the CDC. In order to show why it is important not only to study the forms but also the data that came from those forms, I now turn to the *AIDS Weekly Surveillance Report*.

5.4 AIDS Weekly Surveillance Reports

After case reporters sent the "AIDS Case Report Forms" to them, the CDC would take the data and circulate the latest surveillance findings via a document called the *AIDS Weekly Surveillance Report*. Archival research shows that, at the very least, doctors, researchers, and public libraries across the U.S. received the reports, making them widely available to expert and non-expert audiences upon their publication. Presently, beyond their presence in university archives, some *AIDS Weekly Surveillance Reports* have been digitalized via HathiTrust Digital Library in collaboration with several special collections' archives in the U.S. As I will discuss in more detail in this subsection, the data chosen by CDC officials to be included in the reports vary over the first decade. However, across this period, the reports tend consistently to provide demographic data, morbidity and mortality rates nationally and by state, and transmission and disease information.

I employed archival research methodology for this subsection and utilized grounded theory to track reporting trends over time. Prior to 1988, archives catalogued approximately three to four *AIDS Weekly Surveillance Reports* per year. There appeared to be a trend to archive these reports quarterly, with March, June, September, and December issues being the most prevalent in these collections. For these pre-1988 reports, I selected one week from these four months when available for analysis. When unavailable, I selected the closest available week in the preceding or following month. For instance, if a September issue was unavailable, I referred to either the latest August or earliest October issue. Beginning in 1988, the archives provided nearly thirty issues of the report. As I had already established a quarterly pattern due to constraints faced with earlier reports, I continued to select the latest issue in March, June, September, and December for my archive. In 1989, the CDC shifted to monthly reports instead of weekly and increased the data provided. Due to the length, I selected three months out of the year—April, August, and December when possible, or the nearest months otherwise—for my research. Finally, by 1992, the CDC shifted to a quarterly system instead of a monthly publication rate and once again increased the information included in the report. In this case, I selected only the second quarter publication. I had initially planned to look at both June and December; however, December was unavailable in my materials. This selection process left me with thirty-four reports spanning 1982-1992 as my archive. I then tracked both report categories—such as primary disease, age, or patient groups—and classifications within those categories—for example, for patient groups: heterosexual contact or Haitians—across each report. From this analysis, I then compiled a list across three categories that demonstrates how the CDC's *Surveillance Reports*—despite collecting the necessary data in the "Case Report Form"—obfuscated, removed, or deprioritized information relating to women and people of color.

5.4.1 Race and Ethnic Classifications

In the 1982 to 1992 period, the classifications used within the category Race/Ethnicity remained relatively stable both within the "Case Report Form" and *Surveillance Report*. However, a few small changes had powerful, rhetorical effects on how AIDS in various racial and ethnic groups would be communicated. The earliest report in the archive—titled "Kaposi's Sarcoma (KS), Pneumocystis Carinii Pneumonia (PCP), and Other Opportunistic Infections (OI): Cases Reported to CDC, As of June 15, 1982"—has one of the most inclusive classifications schemes across the decade I have researched. The CDC tracked along six classificatory options: (1) white, not Hispanic; (2) black, not Hispanic; (3) Hispanic; (4) Asian & Pacific Islander; (5) American Indian & Alaska Native; and (6) Unknown.[123] These classifications correspond with those on the "Case Report Form" from which edits were made in 1982. However, by August 1982, the CDC no longer gave data about Asians and Pacific Islanders in their *Surveillance Report* despite still collecting data on them on the "Case Report Form."[124] The only addition to the August report was the inclusion of a classification for Haitians. In June 1983, the CDC reverted back to the initial

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[123] Centers for Disease Control, *Kaposi's Sarcoma (KS), Pneumocystis Carinii Pneumonia (PCP) and Other Opportunistic Infections (OI): Cases Reported to the CDC, As of June 15, 1982* (1982).

[124] Centers for Disease Control, *Kaposi's Sarcoma (KS), Pneumocystis Carinii Pneumonia (PCP), and Other Opportunistic Infections (OI): Cases Reported to the CDC As of August 6, 1982* (1982).

classifications, removing Haitians and adding Asians and Pacific Islanders back to the form; however, this change would be short lived.

Beginning in September 1983, the CDC would only report AIDS case numbers for the following categories: (1) white, not Hispanic; (2) black, not Hispanic; (3) Hispanic; (4) other; and (5) unknown.[125] Through 1986, the "other" and "unknown" classifications remained separate, but by March 1987, these two classifications would be combined into the hybrid "Other/Unknown."[126] In their June 1987 report, the CDC explained for the first time that the "Other" of the new "Other/Unknown" classification included Asian & Pacific Islander and American Indian & Alaska Native numbers and reported the total cases for each racial classification in the footnote.[127] In September 1988, the CDC officially reincorporates Asian & Pacific Islanders and American Indian & Alaskan Natives back into the data table rather than giving total cases in the footnotes.[128] The final change to the Race/Ethnicity categories occurred by April 1991 when the classification "Other/Unknown" was removed completely. Per a footnote, anyone classified in the Other/Unknown category was represented in the "Total" column. As I address momentarily, these patients in the "borderlands" of categorization—to borrow a term from Bowker and Star—reveal much about the symbolic power inflecting the surveillance infrastructure.[129]

In addition to the shifting classifications present in the *Reports*, one further challenge must be addressed. It was not until April 1989 that the CDC reported transmission rates along racial *and* sex groups. Prior to April 1989, a *Report*'s reader could not find, for example, transmission rates for female, Hispanic IVDUs, only for female IVDUs or Hispanic IVDUs.[130] Thus, not only were

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[125] Centers for Disease Control, *Kaposi's Sarcoma (KS), Pneumocystis Carinii Pneumonia (PCP), and Other Opportunistic Infections (OI): Cases Reported to CDC as of September 29, 1982* (1982).

