Title

“A Caring Disease”: Nursing and Patient Advocacy on the United States’ First AIDS Ward, 1983-1995

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“A Caring Disease”
Nursing and Patient Advocacy on the United States’ First AIDS Ward, 1983-1995

DISSERTATION

submitted in partial satisfaction of the requirements
for the degree of

DOCTOR OF PHILOSOPHY

in History

by

Andrea Elizabeth Milne

Dissertation Committee:
Associate Professor Allison Perlman, Chair
Professor Douglas Haynes
Associate Professor Andrew Highsmith

2017

DEDICATION

This dissertation is dedicated to the patients and caregivers that passed through the doors of Ward 5B.

We will not forget you.

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LIST OF ACRONYMS

ACT UP	The AIDS Coalition to Unleash Power
AFDC	Aid to Families with Dependent Children
AIDS	Acquired Immunodeficiency Syndrome
AJN	American Journal of Nursing
ARC	AIDS-Related Complex
ART	Antiretroviral Therapy
ARV	Antiretroviral Drug
ASOs	AIDS Service Organizations
BAPHR	Bay Area Physicians for Human Rights
CAN	California Nurses Association
CAN	Certified Nursing Assistant
CD4	T–Lymphocyte Cell Bearing CD4 Receptor ("T-cells")
CDC	United States Centers for Disease Control and Prevention
CMV	Cytomegalovirus
DNR	Do-Not-Resuscitate
GMHC	Gay Men's Health Crisis
GRID	Gay-Related Immunodeficiency
HIV	Human Immunodeficiency Virus
HTLV-III	Human T-Lymphotropic Virus Type III
ICU	Intensive Care Unit
IVDU	Intravenous Drug User
JANAC	*Journal of the Association of Nurses in AIDS Care*
JHU	Johns Hopkins University
KS	Kaposi's Sarcoma
LAV	Lymphadenopathy-Associated Virus
LPN	Licensed Practical Nurse
LVN	Licensed Vocational Nurse
MCHR	Medical Committee for Human Rights
MD	Doctor of Medicine
MMWR	Morbidity and Mortality Weekly Report
MSM	Men Who Have Sex With Men
NEJM	*New England Journal of Medicine*
NIH	National Institutes of Health
NNU	National Nurses United
NTCU	National Transgender Counseling Unit
OI	Opportunistic Infection
ONF	*Oncology Nursing Forum*

PCP	Pneumocystis Carinii Pneumonia (now known as Pnuemocystic Jirovecii Pnuemonia)
PEPFAR	The U.S. President’s Emergency Plan for AIDS Relief
PrEP	Pre-exposure Prophylaxis of HIV
RN	Registered Nurse
SCU	Special Care Unit
SFDPH	San Francisco Department of Public Health
SFGH	San Francisco General Hospital
STD	Sexually-Transmitted Disease
UCSF	University of California, San Francisco
UNAIDS	Joint United Nations Programme on HIV/AIDS
WHO	World Health Organization
ZFGH	Zuckerberg San Francisco General

LIST OF TABLES

ACKNOWLEDGMENTS

This dissertation was made possible by the generous support of the American Association of University Women (AAUW), which awarded me a 2016-2017 American Dissertation Fellowship. The fellowship enabled me to devote an entire year to research and writing. Were it not for AAUW, my teaching load would have significantly lengthened my time to degree. I am proud to be affiliated with such an incredible institution, and am significantly richer for the time I have spent interacting with its membership.

I also received institutional support for my research at both the departmental and the school level here at UC Irvine. I was accepted to UCI with a Dean's Fellowship from the School of Humanities, and received a Humanities Commons Research Grant that facilitated one of my research trips. The UCI Department of History awarded me both a Charles and Ann Quilter Award for Excellence in Historical Research and a Department of History Travel and Research Award, both of which also facilitated archival trips.

My final research trip (to San Francisco) was especially productive because of the wonderful archivists and scholars it allowed me to connect with. Daniel Bao and Alex Barrows at the Gay, Lesbian, Bisexual and Transgender Historical Society Archive were a source of help, anecdata, and entertainment during my visit. Thanks also go to the staff of the San Francisco Public Library Archives and Manuscript Collections, without whom I might not have realized that the materials I was reviewing were, in fact, the stuff of a dissertation. I am especially indebted to Sally Smith Hughes of the University of California, Berkeley, Regional Oral History Office (ROHO) at the Bancroft Library. Her oral histories—conducted for the ROHO San Francisco AIDS Oral History Series, 1981-1984—were foundational to my dissertation.

Douglas Haynes—the third reader for this dissertation—has been unfailingly supportive, not only of my scholarship, but of my broader interests too, especially my commitment to the advanced study of pedagogy. He agreed to serve on my committee despite tremendous demands on his time, and has been a valuable interlocutor throughout the process.
I am also grateful to my second reader, Andrew Highsmith, who—having only been hired recently—joined my committee late in the game. His enthusiasm and feedback were invaluable to this project, especially in the final stages of the project, when a job offer compressed both my timeframe and his. It also bears noting that Andrew wrote innumerable letters of recommendation on my behalf over the course of the 2016-2017 school year, and allowed me to sit in on—and occasionally contribute to—one of his undergraduate courses.

Allison Perlman became my dissertation adviser five and a half years into my graduate career, but you would never know it for the impact she has had on my work. Her intellectual rigor is matched only by her kindness, both of which she has demonstrated in abundance throughout my time at UC Irvine. Her support and encouragement are the reason this dissertation exists. Indeed, in many respects, Allison is the only reason I made it through the doctoral process at all. I have tried many times to express my gratitude in person, only to get choked up. It seems words fail me here too. Suffice it to say, she is all an adviser should be, and then some. I am truly grateful for the many and bizarre circumstances that brought us together.