[126] Centers for Disease Control, *AIDS Weekly Surveillance Report - March 30, 1987* (1987).

[127] Centers for Disease Control, *AIDS Weekly Surveillance Report - June 29, 1987* (1987).

[128] Centers for Disease Control, *AIDS Weekly Surveillance Report - September 26, 1988* (1988).

[129] Bowker and Star, *Sorting Things Out*, 302.

[130] Centers for Disease Control, *HIV/AIDS Surveillance - Issued April 1989* (1989).

women in general at a disadvantage when it came to data reporting, but women of color in particular were negatively affected. As Kimberlé Crenshaw wrote in her landmark article on intersectionality, too often power imbalances within marginalized communities are ignored and representational politics get in the way of important intracommunity differences.[131] The absence of data about women of color with AIDS specifically communicated that all women or each racial group participated in the same risk behaviors with little need for nuance.

Classification and its subsequent data communicate what is significant to the rhetor creating the schema. When the classificatory system involves surveillance—and in this case public health surveillance—of people, those who appear within the classification apparatus are those who are deemed statistically significant and/or important to render visible. While surveillance practices, especially regarding communities of color, can and should be troubled, it is not unreasonable to suggest that data on AIDS in communities such as Asians and Native Americans or women of color would have been useful to report to the general public. Despite *collecting* the data in "Case Report Forms," the CDC did not *report* the data for a three-year period and offered no intra-group nuance to that data for four to seven years. In that period in the case of the former, the CDC deemed them statistically insignificant by relegating these communities to the "Other/Unknown" category, which was also occupied for those whom no racial/ethnic background existed in the "Case Report Form".

In their discussion of residual or "Other" categories, Bowker and Star wrote that "the constraints of the classifying and (often) dichotomizing imagination" led to the creation of those who could not fit into ordinary categories.[132] These individuals, according to Ritvo, were perceived

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[131] Kimberlé Crenshaw, "Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color," *Stanford Law Review* 43, no. 6 (1991).

[132] Bowker and Star, *Sorting Things Out*, 304.

as monsters or freaks within the classificatory schema because "monsters were united…by their common inability to fit or be fitted into the category of the ordinary—a category that was particularly liable to cultural and moral construction."[133] To speak about racial and ethnic minorities within this context is not to suggest that they were monsters, but to demonstrate how the relegation to the "Other" or surplus category can dehumanize those who are not made visible.

In citing these two works, I suggest that classification systems often fail insofar as there always remains a represented or unrepresented population for which the system does not allow. In the case of Asians or Native Americans in the *Surveillance Report*, the problem is not that these cases are made up of biracial individuals (though some may have been) who do not wholly fit in one category or another. Rather the problem is that the CDC took data it collected and *rendered* it residual or monstrous, first by not reporting it and then by representing the cases under the header "Other/Unknown." These cases were not statistically privileged enough to be visible or nuanced within the classification system. As a result, intervention in these overlooked communities could not be targeted.

5.4.2 Sex & Sexuality

When discussing how sex and sexuality are classified within the Weekly Reports, I have combined the two because, for most of the *Weekly Report*'s history, the CDC treated them as closely linked or interchangeable. Significantly, this interconnectedness was especially symptomatic of the *Weekly Report*. Within the surveillance structure of the "Case Report Form", sex and sexual behavior or identity were two separate questions. The "Report Form" asked whether

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[133] Harriet Ritvo, *The Platypus and the Mermaid, and Other Figments of the Classifying Imagination* (Cambridge, MA: MIT Press, 1997), 133-34.

the case was male or female and later asked, as separate questions, whether they had ever had sex with a male or female partner.[134] The collection of this data is important because it was only when the CDC *distributed* the data that sex and sexuality of a patient became combined in problematic ways to the detriment of marginalized communities.

Over the course of the decade under study, the CDC privileged data reporting on male populations over female. Perhaps ironically as so little was known about the epidemic then, the June 15, 1982 *Report* employed the most nuanced classification system that women would ever see in the epidemic. In this earliest document from my archive, the category "sexual orientation" included six classificatory options: (1) homosexual males; (2) bisexual males; (3) heterosexual males; (4) males of unknown sexual orientation; (5) heterosexual females; and (6) bisexual females.[135] For reasons that remain unclear given the limited knowledge about AIDS at the time, homosexual females and females of unknown sexual orientation were not included as categories. The pre-1982 "Case Report Form" suggests that nothing precluded a patient from being a female with a "sexual preference" for "M," "F," "Both," or "Unk," which could indicate that the June 15, 1982 reporting classifications for heterosexual and bisexual females grew out of AIDS cases reported to the CDC.

Though the presence of two sexual identity classifications in June 1982 hardly seems inclusive compared to male's classificatory options, only a few months later during the week of August 6, 1982 the classification options no longer existed. The CDC included five "sexual orientation" categories in August 1982: (1) homosexual males; (2) bisexual males; (3) heterosexual

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[134] Just because these questions were present on the form does not necessarily mean that *in practice* reporting authorities would complete the Case Report Form fully or without bias. It is conceivable that some reporters may not have asked female cases, for example, if they had ever had sex with a woman because women who had sex with women were not deemed at risk. However, this is a problem of practice rather than the surveillance apparatus itself replicating (hetero-)sexism.