While they did not serve on my dissertation committee, several members of the UCI History Department also deserve mention here. Jon Wiener—my first adviser—saw my potential and continued to trumpet it long after he retired. Adria Imada—my second adviser—is the reason I had a top-tier publication to my name before I graduated. Emily Rosenberg believed in me, especially when the chips were down. Sharon Block was a consistent source of advice and insight. Jessica Millward supported and fought for me for seven straight years. Nancy McLoughlin provided me with invaluable moral support and equally-invaluable access to her canine companion, Jed. (Jed, it should be noted, is a very good boy.) I am also thankful to the many historians of HIV/AIDS with whom I have had the pleasure of interacting over the past few years, including Elizabeth Clement, Dan Royles, George Aumoithe, Kenneth Surles, Emily Hobson, Thomas Blair, and Kevin McKenna. They at once challenged me and—especially when I was my most isolated—helped me see the value in my work.

I owe a tremendous debt to several of my graduate school colleagues, chief among them Marlon Gruen, Adam Thomas, and Laurie Dickmeyer. Laurie—in addition to being a wonderful editor, sounding board, and support system—was also a top-notch roommate. I wish I was half the help to her that she was to me over the past half-decade, but I know I was not. After all, she introduced me to both "Drag Race" and "Unhhhh." I cannot, and will not, compete with that.

Keegan Shepherd, now graduated from the University of South Florida, helped me pull together my citations when I found myself trying to do in two weeks what I had anticipated doing over the course of three months. I met him through Twitter, and had only spent time with him in-person twice, yet he set aside his own dissertation to help me. He is a squirrelfriend for life.

I would be remiss if I did not mention my longest-serving mentor. In the winter of 2005, my freshman year at Bryn Mawr College, Sharon Ullman wrote "I respect you" on my U.S. history 1945-present capstone paper. She has been my champion and unofficial adviser ever since. She is the reason I fell in love with American history, the reason I became interested in the history of HIV/AIDS, the reason I decided to attend graduate school, and—in the most precarious moments of my career—the reason I refused to give up. I will never be able to repay the intellectual debt I owe her. Instead, I will do for others what she has done, and continues to do, for me.

Many of the people who motivated me to pursue higher education are no longer here. With this degree I am proud to join the ranks of my late Aunt, Unjali Walsh, Ph.D., and my late-grandfather, Prabakar Akolekar, Ph.D. Equally brilliant was my late grandmother, Sidney Boyle, who typed (and edited) both of those dissertations, and with whom I shared a home for over a decade. My granny taught me to love books, challenge authority, and curse like a sailor. An amateur historian herself, I feel her absence especially keenly right now.

My father, Donald Milne, is equally missed, and loved beyond measure.

All the support mentioned above is dwarfed by that of my little brother, Jonathan Milne, and my mother, Nalini Akolekar. Jonathan was quick with a joke in the moments I needed them most, and equally quick to praise me whenever I "finished my homework." He has worked harder—and faced more adversity—than most people ever do. Far from responding with bitterness, he is the most sensitive, kind, and giving person I know. If I am resilient, it is because I have Jonathan to model myself after.

My mother was not a huge fan of my choice to get a doctorate; she felt, and still feels, that my talents might have been better served in other venues. And yet, over the past seven years, she has edited countless documents, talked me off countless cliffs, and nagged me about my dissertation countless times. Instead of grumbling about my ever-deteriorating financial situation, and the career choice that precipitated it, my mom would remind me that this, too, shall pass. When those moments did not pass fast enough, she wrote me a check to get me through to the next payday. Our (multiple) daily phone conversations kept me sane, and provided an invaluable daily reminder that my family—not my degree—is my top priority. My mom read and edited my entire dissertation in the span of a week, and travelled across the country to attend my graduation despite a bad case of pneumonia. Whenever my back is against a wall, my mom tells me that it is time to "pull up your socks and go to your happy place." It has become our family motto—a directive we only pull out when absolutely necessary. I have pulled my socks up a great-many times over the past seven years. Every time I hear my mom's voice on the other end of the phone, I have arrived at my happy place.

CURRICULUM VITAE

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ABSTRACT OF THE DISSERTATION

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By

Andrea Milne

Doctor of Philosophy in History

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Associate Professor Allison Perlman, Chair

This dissertation examines the radical activism performed by the nurses who constructed and ran the United States’ first AIDS ward: San Francisco General Hospital Ward 5B. By examining these healthcare pioneers’ emotional, political, and intellectual labor—and the tensions and contradictions that characterized their work—*A Caring Disease* re-conceptualizes AIDS advocacy in the 1980s: what it was, and who performed it. It uses the ward’s official records, oral histories, professional publications, media coverage, and legal documents to demonstrate that the nursing staff’s radical practices (and the queer, feminist politics informing them) shaped AIDS care and activism at both a local and national level. Existing literature on the history of AIDS privileges the direct-action advocacy of ACT UP, and in so doing places the start of the People with AIDS (PWA) movement in 1987. In asserting the larger importance of feminized, affective, and paid labor in the politics of the epidemic, *A Caring Disease* reperiodizes and diversifies the movement.

INTRODUCTION

Something is happening in San Francisco. That was the message Donald G. McNeil Jr. sent in his October 5, 2015 *New York Times* article, "San Francisco is Changing the Face of AIDS Treatment." For anybody familiar with the devastation wrought throughout the city in the first two decades of the epidemic, the statistics McNeil quoted were hard to fathom. In 1992, the height of the AIDS epidemic, the virus claimed 1,641 San Franciscans. In 2014, however, only 177 died. Moreover, most of those 177 people did not even die of AIDS; they died of heart disease, cancer, and other conditions associated with old age. The statistics regarding diagnosis were similarly exciting. In 1992, San Francisco saw 2,332 citizens test positive for the virus, compared to 302 in 2014. The article went on to note that San Francisco was also leading the country when it came to maintaining the health of its poz[1] population: 82 percent of residents were receiving care in 2014, compared to 39 percent nationally. As a result, 72 percent of poz individuals in SF are "virally suppressed"—in other words, their viral load is so low as to be undetectable, effectively rendering them non-infectious. Compare this to a 30 percent suppression rate nationwide. Anthony Fauci, the longtime director of the National Institute of Allergies and Infectious Diseases (he held the same position at the start of the AIDS crisis) said of San Francisco, "If it keeps doing

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[1] "Poz" is a term used by, and to refer to, people who are HIV positive. The term only came into existence after the identification of the virus and development of HIV testing. Before then, "PWA" (person with AIDS/ARC) was the terminology used to refer to all people showing symptoms of infection.

what it is doing, I have a strong feeling that they will be successful at ending the epidemic as we know it. Not every last case—we'll never get there—but the overall epidemic."[2]

Something is definitely happening in San Francisco, but, as the *New York Times* article went on to explain, what is happening is not new. The reduction in HIV diagnoses, untreated persons, and AIDS deaths is directly attributable to the San Francisco model of AIDS Care. While the impact of the model is clearer now than it has ever been before, the model—and the theoretical foundation on which it is built—is as old as the AIDS crisis itself.

This dissertation focuses on the group most directly responsible for the creation of the San Francisco model: the nurses who, in 1983, founded and staffed the world's first dedicated AIDS unit. San Francisco General Hospital Ward 5B was equal parts fishbowl and living laboratory. The world watched as the nurses, all of whom volunteered to work with people with AIDS (PWAs), improvised a system of care tailored to their unique constellation of needs.[3] Within its first year of operation, the special care unit had already

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2. Donald G. McNeil, Jr., "San Francisco Is Changing Face of AIDS Treatment," *The New York Times*, October 5, 2015. https://www.nytimes.com/2015/10/06/health/san-francisco-hiv-aids-treatment.html.

3. When referring to 5B's patient population, this dissertation uses the diagnoses and identity categories that were correct at the time. Before the discovery of the HIV virus, the primary term used to describe individuals demonstrating acute immunodeficiency was people with AIDS (PWAs). Persons who showed early signs of infection but were not acutely ill (people who we would today refer to as HIV-positive) were diagnosed with ARC: AIDS Related Complex. Because this term is no longer accurate, "A Caring Disease" always employs "PWA" *unless* a source specifically mentions and AIDS diagnosis or people living with ARC as a group. When discussing this same patient population *after* the advent of HIV testing, the terms "HIV positive," "seropositive," and "poz" will appear interchangeably. While it is more accurate today to refer to the social justice movement born of the crisis as the HIV/AIDS Rights Movement, and to refer to the both the PWA and poz communities, the

succeeded well beyond expectations. As a result, this small cadre of nurses came to be regarded not (as nurses too often are) as the handmaidens of doctors, but as the world's foremost experts on caring for PWAs. In San Francisco, many of the nurses became local celebrities.

The city's newly-empowered caregivers made use of their status as medical authorities to intervene in national debates on a wide range of topics, including patient's rights, labor rights, infection control, medical ethics, health care reform, and the role of local communities in medicine. They also encouraged *other* nurses to talk, especially about the controversial topics that their profession had always studiously ignored: namely, sex, death, and stigma. In so doing, the 5B staff argued that ethical nursing care was, and always had been, political. By examining these nurses' intimate, activist, and intellectual work on behalf of PWAs—and the complicated consequences thereof—"A Caring Disease" re-conceptualizes what it means to be an AIDS activist. It demonstrates that care can, itself, be a form of radical political expression.[4]

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dissertation only does so in those areas that deal with the late 1990s. "A Caring Disease" uses the term "patient"—which many feel implies passivity—*only* when referencing individuals in the care of a medical professional.

In the same way that the dissertation does not modernize diagnoses or health status descriptors, it discusses sexual orientation using the language of the time. Readers will accordingly notice a narrowness in the terminology used to describe gender and sexual diversity: "gay," "lesbian," and "homosexual," are the identifiers that appear in the sources. It bears remembering, then, that these terms smack of cis- and heteronormativity. It is equally important to note that the medical establishment played a crucial role in creating and policing these identities. The term "queer" appears in this narrative to discuss identity post-1990. While many still saw the term as pejorative at that time, the 1990 formation of Queer Nation suggests that a largescale reimagination of gender and sexuality was underway by that time.

4. This dissertation describes the physical, emotional, and intellectual labor undertaken by the nurses of Ward 5B as "radical," in recognition not only of the political valences of even the nurses' most quotidian work, but also in recognition of the longer

The dissertation is so named because the disease made it possible for the 5B nurses to assume a position of authority. In the early years of the epidemic, doctors and nurses referred to AIDS as a "disease of caring," as opposed to a disease of curing. When Ward 5B opened, the virus that causes AIDS (human immunodeficiency virus, or HIV) had not yet been identified, and there was no test for it. The people that came to San Francisco General Hospital were there because they had passed through the latency period: they were either acutely ill, actively dying, or, in many cases, had nowhere else to turn. The early twentieth century had seen both the invention of penicillin and a cure for polio, and later, in 1980, the World Health Organization declared that the smallpox virus had been completely eradicated. Following what many regarded as a golden age of medicine, physicians—specialists trained to regard death as a defeat—found themselves ill-equipped to face the epidemic.[5] In the absence of a cure for AIDS, they had to learn how to accept the death of otherwise healthy people, and shift their focus to palliative care. The nurses, on the other hand, were generalists, trained to focus on patients' quality of life, however grim their prognosis may be. Treating people with AIDS forced a paradigm shift for doctors in which,

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history of radical health activism that enabled the ward's success. The nurses did not merely endeavor to provide PWAs the care they were systematically denied elsewhere in the city, they—both explicitly and by way of example—argued for a fundamental shift in American health care provision. On this point Ward 5B founder Clifford Morrison was very explicit. In the 1990s, he told the San Francisco AIDS Oral History Project, "I always said from the beginning that everything that I was doing, and the nursing model… were very relevant and very applicable to everything, not just AIDS care…I want to see all patients cared for under the same model that we're using with these patients." Clifford Morrison, M.S., M.N., R.N., F.A.A.N., "Organizer of the AIDS Ward, San Francisco General Hospital," oral history conducted by Sally Smith Hughes in *The AIDS Epidemic in San Francisco: The Response of the Nursing Profession, 1981-1984, Volume III*. 130.