[135] Centers for Disease Control, *KS, PCP, OI Report - June 15 1982*.

males; (4) males of unknown sexual orientation; and (5) females.[136] Two points must be made about this change. First, though it ought not need to be stated, "female" is not a sexual orientation; it is a sex, and that data was already provided on the first page of the August 6, 1982 *Weekly Report* under rates by sex. Second, the absence of any sexual orientation left women unmarked. In the case of sexuality, the unmarked always refers to the privileged category: heterosexual. This is especially unfortunate because the June 15, 1982 *Weekly Report* indicated one bisexual female case; a few months later, she has disappeared entirely into the implicit classification *heterosexual female*.[137]

By June 27, 1983, the CDC would make another change to how sex and sexual identity appeared in the *Weekly Report*. The category for sexual orientation no longer existed in the *Weekly Report*. Instead, particular sexualities became "risk groups," the first in the hierarchy being "homosexual or bisexual."[138] Despite "homosexual or bisexual" not being sexed, the table's data showed that this classification belonged solely to men with only males having case numbers reported. Later, the CDC would make explicit that "homosexual or bisexual," as first a single and later two separate classifications, referred only to men. In 1983, the CDC did not consider heterosexuality to be a risk category, though presumably some heterosexual cases appeared in the "No Apparent Risk Group or Unknown" risk group classification. For nearly a year, these classificatory options remained unchanged. For women, the "No Apparent Risk Group or Unknown" would remain the second or third largest transmission category, which numbered in the high 30% of all female AIDS cases. This high percentage of "other" cases may have meant that

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[136] Centers for Disease Control, *KS, PCP, OI Report - August 6, 1982*.

[137] Centers for Disease Control, *KS, PCP, OI Report - June 15 1982*.

[138] Centers for Disease Control, *Acquired Immune Deficiency Syndrome (AIDS), Kaposi's Sarcoma (KS), Pneumocystis Carinii Pneumonia (PCP), and Other Opportunistic Infections (OI): Cases Reported to CDC as of June 27, 1983* (1983).

the classifications used in the *Weekly Report* were not doing the labor needed to make clear how AIDS was transmitted. In the September 26, 1983 *Report*, "homosexual or bisexual" came to modify "men" in the classification, and the CDC created the classification "heterosexual contact" with a person with or at risk for AIDS as a new "patient group"—a new term for "risk group."[139] At this point, female AIDS cases could only be heterosexual or other, despite twice as many options for male cases.

A final point about the privileging of male visibility over female in the *Weekly Report* relates to the curious presence of sex work later in reports. In the March 30, 1987 *Weekly Report*, a footnote explained that "men reported only to have had heterosexual contact with a prostitute" were considered part of the "undetermined" transmission category rather than "heterosexual" or even homosexual or bisexual.[140] Again, two points ought to be mentioned here. First, the *Weekly Report* did not tell the reader where women who engage in sex work might appear in the statistics—heterosexual or unknown—only where *men* appear. This is despite the fact that sex workers were *more* at risk than their johns for HIV transmission.[141] It further exemplifies how women's bodies are most often taken into consideration when they are seen as vectors and vessels of disease transmission rather than as possible patients in need of care.[142] Second, it is incredibly unclear why a sex act, of all things, is not represented alongside any sexual behavior. I first assumed that perhaps the CDC was making assumptions about safe sex practices, such as condom use; however, considerations for such precautions did not appear to be anywhere in the other sexual

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[139] Centers for Disease Control, *Acquired Immunodeficiency Syndrome (AIDS): Weekly Surveillance Report, September 26, 1983* (1983).

[140] Centers for Disease Control, *AIDS Report, March 30, 1987*.

[141] Patton, *Last Served*, 67, 96-97; Corea, *The Invisible Epidemic*, 84-85.

[142] Ruth Faden, Nancy Kass, and Deven McGraw, "Women as Vessels and Vectors: Lessons from the HIV Epidemic," in *Feminism & Bioethics: Beyond Reproduction*, ed. Susan M. Wolf (New York: Oxford University Press, 1996).

transmission classifications. As such, I can only suggest that this footnote and data reporting practice was just one more way that information was collected about men and not women.[143]

5.4.3 Transmission Categories

By mid-1983, the CDC began including "risk groups" in the *Weekly Report*. Over the next decade, this category would change to "patient characteristics, "patient groups," and "transmission categories;" however, the category itself communicated the same information: likely modes of AIDS exposure. The first time the category appeared in 1983, it included the following five classifications, broken down into columns for male and female data: (1) "homosexual or bisexual;" (2) "IV Drug User, No History of Homosexuality;" (3) "Haitian, No History of Homosexuality or IV Drug Use;" (4) "Hemophiliac, No History of Homosexuality, IV Drug Use or Haitian;" and "No Apparent Risk Group or Unknown."[144] As these classifications suggest, the CDC hierarchically ranked modes of transmission, though later the explicit language of "no history of" would be removed from the classifications. For example, in the early years of single-risk of transmission, a man who was both homosexual and a hemophiliac would be classified only as a "homosexual or bisexual" within the *Weekly Report* because it was the highest ranked or most likely explanation for transmission. Later in 1984, "Heterosexual Contact" and "Transfusion with Blood/Blood Products" were added as risk classifications.[145] By September 24, 1986, the CDC

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[143] Notably, the *Weekly Report* only addressed sex work in the context of male and female sexual encounters. The only rationale I can offer is that perhaps all gay men were categorized as male-to-male sexual risk with little interest by the CDC to understand more about the nature of the sexual encounters.

[144] Centers for Disease Control, *AIDS, KS, PCP, OOI Report June 27, 1983*. It should also be noted that many men may have engaged in same-sex sex acts and failed to answer truthfully for a variety of reasons or that case reporters may have made assumptions about the patient's sexual behavior. As evidenced by Rock Hudson, many men who engage in same-sex intercourse can pass as heterosexual, further complicating the CDC data.

[145] Centers for Disease Control, *Acquired Immunodeficiency Syndrome (AIDS) Weekly Surveillance Report, September 24, 1984* (1984).

had removed Haitian as a risk category and began recording both single- and multi-risk categories. An example of a multi-causal classification would be “IV drug use; receipt of [blood] transfusion.” At times, these multi-causal classifications listed up to four different, possible causes for HIV transmission. Typically, those multi-causal risk categories with the most cases occurred at the intersection of IV drug use and homosexual/bisexual male or heterosexual contact.