[5] Peter Washer, *Emerging Infectious Diseases and Society* (Basingstoke: Palgrave Macmillan, 2010), 45–65.

as Dr. Lisa Capaldini explained, "there are no failures; every problem is an opportunity to help someone."[6] The result was a recalibration of the balance of power, one in which doctors learned that there were many areas of healthcare in which their training was deficient. They needed more than aid from their nurses. Indeed, they needed instruction. As doctors re-conceptualized their roles in the lives and deaths of their patients, nurses became leaders in, and models of, compassionate AIDS care. As the first and most-effective special care unit nursing team, the men and women working on ward 5B set the standard by which doctors and nurses around the country judged their efficacy. The nurses of Ward 5B received the most media attention, enjoyed the highest professional accolades, and, having been memorialized in books and on film, have best endured the erosion of public memory.

Demonstrating that the kind of labor performed by 5B's nurses constituted radical political action enables a larger theoretical conversation about what AIDS activism looks like and who gets to perform it. Scholarship on the earliest years of the pandemic has usually focused on institutionalized responses mounted by big-name government officials, public health professionals, and gay community groups. These accounts too often treat these responses as atomized. Where early AIDS activism *is* mentioned, it is usually with regard to prominent white male figures within the gay liberation movement, especially Larry Kramer, Richard Berkowitz, and Michael Callen.[7] An in-depth examination of the

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[6] Ronald Bayer and Gerald M. Oppenheimer, *AIDS Doctors: Voices from the Epidemic: An Oral History* (Oxford: Oxford University Press, 2002), 75.

[7] Representative examples include: Randy Shilts, *And the Band Played On: Politics, People, and the AIDS Epidemic* (New York: St. Martin's Griffin, 2007); and Larry Kramer, *The Normal Heart* (New York, NY: New American Library, 1985).

politics of Ward 5B reveals that scholars of the disease need to attend to the labor performed by a diverse range of individuals who responded to AIDS, from social workers and home health aides to family members and clergy. AIDS was "a disease of caring," so it is vital that the historical literature center the role caregivers played in the most important patient-advocacy movement of the twentieth century.[8]

Centering nursing and the politics of care in the history of the AIDS Rights Movement changes its periodization, and diversifies the activist community. It especially expands the role women—including lesbian-identified women—played in political response to the epidemic. (Half of the nurses on 5B were women and approximately half of those women were lesbians). The project effects these interventions by offering an alternative to two analytic binaries common to HIV/AIDS scholarship: service-delivery vs. direct-action organizing, and institutional vs. grassroots responses to the crisis. The former implies that the AIDS Rights Movement did not radicalize until the AIDS Coalition to Unleash Power (ACT UP) formed in 1987, six years after the virus' emergence and four years after 5B opened.[9] The latter suggests a rigid separation between government,

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For more comprehensive critiques of this tendency, see Deborah Gould, *Moving Politics: Emotion and ACT UP's Fight against AIDS* (Chicago: University of Chicago Press, 2009).

[8] It is important to note that the power dynamics at play on Ward 5B were complex and contingent, and also that the power differential between healthcare provider and patient is always fluid. Being an informed patient (or even a "good patient") *also* requires affective labor. While it is not the focus of this dissertation, PWAs' understanding and performance of their role as 5B patients was instrumental to the ethos and day-to-day function of the 5B. The patients' political, intellectual, and affective investments in the ward's mission were crucial to its success.

[9] Increasingly, literature on the HIV/AIDS movement is critiquing what Emily Hobson called "ACT UP Exceptionalism" in *Lavender and Red*. ACT UP exceptionalism posits that the New York City-based direct-action advocacy group was the epicenter of AIDS

medicine, and grassroots advocacy that the San Francisco model of AIDS care actively discouraged. The history of the San Francisco model of AIDS Care and the nurses who founded it suggests that many women, particularly lesbian women, labored in the liminal spaces characteristic of radical health care activism. This is an important intervention because so much of the scholarship on women's roles in AIDS activism elides them completely, or emphasizes their alienation from the broader movement.[10] In

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activism, and that the epidemic radicalized a previously apolitical population. Hobson focuses specifically on San Francisco—the locus of the gay and lesbian left—to demonstrate that the opposite was true, that radical responses to AIDS preceded ACT UP, and were enabled by decades of activism explicitly linking gay liberation to the elimination of other forms of oppression, including racism, capitalism, and war. By decentering New York City and the AIDS Coalition to Unleash Power, Hobson expands the political and demographic landscape of HIV/AIDS activism. In so doing, Hobson also places the beginning of radical AIDS activism years before traditional narratives, which treat the 1987 formation of ACT UP as *the* inciting event. "A Caring Disease" makes a similar theoretical intervention: rejecting the binary distinction made between service delivery and direct action changes the definition, scope, and possibilities of AIDS radicalism. Emily K. Hobson, *Lavender and Red: Liberation and Solidarity in the Gay and Lesbian Left* (Oakland: University of California Press, 2016).

If not as explicitly stated, the following histories of HIV/AIDS activism make similarly compelling arguments against ACT UP Exceptionalism: Dan Royles, "'Don't We Die Too?'": The Political Culture of African American AIDS Activism" (PhD diss, Temple University, 2014); Stephen J. Inrig, *North Carolina and the Problem of AIDS: Advocacy, Politics, and Race in the South* (Chapel Hill: The University of North Carolina Press, 2011).

AIDS exceptionalism is a reflection of the sheer number of ACT UP members who were (and are) productive academics and artists, from Sarah Schulman and Larry Kramer to Douglas Crimp and Thomas L. Long. The vast majority of these texts (and all of those mentioned above) are rich primary and secondary-source explorations of the organization and its larger significance. Others, like *How to Survive a Plague*—both the film and the book that followed it—obscure the historical record, sanitizing and imposing a marketable narrative structure on an inherently messy and frustrating story. *How to Survive a Plague*, directed by David France (2013; United Kingdom: Network Releasing, 2014), DVD; David France, *How to Survive a Plague: The Inside Story of How Citizens and Science Tamed AIDS*, (New York: Knopf, 2016).

10. Scholars are increasingly bucking this narrative, which, per Jennifer Brier, exists in part because some of the most prominent AIDS activists and journalists of the crisis elided lesbians in their accounts of the movement. This is part of a larger narrative that posits that the gay community—and particularly, the gay press—did not pay attention to

demonstrating that paid care labor was central to the AIDS Rights Movement, "A Caring Disease" reaffirms that women deserve a prominent place in the historiography of AIDS.

CONTRIBUTION TO THE LITERATURE

AIDS until activists like Larry Kramer forced the issue. Jennifer Brier, "Locating Lesbian and Feminist Responses to AIDS, 1982-1984," *Women's Studies Quarterly* 35, no. 1/2 (2007): 234–48; Randy Shilts, *And the Band Played On*; Larry Kramer, *The Normal Heart;* Larry Kramer, *Reports from the Holocaust: The Making of an AIDS Activist* (New York: St. Martin's Press, 1989); Rodger Streitmatter, *Unspeakable: The Rise of the Gay and Lesbian Press in America* (Boston: Faber & Faber, 1995).

Tamar Carroll demonstrates the importance of alliances with feminist groups (particularly WHAM—Women's Health Action Mobilization) to the success of ACT UP. Jennifer Brier demonstrates that from the earliest days of the crisis, lesbian women were contributing to discourse around safe sex and the meanings of gay love. Emily Hobson also undermines the narrative of lesbian invisibility by demonstrating that the gay liberation was never an isolated political movement. She demonstrates that the LGBTQ Left embraced a range of causes, from demilitarization and Central American solidarity to women of color feminism. Tamar W. Carroll, *Mobilizing New York: AIDS, Antipoverty, and Feminist Activism* (Chapel Hill: The University of North Carolina Press, 2015); Brier "Locating Lesbian and Feminist Responses to AIDS, 1982-1984"; Hobson, *Lavender and Red.*

While women were involved in AIDS activism from the beginning, as Paula Treichler noted in her field-defining work of critical theory, women living with AIDS still languished without a diagnosis or support for over a decade. Integral as feminism and the women's health movement were to the rhetorical and strategy of AIDS Rights Movement, women continue to receive unequal treatment to this day. According to 2015 reports by AMFAR and UNAIDS, Women constitute more than half of all people living with HIV, and AIDS-related illnesses remain the leading cause of death for women of reproductive age. Paula Treichler, *How to Have Theory in an Epidemic: Cultural Chronicles of AIDS*, (Durham: Duke University Press Books, 1999); Maxine Wolf, "Who's 'The Cure' For? Women Living With HIV/AIDS" (speech, National Conference on Women & HIV, Pasadena CA, May 1997), accessed June 24, 2017, http://www.actupny.org/documents/maxine-women.html; "Statistics: Women and HIV/AIDS," amfAR, accessed June 24, 2017, http://www.amfar.org/about-hiv-and-aids/facts-and-stats/statistics--women-and-hiv-aids/; "2015 Progress Report on the Global Plan towards the Elimination of New HIV Infections among Children and Keeping Their Mothers Alive," UNAIDS, accessed June 24, 2017, http://www.unaids.org/en/resources/documents/2015/JC2774_2015ProgressReport_GlobalPlan.

While not centering care labor as “A Caring Disease” does, there is a small body of AIDS scholarship that has likewise challenged the false dichotomies between activism and service, and institutional and grassroots action common to the historiography of the disease. In *Infectious Ideas*, Jennifer Brier challenges the commonly-made distinction between “AIDS activism” and “AIDS Service Organizations” (ASOs), noting that doing so gives her “access to a wide range of people who worked to fundamentally change both the state’s response and the response to AIDS produced by white AIDS service providers.”[11] She did so recognizing an earlier theoretical contribution by Cindy Patton, whose 1990 book *Inventing AIDS* critiques simplified descriptions of early AIDS activism. She note that by-then institutionalized ASOs embraced a reductive vision of AIDS work that “stood in sharp contrast to the early community activism, in which there were few distinctions between organizers, activists, people living with AIDS, and sympathetic medical workers.”[12] In a crisis of the AIDS epidemics’ scope and scale, distinguishing between service and activism is impractical at best. Unlike Patton and Brier, however, “A Caring Disease” also rejects the dichotomy between institutional and the grassroots labor. Catherine Batza demonstrates that the state played an “unlikely, and often unintentional” role in the development of gay and lesbian health services and community organizing in the 1970s; in the case of Ward 5B, it is harder still to see where the state ends and “the people” begin.[13]

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[11] Jennifer Brier. *Infectious Ideas: U.S. Political Responses to the AIDS Crisis,* (Chapel Hill: The University of North Carolina Press, 2011). 4.

[12] Cindy Patton, *Inventing AIDS* (New York: Routledge, 1990).

[13] Catherine P. Batza, “Before AIDS: Gay and Lesbian Community Health Activism in the 1970s” (PhD diss, University of Illinois–Chicago, 2012), xi.

In historicizing the radical labor performed by caregivers affiliated with a major medical institution (and supported by the San Francisco Department of Public Health), "A Caring Disease" offers a corrective to the binary opposition between community and establishment responses to the virus imposed in most histories of the AIDS crisis of the 1980s and 1990s. Thomas R. Blair argues against this impulse too, focusing specifically on how it narrows our understanding of safe sex. While it is true that many responses to the AIDS crisis were born of tensions between the gay and medical communities, Blair contends that the relationship between the two were not as dichotomous as Steven Epstein and Jennifer Brier's otherwise field-defining books suggest.[14] Blair does this by demonstrating the critical importance of what he called "socially amphibious" actors—individuals who identified as both health professionals and members of the gay community—to the development and popularization of guidelines for safe sex.[15] "A Caring Disease" takes this intervention a step further. Where Blair focuses on gay and gay-allied professional organizations like the Bay Area Physicians for Human Rights (BAPHR) and the National Coalition of Gay Sexually Transmitted Disease Services, this dissertation highlights the important work done by "amphibious" actors *within* a state-funded medical institution.