One of the most important observations about the risk categories is that—as activists have pointed out—they offered a lot of information about men and very little about women. With regards to single-risk exposure classifications, this imbalance may at first not seem like a significant issue; after all, the only classification that excludes women is “male homosexual/bisexual contact.” However, when the CDC began to include multi-risk classifications, the exclusion grew exponentially. In the 1986 to 1992 period, the CDC employed anywhere from twenty-three to twenty-five multi-risk classifications, and ten to twelve of those included variations of homosexual/bisexual men. Thus, not only was women homosexual or bisexual behavior not being reported on, but neither were any of the possible, multi-risk factors leading to HIV transmission. Additionally, because most of the multi-risk factor classifications were not presented with sex-separated data, it is unclear to which multi-casual risk factors women were most exposed.

A final consideration is the CDC’s fixation on sexual identity over sexual behavior. As previously stated, Cindy Patton once argued that far more telling for transmission risk than sexuality was whether or not a person—regardless of sexuality—was the receptive partner in intercourse. While on the “Report Form” the case reporter would respond to questions about the sex and sexual behavior of the case, the CDC took that sexual behavior information and reported it as sexuality. Thus, a “Report Form” that listed a case’s sex as “male” and yes to “sex with male” and “sex with female” would report that case’s risk as “homosexual/bisexual contact.” This would obviously cause a problem if the same case was a female as she would be considered “heterosexual contact” with the same responses. However, by the late 1980s, the CDC’s commitment to identity over behavior in multi-risk transmission classifications began to be absurd. In 1991, for example, a man could be classified with the multi-risk transmission of “Male homosexual/bisexual contact; heterosexual contact.”[146] While at first “homosexual/bisexual contact” seemed to indicate behavior as opposed to identity, the inclusion of a multi-risk classification like homosexual/bisexual contact and heterosexual contact suggests something more complex. In the strictly behavioral sense, a person who has homosexual and heterosexual contact would have bisexual contact; thus, heterosexual contact is already implicit in the single risk “Male homosexual/bisexual contact” classification. Rhetorically, this implies that the CDC may not have been thinking solely in terms of behavior when using “homosexual contact” versus the earlier “homosexual.” It also suggests that the focus on the blurred identity/behavior classification made the classification useless as all it told the reader was that the individual had sex, which offers very little help for surveillance purposes.

5.4.4 Discussion

By analyzing the “Case Report Form” together with the *Weekly Surveillance Report*, we gain a better understanding of how the CDC produced information about the AIDS epidemic. Examining the process of knowledge production reveals that the CDC gathered a wide variety of potential data, but for reasons that remain unclear only reported a small percentage of possible

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[146] Centers for Disease Control, *HIV/AIDS Surveillance - Issued April 1991* (1991).

classificatory combinations. This “black box” is a site of possible, future inquiry with individuals behind the decision-making process. However, the existing information suggests that it would be possible to go back to the “Case Report Forms”—should they still exist—and glean some knowledge that was lost in translation by looking at unexamined classifications.

Based on the information the CDC did release, it is apparent that women, especially women of color and WSW, were largely left out of the surveillance apparatus. I have shown that for many years, surveillance apparatuses did not report on transmission rates in women of color, thus communicating that these women were statistically insignificant and/or residual. However, we now know that women of color are disproportionately affected by HIV/AIDS. I have also demonstrated how the conflation of sex and sexuality, the removal of sexual orientation, and the consistent privileging of men in data reporting contributed to the lack of information about women with AIDS. That is, women were not visible because in the process of collecting and reporting data, some data—that which specifically represented AIDS in women—was left out. With a dearth of information missing about the epidemic in women, experts and officials could point to the low AIDS rates in women as “evidence” that funding and research was better employed elsewhere. However, the rationale that few cases in women meant there was little need to offer nuance to data did not hold up in practice when it came to “innocent victims.” The CDC did report extensively on remarkably small numbers of healthcare workers across a variety of classifications by July 1992. In fact, they had reported on singular cases of healthcare transmissions in even earlier footnotes.[147] Thus, if the CDC could report on singular cases in healthcare settings and given the concerningly high percentage of “other/unknown” transmission risks among women, the argument

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[147] Centers for Disease Control, *HIV/AIDS Surveillance Second Quarter Edition - Issued July 1992* (1992).

that percentages were too low to justify tracking other sexual behaviors women might engage in, for instance, does not appear to hold up in practice.

5.5 Conclusion

Women like elliot and Smith in the opening anecdote to this chapter were justified in their confusion over whether or not women who have sex with women could transmit AIDS sexually. The reality is that at least through 1992 the CDC did not collect data about their risk save for those cases relegated to the "other/unknown" category, which were obscured amidst those cases with incomplete data or other, unaccounted for risks. For some, the number of AIDS cases might not seem significant enough to track; however, insignificance supported by data is very different than insignificance via omission. Through a variety of documented transmission risks like IVDU or having sex with men, WSW *did* contract AIDS, and their female partners were left with little information about how to protect themselves. For several reasons the data on such risk might have been grossly underreported in "Case Report Form"s, but the information was not absent entirely. Through the process of translating data collection to surveillance information, someone at the CDC made the decision to focus their surveillance energies elsewhere. This was not a problem unique to WSW either. Categorically, women *were*—as activists claimed—underrepresented in CDC data.

In this chapter, I have demonstrated in what ways activists were correct, yet I have also complicated their argument to suggest that, in some regards, the data they sought could have existed. The "Case Report Form" was capable of collecting data about, for instance, AIDS rates in bisexual women; however, the issue was that that data was deemed unimportant in the process to publishing the *AIDS Weekly Surveillance Report*.[148] I have shown that both institutionalized sexism and heterosexism were written into documents like the "Case Report Form" and *AIDS Weekly Surveillance Report* and that they contributed to a narrative that supported AIDS as a heterosexual disease among otherwise unmarked women. Eventually, the *Surveillance Report* would show that women of color in particular suffered in disproportionate numbers, but that data would not be available until the latter half of the 1980s. As a form of surveillance, epidemiological surveillance is ethically charged. In the case of HIV/AIDS, who is made visible is literally the difference between a life counted and a silent death. Accurate surveillance is even more critical due to the various governmental bodies that used data to distribute funding for AIDS education and social services. So while visibility within surveillance apparatuses for marginalized communities can be life-threatening in certain cases it can also be life-sustaining.