"A Caring Disease" also intervenes in the historical literature on nursing. AIDS underscored the importance of care and elevated nurses as no other infectious disease has in modern history, yet doctors' contributions have thus far received far more scholarly

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[14] Thomas R. Blair, "Safe Sex in the 1970s: Community Practitioners on the Eve of AIDS," *American Journal of Public Health* 107, no. 6 (April 20, 2017): 872–79; Steven Epstein, *Impure Science: AIDS, Activism, and the Politics of Knowledge* (Berkeley: University of California Press, 1996); Brier, *Infectious Ideas.*

[15] Blair, "Safe Sex in the 1970s."

attention.[16] Donald Abrams, M.D.—the co-director of the SFGH AIDS program—is just one of many physicians and public health officials who acknowledged the primary role the nursing staff played in constructing the San Francisco model of AIDS Care. In 1992 he told an interviewer that "The docs don't have much input and really can't take much credit for the success of 5B… And the nurses are very proud of that."[17] "A Caring Disease" will be the first historical study of AIDS nursing, and will demonstrate that the staff of Ward 5B saw their work as a continuation of a far longer, multi-issue political struggle to change their profession.[18] The units quest to provide ethical care to PWAs meant challenging

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[16] Bayer and Oppenheimer only interviewed five nurses for *Shattered Dreams*. They did not interview nurses at all for *AIDS Doctors*. Gerald M. Oppenheimer and Ronald Bayer, *Shattered Dreams? An Oral History of the South African AIDS Epidemic*, (Oxford: Oxford University Press, 2007); Bayer and Oppenheimer, *AIDS Doctors*; Randy Shilts, *And the Band Played On*.

There are also a number of autobiographies and primary-source books devoted to physicians' responses to the AIDS crisis, for example: C. Everett Koop, *Koop: The Memoirs of America's Family Doctor* (New York: Harper Collins, 1993); *The New York Times*, *Everett Koop: America's Doctor* (The New York Times Company, 2014); Kate Scannell, *Death of the Good Doctor: Lessons from the Heart of the AIDS Epidemic* (San Francisco: Cleis Press, 1999); Dr Peter A. Selwyn M.D and Peter A. Selwyn, *Surviving the Fall: The Personal Journey of an AIDS Doctor* (New Haven: Yale University Press, 2000).

[17] Donald I. Abrams, M.D., "The KS Clinic, Lymphadenopathy and AIDS-Related Complex, and the County Community Consortium," an oral history conducted in 1992 by Sally Smith Hughes in *The AIDS Epidemic in San Francisco: The Medical Response 1981-1984, Volume II,* an oral history conducted in 1992-1993, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 1996. 34.

[18] The only text related to AIDS nursing that was not written for nurses is an anthropological study of a group of nurses by Peggy McGarrahan. While a fascinating study, it provides little historical or political context, focusing instead on the way the nurses understood and performed their work. Peggy McGarrahan, *Transcending AIDS: Nurses and HIV Patients in New York City* (Philadelphia: University of Pennsylvania Press, 1994).

orthodoxies of care within a deeply conservative field, and challenging hierarchies and homophobia in American medicine.[19]

While "A Caring Disease" will be the first intensive study of 5B's nurses, it will not be the first history of the ward. Geunter Risse wrote a detailed chapter on the facility for his 1999 book, *Mending Bodies, Saving Souls: A History of Hospitals*. His account is the most comprehensive academic text on the country's first AIDS unit to date. Perhaps because it

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[19] When the AIDS epidemic arrived in the United States, the nursing profession was in a state of tumult. Nurses remained mired in an ongoing, struggle around unionization that was by-then decades old. Longer still was the struggle nurses waged—well over a century by then—to have their profession seen and compensated *as* a profession, as opposed to the natural vocation of righteous white women (or, conversely, the dirty work of women of color). The messages of the Women's Liberation Movement of the 1970s had prompted demands for equal treatment and fair compensation, and encouraged a generation of nurses to question the hierarchies and intentions of the institutions educating and employing them. These existential and practical conversations occurred contemporaneously with, and were impacted by, Ronald Reagan's restructuring of the American healthcare system, which devalued nurses labor and placed profits over patients. This was the political terrain upon which the nurses of 5B—most of whom grew up with the Great Society's community health programs and the radicalism of the Civil Rights Movement—decided to construct the San Francisco model of AIDS care. Janice Rider Ellis and Celia Love Hartley, *Nursing in Today's World: Challenges, Issues, and Trends*, (Philadelphia: Lippincott, 1992); Elaine E. Beletz. "Organized Nurses & Collective Bargaining: Options, Participation, and Militance" in *Power, Politics, and Policy in Nursing*, ed. Rita Wieczorek (New York: Springer, 1985), 229; Citing B. Hopping, "Professionalism and Unionism: Conflicting Ideologies," *Nursing Forum*, 1971, 15, 372-257; Rita Reis Wieczorek, "Response" in *Power, Politics, and Policy in Nursing*, ed. Rita Wieczorek (New York: Springer, 1985), 255; Susan M. Reverby, *Ordered to Care: The Dilemma of American Nursing, 1850-1945* (Cambridge: Cambridge University Press, 1987); Patricia D'Antonio, *American Nursing: A History of Knowledge, Authority, and the Meaning of Work* (Baltimore: Johns Hopkins University Press, 2010); Ann Costello Galligan, "Reaching for Power from Within," in *Power, Politics, and Policy in Nursing*, ed. Rita Wieczorek (New York: Springer, 1985); Citing Dorothy A. Brooten, Laura Lucia Hayman, and Mary Duffin Naylor, *Leadership for Change: A Guide for the Frustrated Nurse* (Philadelphia: Lippincott, 1978); Helen M. Lerner, "Educating Nurses for Power," in *Power, Politics, and Policy in Nursing*, ed. Rita Wieczorek (New York: Springer, 1985), 91-92; Alice Sardell, *The U.S. Experiment in Social Medicine: The Community Health Center Program, 1965-1986* (Pittsburgh: University of Pittsburgh Press, 1989); Bonnie Lefkowitz, *Community Health Centers : A Movement and the People Who Made It Happen*, (New Brunswick: Rutgers University Press, 2007).