While the surveillance case definition informed much of how AIDS surveillance was constructed, this chapter demonstrates why definition and classification ought to be considered as separate but interlocking entities. The definition made up only one part of the "Case Report Form", which also included categories and classifications that could have compensated for the weaknesses of the definition. In some respects, it could have. However, ultimately, in the case of AIDS, the "Case Report Form" and the Surveillance Weekly Report together further replicated and strengthened inequalities. By examining classifications in epidemiological surveillance apparatuses for master narratives about disease and risk, a more robust understanding about disease outbreak and response can be made legible.

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[148] I want to clarify here as I have elsewhere that the fact the "Case Report Form" could collect the data does not mean that those filling out the forms did so accurately and without bias. So while it was possible for bisexual women to appear on the "Case Report Form," the reporter would have had to ask all the questions related to sexual behavior and reported her responses accurately rather than make assumptions about her behavior.

6.0 Conclusion

On July 14, 1992, Elizabeth Glaser stood before the Democratic National Convention and declared before the Nation that she was an HIV-positive woman. Glaser spoke about not being heard by the Reagan and Bush Administrations, about the government misleading the public with regards to funding, about the loss of her daughter to AIDS. In telling her story, she explained:

> I started out just a mom, fighting for the life of her child. But along the way I learned how unfair America can be today, not just for people who have HIV, but for many, many people—poor people, gay people, people of color, children. A strange spokesperson for such a group: a well-to-do white woman. But I have learned my lesson the hard way, and I know that America has lost her path and is at risk of losing her soul. America wake up: We are all in a struggle between life and death.[1]

Unlike many women with AIDS, Glaser lived a relatively privileged life; she was the daughter of a CEO, well educated, and the wife of an actor. She had the means—and the right demographics—to make women with HIV/AIDS a national talking point. Her DNC speech remains an iconic American speech. One month later at the Republican National Convention, Mary Fischer—another affluent, white woman who contracted HIV "innocently"—continued to make HIV/AIDS in women visible.[2] Unlike Glaser, however, Fischer applauded Republican efforts to stop the

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[1] "Elizabeth Glaser - 1992 Democratic National Convention Address," 1992, https://www.americanrhetoric.com/speeches/elizabethglaser1992dnc.htm?pagewanted=all.

[2] While acknowledging her positionality as a white, wealthy woman, Fischer—unlike Glaser—seemed to dismiss it directly afterward. She stated that, though she was a white woman, she was "one with the black infant struggling with tubes in a Philadelphia hospital," and though she contracted HIV within the bond of marriage and had a supportive family, she was "one with the lonely gay man sheltering a flickering candle from the cold wind of his family's rejection." "Mary Fischer - 1992 Republican National Convention Address," 1992, https://www.americanrhetoric.com/speeches/maryfisher1992rnc.html.

epidemic, but reminded her listeners that there was still much work to be done. Her speech, too, remains famous.

By 1993, the tide began to turn for women and AIDS. In addition to Glaser's and Fischer's national conventions speeches in the summer of 1992, two other events made it possible for women to finally begin to be better represented in the AIDS epidemic. First, as I have mentioned throughout this project, the 1993 surveillance definition of AIDS included the first gynecological abnormality as an AIDS symptom. While the victory was small given that it was not the most prevalent gynecological abnormality among women, the inclusion of invasive cervical cancer no doubt made a difference for some women with AIDS. Second, in 1993 the Food and Drug Administration revised its *General Consideration for the Clinical Evaluation of Drugs* to finally include "women of child-bearing potential" more inclusively into clinical research. Relatedly, between 1990 and 1994, the federal government established and began expanding the reach of the Office on Women's Health, which was responsible for pursuing a national agenda to improve women's health outcomes. Perhaps unsurprisingly, as developments such as these occurred, the number of AIDS by the end of 1992 was 6,295 women.[3] By the end of 1993 with the implementation of the new surveillance definition, that number rose to 16,824 new cases of women with AIDS. Throughout the 1990s, the number of new cases in women per year would decrease, but would ultimately never drop below 10,000 new cases per year.

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[3] Centers for Disease Control, *HIV/AIDS Surveillance Report: US. HIV and AIDS Cases Reported Through December 1993*, U.S. Department of Health and Human Services (Atlanta, 1994).

6.1 Rewriting the AIDS Narrative

In this dissertation, I have sought to intervene in the existing literature on the early U.S. AIDS epidemic by exploring the 1981-1993 period through the perspective of women with AIDS. This is an underexplored, but no less important history to tell. When women do appear in existing narratives, it is frequently—as I have demonstrated—through examinations of AIDS activism. Such scholarship is important, and activist efforts made a different in key victories for women with AIDS. However, this project grew out of a desire to understand *how* the U.S. came to a point where activists even needed to fight for most women to be included in epidemiological data. In the process of researching this question, I have found evidence to support three assertions. I have made these arguments across the previous four chapters.