functions as the conclusion of a book that spans two continents and several centuries, however, the 5B case study feels incomplete. Risse's larger work demonstrates that hospitals and their antecedents were originally places that focused on easing patients' physical and spiritual suffering, until the rise of modern medicine abstracted the patient and prioritized the physical body. Using the experiences of a patient named Warren J. as a framing mechanism, Risse's conclusion implies that 5B—and the AIDS crisis more generally—signaled a trend toward a more egalitarian relationship between care and cure. In the two decades since its publication, that conclusion has not born out. As a microhistory, "A Caring Disease" does not have the same limitations that accompany a project of *Mending Bodies, Saving Souls*' size and scope. Risse's narrative structure requires a focus on continuities between 5B and other medical institutions throughout history, while "A Caring Disease" emphasizes its differences, and the conflicts wrought by the nursing staffs' innovative approach to patient care. Both approaches have merit. This dissertation is thus a corollary to, not a correction of, Risse's field-defining work.[20]

"A Caring Disease" is also a corollary to Thomas Blair's "Plague Doctors in the HIV/AIDS Epidemic: Mental Health Professionals and the 'San Francisco Model,' 1981-1990." As the title suggests, Blair positions psychiatrists, psychologists, and counselors as "plague doctors." Daniel Fox described the plague doctor paradigm in the late 1980s. He argues that doctors have responded to contagion in similar ways for hundreds of years. A small group of physicians—at unknown risk to themselves and their loved ones—are tasked with establishing expertise in the new disease. The knowledge they acquire

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[20] 20. Guenter Risse, *Mending Bodies, Saving Souls: A History of Hospitals* (Oxford: Oxford University Press, 1999).

becomes the basis for their careers, and, in many cases, gives rise to new public health institutions or practices.[1] The plague doctor paradigm has been deployed time and again to describe the physicians that took up the challenge of AIDS in the 1980s.[1] By examining the role mental health professionals played in the development and success of the San Francisco model, Blair demonstrates that mental health professionals were a crucial intermediary between the medical establishment and the community, and are thus equally deserving of the "plague doctor" moniker. While it does not explicitly invoke the plague doctor paradigm, the argument underlying "A Caring Disease" mirrors Blair's concern that histories of the medical response to AIDS have, up to this point, been too narrowly defined.[21]

This dissertation is framed by scholarship on intimate and affective labor, and literature on the role emotion plays in activism. In *Moving Politics: Emotion and ACT UP's Fight against AIDS*, Deborah Gould employs the word "affect" to describe "nonconscious and unnamed, but nevertheless registered, experiences of bodily energy and intensity that arise in response to stimuli impinging on the body."[22] Rhiannon Trozzi Andreini, and Debra Salazar, among others, have, like Gould, demonstrated that affect is central to the framing and success of social justice movements, especially in the case of AIDS—"A Caring Disease"

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21. Thomas Blair, "Plague Doctors in the HIV/AIDS Epidemic: Mental Health Professionals and the 'San Francisco Model,' 1981-1990." *Bulletin of the History of Medicine* 90, no. 2 (2016).

22. "A Caring Disease" has adopted her definition of the term, with the caveat that "body" be understood as encompassing both the corporeal and the mental. Gould, *Moving Politics*, 19.

reveals that the same is true of affective *labor*.[23] As Gould explains in *Moving Politics*, "The *movement* in 'social movements' gestures toward the realm of affect; bodily intensities; emotions, feelings, and passions; and toward uprising."[24] "A Caring Disease" asks what happens when scholars decenter direct action advocacy in the history of HIV/AIDS, focusing instead on the activism of caregivers, paid and unpaid. If Gould suggests that rationality and emotion necessarily co-created radical action of the sort performed by ACT UP, intensive study of 5B reveals that the same is true the radical action performed by intimate caregivers .[25] It would be wrong to dismiss the affective labor practices on Ward 5B as irrational, but it would be equally incorrect to describe them as strictly logical.

"A Caring Disease" uses the terms "affective labor" and "intimate labor" interchangeably when describing the work 5B's nurses did on the ward, not because one term maps perfectly onto the other, but because both describe the kind of work that took place on Ward 5B.[26] In 1999, Michael Hardt described affective labor as a form of

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23. Andreini Rhiannon Trozzi, and Debra J. Salazar, "Emotions and Movement Framing: A Content Analysis from the Black Power and ACT UP Movements," (Paper presented at the annual meeting of the Pacific Northwest Political Science Association, Portland Oregon, 2008).

24. Gould, 3.

25. At times, the text seems to conflate emotion and affect in problematic ways. This does not, however, negate the field-defining importance of Gould's work.

26. It is important to note that the term "emotional labor" (coined by Arlie Hochschild in the 1980's) does not appear in this dissertation, although it is incredibly important for understanding the personal and structural cost of a kind of labor that all people (and particularly all women) must perform. However, the concept of "emotion" imposes more limits than does "affect" or "intimacy." Affect and intimacy are productive of emotion, while the converse is not always the case. While all people perform emotional labor in one way or another, then, the same cannot be said of affective or intimate labor. Arlie Hochschild, *The Managed Heart: Commercialization of Human Feeling* (Berkeley: University of California Press, 2003), 7-11.

"immaterial labor," or, working for an intangible product, that, for most of human history, was exclusively associated with women. Nursing, teaching, and parenting, for example, all generate products that cannot be accurately quantified—though the Information Age has seen numerous efforts to that effect.[27] Although women's work has always been treated as less valuable than men's labor, its inchoate nature in no way negates its power. Ward 5B's nursing staff incited feelings of comfort, knowledge, and community in their patients: those outcomes are as much if not more crucial to the function of the biopolitical state than a widget.[28] "A Caring Disease" thus deploys the term "affective labor" to describe what feminist sociologist Dorothy Smith calls "labor in the bodily mode," labor that produces a range of affects, be it a health affect, an emotional affect, or affect in the sense of movement.[29]

The power dynamics at play on Ward 5B were complex and contingent. Moreover, the power differential between healthcare provider and patient is always fluid. Being an informed patient (or even a "good patient") *also* requires affective labor. While it is not the focus of this dissertation, PWAs' understanding and performance of their role as 5B patients was instrumental to the ethos and day-to-day function of the 5B. The patients' political, intellectual, and affective investments in the ward's mission were crucial to its success.