First, I have argued that women's exclusion from the early U.S. AIDS epidemic must be understood as part of women's history and relationship with the medical establishment. I advanced this argument most thoroughly in Chapter Two where I offered an extensive historical account of this relationship, most prominently from the late nineteenth century to the 1980s. There I suggested that women with AIDS's accounts of being disbelieved by their physicians has roots both in sexist beliefs about the uterus and hysteria. From the middle ages onward, cultural beliefs existed that portrayed women as deceitful, which was reaffirmed with hysteria's framing women as con artists who desired to escape their womanly duties. I also asserted that the longstanding belief that women were just men with uteruses—or that the "normal" human body defaulted to male in research—may have implicitly contributed to biomedical experts assuming the same opportunistic infections would appear in women as in gay men. Furthermore, I discussed historical barriers to research that influenced how research was conducted during the epidemic. Particularly, I covered the consistent de-prioritization of research on women's health and the guidelines against including women in clinical trials. The overemphasis on women as mothers was additional evidence for how women come to be defined by the womb and relationships to others. In terms of research, this meant fewer resources and funding went to researching AIDS in women, which could have led to quicker change.

Second, through my case studies, I have demonstrated how names, definitions, and classifications are interrelated rhetorical techniques that have the power to shape narrative. While these techniques have been frequently treated as interchangeable, I have explored how each functions somewhat differently than the other. In doing so, I hope to have persuaded fellow rhetoricians to take more care in identifying the techniques with which they employ for analysis. In Chapter Three, I engaged specifically with naming as a rhetorical act. To name something is to bring it into existence, shows it as worthy of communal attention, and importantly makes that phenomenon knowable. I also explored the affective dimensions of naming to examine how names function as part of a system that builds affective ties between ideas. I suggested that affective bonds "stick" to names long after names fall out of use. In Chapter Four, I turned to definitions. Unlike names which may carry across discursive contexts, I have argued that definitions are bound to the discursive context in which it was created. In the case of AIDS, while the name "AIDS" could travel across epidemiological, clinical, and political contexts, the AIDS surveillance definition's forced usage across contexts was remarkable disastrous for women. In Chapter Five, I looked at classification, which is the most rigid and brutal of the three techniques. That rigidity, in part, is due to the maximization of similarities and differences to strip away most nuances. Among the three techniques, classification also most significantly emphasized the stark interrelatedness between phenomena. Whereas names drew connections between all manner of disparate phenomena, classification relied more on contrast. For example, the name "woman" can be applied to a wide range of bodies and gender identities; however, to classify someone as a woman is most often—but not always—a binary decision based on sex organs.

Third, I have maintained that biomedical institutions charged with creating knowledge infrastructures in the epidemic developed infrastructures that would confirm what they anticipated they would find. This confirmation bias meant that there was no "objective" data to make most women visible, nor was there evidence to support a systemic change in biomedical institutions on behalf of women with AIDS. In Chapter Two, I accounted for historical bias against women, which already undermined their position as credible patients. While not explicit, this sexist foundation built within the biomedical establishment certainly contributed to invisibility. In Chapter Three, I demonstrated how early names like "gay cancer" primed the AIDS narrative to focus on a specific community and contributed to sexing and sexualizing the epidemic. In Chapter Four, I showed at length how the CDC represented the AIDS surveillance definition as being more stable or "objective" than it actually was. I also explored how the definitions themselves and their surrounding content added to the belief that AIDS primarily affected gay men. This assertion is not to claim that gay men were not disproportionately affected, but that the restrictive view of the AIDS patient was both sexist and heterosexist by excluding other populations. Finally, in Chapter Five, I closely analyzed the "Case Report Forms" and *AIDS Surveillance Weekly Report* to understand how the "objective" data reaffirmed that AIDS was a predominantly gay male disease. Due to translational errors—that is, the transference between data collection and data reporting—the CDC offered much more nuanced data about men (and specifically homosexual and bisexual men) and placed homosexual sex acts as highest in the transmission hierarchy. This meant that individuals with multiple risks of transmission were, for many of the early years, being misplaced within the AIDS transmission hierarchy. Furthermore, within these hierarchies, intersectional identities were not accounted for, meaning that data about women of color, for instance, was completely absent in the CDC data for many years. Together, these problems narrowed the epidemic's reality and reinforced an inaccurate narrative.

6.2 Moving Forward, Looking Back: Lessons from the AIDS Epidemic

I opened this conclusion with an extended quote from Elizabeth Glasner's 1992 speech at the Democratic National Convention. I did so because, unfortunately, it is just as timely in our present moment as it was thirty years ago. America is no fairer to vulnerable populations than it ever was; in fact, with the rise of the alternative-right, or alt-right, movement, we may be worse. America has, indeed, lost her path in the middle of another pandemic, and we are in the midst of learning hard lessons about behavioral change for the sake of others' health. While it has more frequently been likened to the 1918 Influenza Pandemic, there is much that the AIDS epidemic can teach us about the Covid-19 epidemic in the U.S. As a conclusion to this dissertation, I want to offer some thoughts—based in my own AIDS research—about Covid-19 parallels and framing issues. As this pandemic has lasted several months (and will be around for much longer) and I have been lost in the 1980s during a different pandemic, I must emphasize that these are preliminary ideas. However, I think they are important to put to page.

On February 11, 2020, the World Health Organization's (WHO) Director-General gave remarks, in which he announced the name of the novel coronavirus disease: Covid-19. The name was created through conversations between the WHO, the World Organization for Animal Health and the Food and Agriculture Organization of the United Nations. These organizations had to follow agreed upon guidelines that would ensure the name would not refer to "a geographical location, an animal, an individual or group of people, and which is also pronounceable and related to the disease."[4] Director-General Adhanom Ghebreyesus explained, "Having a name matters to prevent the use of other names that can be inaccurate or stigmatizing." The WHO's response was quick; it had only been a little more than a month since the WHO had focused on Covid-19 pandemic in earnest that the name was announced. By comparison, it would take the U.S. more than a year to give AIDS its name, and, as evidenced by the WHO's present remarks, a lot can transpire in a disease narrative in a year.

Unfortunately, Covid-19 has not escaped alternative naming, particularly here in the U.S. among conservative politicians. Secretary of State Mike Pompeo, Senator Tom Cotton, Representative Kevin McCarthy, Representative Paul Gosar, and President Donald Trump have all been quoted as using names like "Wuhan Virus," "the Chinese coronavirus," and "Kung Flu."[5] Consistently, arguments in support of these names' usage emphasize that Wuhan, China was the city of origin, which somehow removes any racist, nationalist implications because of its apparent "truth."[6] This is, obviously, not the case. As I mentioned in my conclusion to Chapter Three, journalists have likened "Wuhan Virus" and "Kung Flu" to "gay cancer." In both cases, these names functioned to stigmatized a marginalized population, though the intent behind such stigmatization—god's wrath versus unmodern culture—differs. However, it is not enough to stop

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[4] "WHO Director-General's Remarks at the Media Briefing on 2019-nCoV on 11 February 2020," 2020, https://www.who.int/dg/speeches/detail/who-director-general-s-remarks-at-the-media-briefing-on-2019-ncov-on-11-february-2020.

[5] "Conservatives Try to Rebrand the Coronavirus," The Atlantic, 2020, https://www.theatlantic.com/ideas/archive/2020/03/stop-trying-make-wuhan-virus-happen/607786/; "Kellyanne Conway Reacts to Trump's Use of 'Kung Flu,' Months After Calling Term 'Highly Offensive'," 2020, https://www.politico.com/news/2020/06/24/kellyanne-conway-trump-kung-flu-coronavirus-337682; "Trump Again Refers to Coronavirus as 'Kung Flu'," The Hill, 2020, https://thehill.com/homenews/administration/504224-trump-again-refers-to-coronavirus-as-kung-flu; Katie Rogers, "Politicians' Use of 'Wuhan Virus' Starts Debate Health Experts Wanted to Avoid," *The New York Times*, March 10 2020, https://www.nytimes.com/2020/03/10/us/politics/wuhan-virus.html.

[6] As with any early days in a pandemic, we may discover that it was, in fact, originating from somewhere else and that Wuhan saw the first cases. As I have mentioned in my historical account of where AIDS' history begins, one of the first AIDS cases in the U.S. occurred in the 1960s in a Midwestern teen boy of color.

the analysis there. Turning to primary source material on Gaetan Dugas or other individuals/communities portrayed as a foreign threat invading and sickening Americans must be a part of that research as well. Such a project would draw from Asian studies, post-colonial studies, and globalization to understand with more nuance all the affectively sticky ties attached to the surface of these damaging Covid-19 names.

I also believe that my dissertation can reveal something about surveilling and tracking Covid-19. As my case studies about women and AIDS failing to meet certain criteria suggested, many people will slip beyond epidemiological surveillance infrastructures for a variety of reasons. Some will never get tested because testing remains unavailable or inaccessible. Others may die before a diagnosis can be made. Still others will remain asymptomatic. Moreover, epidemiology remains state controlled. Not all Covid-19 tests are reported to the CDC, and the number of positive tests reported does not correspond to the number of cases.[7] A single patient who is tested three times would be reported to epidemiological surveillance centers as three positive tests. This very situation is what epidemiologists wanted to avoid in the AIDS crisis and was responsible for the separately tracked HIV and AIDS reporting. Someone unaware of how these Covid-19 case numbers versus testing numbers differ may be misled as to what the epidemic currently looks like in the U.S. I believe, based on the nature of surveillance tracking at the present, Covid-19 numbers are probably much higher than the data shows.

While further research into epidemiological infrastructures for Covid-19 should be done (and earlier rather than later), a secondary project must examine how such data is being used, to what ends, and how audiences receive the message. As it has been said multiple times throughout this pandemic: when public health measures are working, those efforts remain largely invisible.

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[7] "Testing Data in the U.S.," Centers for Disease Control, updated July 4, 2020, 2020, https://www.cdc.gov/coronavirus/2019-ncov/cases-updates/testing-in-us.html.

Or, decreasing cases of Covid-19 from week to week does not mean that the virus was less transmittable than expected, but that people's precautionary measures like social distancing and mask wearing has made a difference.

Finally, the AIDS and Covid-19 epidemics share a common humanity problem: the belief that as long as one is not at risk, one is not affected. In the AIDS crisis, this manifested as people believing AIDS was God's wrath upon gay men for their "sinful" lifestyle; for these people, AIDS truly was a "gay plague" in the biblical sense. But as we later found out, the expendable included people with addiction issues, communities of color, women, and the disabled. In this regard, so very little has changed. If AIDS was an epidemic that told the story of heterosexism in America, then Covid-19 is an epidemic that speaks to the rampant ableism and capitalism in this country. Who we are willing to sacrifice—our parents, grandparents, those with autoimmune disorders, the essential workers who must report—in order to have luxuries again speaks to our own social sickness. Like any event where thousands of lives seems a small price to pay, we must understand what persuasive tools are harnessed to make such an idea palatable, especially when the solution requires very little on the part of the individual—whether than be condom use and knowing one's serostatus or wearing a mask and only leaving the house when necessary. Understanding *that* logic and its temptations is one place rhetoricians of health and medicine can intervene.

Appendix A Abbreviations

ACT UP	AIDS Coalition to Unleash Power
AP	Associated Press
ASFV	African Swine Fever Virus
BAR	*Bay Area Reporter*
CDC	Centers for Disease Control
GCN	*Gay Community News*
IVDU	Intravenous drug user
JAMA	*Journal of the American Medical Association*
KS	Kaposi’s sarcoma
LAT	*Los Angeles Times*
MMWR	*Morbidity and Mortality Weekly Report*
MSM	Men who have sex with men
NEJM	*New England Journal of Medicine*
NYT	*New York Times*
OI	Opportunistic infection
PCP	*Pneumocystis carinii* pneumonia
PID	Pelvic inflammatory disease
PWA	Person with AIDS
SSA	Social Security Administration
SSI	Social Security Income
UPI	United Press International
WaPo	*Washington Post*
WHO	World Health Organization
WSW	Women who have sex with women

Appendix B Timeline[1]

Date	Event
Nov., 1980	Dr. Michael Gottlieb at UCLA sees a young gay man with PCP.
Feb., 1981	In New York, Dr. Alfred Friedman-Klein sees two young, gay men with KS; in San Francisco, Dr. Marcus Constant diagnoses his first cases of KS.
May 18, 1981	At the *New York Native*, Dr. Lawrence Mass publishes the first article on a mysterious new disease afflicting gay men.
May, 1981	Dr. Gottlieb reports five cases of PCP in Los Angeles to the L.A. Public Health Department and CDC; the CDC forms a taskforce.
June 5, 1981	The *MMWR* reports on the five L.A. PCP cases; AP, the *LAT*, and the *Chronicle* cover the *MMWR* report.
July 3, 1981	*NYT*'s Lawrence Altman covers an *MMWR* story about forty-one gay men diagnosed with KS and/or PCP.
Dec., 1981	The name gay-related immune deficiency (GRID) begins to circulate; U.S. government describes it as "an epidemic of immunosuppression."
Dec. 10, 1981	*NEJM* publishes three articles about the epidemic.
May 31, 1982	*LAT* publishes first front-page news story about the epidemic.
June 18, 1982	CDC reports IVDUs having KS and OOI.

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[1] I am indebted to James Kinsella's *Covering the Plague* for many of the entries on this timeline. I also drew from "A Timeline of HIV/AIDS," https://www.hiv.gov/sites/default/files/aidsgov-timeline.pdf.

July 9, 1982	CDC reports the epidemic among Haitian communities.
July 16, 1982	CDC reports the first cases among hemophiliacs; CDC now using “AIDS.”
Sept. 24, 1982	CDC defines AIDS surveillance definition for the first time.
Dec. 17, 1982	CDC publishes study on AIDS in infants.
Jan. 7, 1983	*MMWR* reports cases of AIDS in women whose partners had AIDS.
Mar. 7, 1983	*Native* publishes Larry Kramer’s famous piece “1,112 and Counting”
Apr. 11, 1983	AIDS is *Newsweek*’s cover story
May 6, 1983	*JAMA* publishes Dr. James Oleske’s “routine household contact” theory; the theory’s retraction does not receive the media coverage the initial story did.
May 18, 1983	Patrick Buchanan publishes an article on “Gay Plague,” citing it as God’s punishment for homosexuality.
May 20, 1983	*Nature* publishes report from the Pasteur Institute announcing the discovery of the AIDS virus, named LAV.
May 25, 1983	AIDS appears on the front page of the *NYT* after it is cited as the U.S.’s “No.1 Health Priority.”
Mar. 28, 1984	The San Francisco bathhouse debate begins.
Apr. 9, 1984	*Native* publishes a report on the France’s AIDS virus discovery.
Apr. 23, 1984	Secretary of Health Heckler announces that Robert Gallo has discovered the AIDS virus, named HTLV-III.
Mar. 30, 1985	The first AIDS antibody test is released.
June 28, 1985	The *MMWR* publishes the first revision to the AIDS surveillance definition.
July 1985	*Life* magazine’s cover story challenges the idea that heterosexuals are safe from AIDS.
July 23, 1985	UPI reports that Rock Hudson has AIDS.
Sept. 1985	Ryan White is not permitted to attend school
Sept. 15, 1985	President Ronald Reagan mentions AIDS publicly for the first time.

Oct. 2, 1985	Rock Hudson dies.
Dec. 6, 1985	The Public Health Service releases guidelines for preventing transmission between mother and child for the first time.
May 1986	The International Committee on the Taxonomy of Viruses decides that the AIDS virus will be known as HIV.
Oct. 23, 1986	Surgeon General Koop releases a report on AIDS calling for early AIDS education.
Oct. 24, 1986	CDC reports that AIDS are disproportionately affecting communities of color.
Nov. 4, 1986	LaRouche Initiative defeated in California.
Jan. 1987	U.S. government calls for mandatory HIV testing for prisoners and immigrants.
Feb., 1987	Activist Cleve Jones creates the first panel for the AIDS Memorial Quilt.
Mar., 1987	Larry Kramer founds ACT UP.
Mar. 31, 1987	AZT is shown to stop the progress of AIDS.
May 31, 1987	President Reagan gives his first public speech about AIDS.
Aug. 14, 1987	The *MMWR* publishes the second revision to the AIDS surveillance definition.
Oct. 11, 1987	The AIDS Memorial Quilt goes on display for the first time.
Oct. 14, 1987	The Helms Amendment is adopted into federal law, privileging the promotion of sexual abstinence in AIDS education materials and forbidding any promotion of homosexuality.
Nov., 1987	Randy Shilts' *And the Band Played On* is published.
May 26, 1988	Surgeon General Koop launches the first HIV/AIDS education campaign.
Oct. 11, 1988	Activists shut down the FDA in protest of better access to AIDS treatments; the AIDS Memorial Quilt goes on display for the first time.
Dec. 1, 1988	World AIDS Day observed for the first time.
July, 1989	The first organization for women with AIDS in the southeastern U.S. is formed by Dàzon Dixon Dallo.

Sept. 18, 1989	National Commission on AIDS meets for the first time.
Apr. 8, 1990	Ryan White dies of AIDS-related complications.
May 21, 1990	ACT UP protests at the NIH to demand more treatments and trial access for people of color and women.
July 26, 1990	The federal government passes the Americans with Disabilities Act, granting protections to people with AIDS, among others.
1992	AIDS becomes the leading cause of death among men ages 25-44 this year.
May 11, 1992	The Helms Amendment declared unconstitutional on the grounds that it is too vague.
May 27, 1992	FDA licenses the first rapid HIV test kit.
Jan. 1, 1993	The third revision to the AIDS definition goes into effect. This is the first version to include a gynecological abnormality—invasive cervical cancer.

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