27. We see the results of these efforts in our everyday lives. Hospitals, for example, quantify quality of care by studying patient health outcomes and satisfaction. One could argue that 5B archive's collection of thank-you notes and patient drawings illuminate the contours of their nurses' labor more effectively, as they speak to the situatedness of both the nurse-patient relationship and its productivity. Michael Hardt, "Affective Labor," *boundary 2* 26, no. 2 (1999): 89-100.

28. *Ibid*.

29. Dorothy E. Smith, *The Everyday World as Problematic: A Feminist Sociology* (Toronto: University of Toronto Press, 1988).

"Intimate labor" is a newer concept. Eileen Boris and Rhacel Salazar Parreñas introduced intimate labor in their 2010 edited volume, *Intimate Labors: Cultures, Technologies, and the Politics of Care*. They use the term to facilitate analysis of laboring populations that are rarely thought of as engaged in the same project, namely care workers, domestic workers, and sex workers. In so doing they "[deny] the separation of home from work, work from labor, and productive from nonproductive labor that has characterized capitalist globalization."[30] Boris and Parreñas argue that all of these jobs (albeit to different extents) are shaped by, and shape, social context. They also illuminate gender, race, class, and sexual dynamics in society. Care workers, domestic workers, and sex workers all perform tasks that require what Boris and Parreñas refe to as "bodily and psychic intimacy"; that intimacy involves the voluntary or involuntary production of personal knowledge that leaves the subject of labor vulnerable to exposure. This framework is especially instructive when considering the stigma that accompanied an AIDS diagnosis in the early years of the crisis, and the invasive questions and medical procedures that followed.[31] The concept of intimate labor is also important because it addresses what Ward 5B founder Clifford Morrison wrote about as a kind of stigma-by-association. Boris and Parreñas write that "the presence of dirt, bodies, and intimacy… [here one might add pathologized sexuality and contagion] helps to stigmatize such work and those who perform it."[32]

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[30] Rhacel Salazar Parreñas and Eileen Boris, eds., *Intimate Labors: Cultures, Technologies, and the Politics of Care* (Stanford, CA: Stanford Social Sciences, 2010), 1-2.

[31] *Ibid.*, 2-5.

[32] *Ibid.*, 2.

ORDER OF OPERATIONS

"A Caring Disease" is the product of archival research conducted at the San Francisco Public Library (The SFGH Ward 5B/5A Archives) and the Gay, Lesbian, Bisexual and Transgender Historical Society (Shanti Project Records). It also relies heavily on the several-thousand pages of oral histories Sally Smith Hughes collected for the San Francisco AIDS Oral History Project; those interviews are available in print at the University of California, San Francisco Library, or online through the Bancroft Library's Regional Oral History Project website. The dissertation also draws on two journalists' contemporaneous accounts of the ward. Randy Shilts occasionally described 5B in *And the Band Played On*, which, thirty years later, remains the definitive account of the early years of the HIV/AIDS crisis; he also wrote newspaper stories on the topic for the *San Francisco Chronicle.* Carol Pogash wrote contemporaneous accounts of the ward for *The San Francisco Examiner*; in 1992 she published *As Real as it Gets: The Life of a Hospital at the Center of the AIDS Epidemic*, which featured an introduction by Shilts.

Chapter One introduces the historical, sociopolitical, cultural, and medical landscape that both necessitated and enabled the creation of ward 5B. The ward's existence was a political statement against homophobia and AIDSphobia in medicine, and a controversial one at that. Examining the innovative approaches to patient care and hospital policy for which the ward gained acclaim demonstrates that 5B's praxis was born of leftist principles that preceded the epidemic. The intimate labor performed by 5B nurses—which required a greater physical and emotional investment than the labor performed by the average RN—must be understood as political activism. In an atmosphere of homophobia and

AIDSphobia, the nurses' nontraditional approach to patient relations was as much a form of political messaging as it was a form of care and empathy. From the Elizabeth Taylor Lounge, to the tap-dancing volunteer caterers, to the lesbian nurses who constituted the first wave of volunteer caregivers, 5B's queer, feminist ethic was baked into the space from the beginning. The San Francisco model of AIDS Care that the nurses constructed in that space was equally inextricable from the ward's radical politics. Best intentions notwithstanding, the 5B patient experience was not—could not—be uniform. In this respect, the special care unit offers interesting insight into the social and political stratifications that characterized the City of San Francisco in the 1970s, 1980s, and 1990s.[33] Chapter One is based on a wide range of sources, from oral histories conducted with the nurses through the San Francisco AIDS Oral History Project, to contemporary books and media accounts, to the ward archives, currently housed at the San Francisco Public Library.

As the AIDS virus cut a swath through San Francisco, hospitals became part of the fabric of gay life in the city. Going to the hospital—even as a patient—became more of a social experience. As the only AIDS special care unit in the world, SFGH held a heightened significance for the community, and it became the focus of numerous charitable and volunteer efforts. The nurses on Ward 5B did not just accept the city's goodwill, they courted it. Even before opening, the ward's founder, Clifford Morrison, built relationships with individuals and organizations operating in the community, and invited them to be a

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[33] For more information on this topic, see Cathy J. Cohen, *The Boundaries of Blackness: AIDS and the Breakdown of Black Politics* (Chicago: University Of Chicago Press, 1999).

part of the work happening on 5B. In the midst of what Daniel Fox describes as a "crisis of authority" in the health polity, the nurses rejected the hierarchies of the medical profession, opting instead to empower and lend institutional legitimacy to grassroots efforts on behalf of San Francisco's PWAs.[34] Chapter Two examines three different community-integration efforts: the 5B Volunteer Program, The Shanti Project, and ad-hoc volunteer efforts by individuals like "Brownie" Mary and groups like Rita Rocket's Brunch Bunch. While integrating the outside community onto the ward brought down costs and improved the patient quality of life, it also birthed a political contradiction on the ward common to radical health activism. The nurses' efforts to ameliorate the impact of inadequate federal support for PWA care unintentionally suggested that the Reagan Administrations' vision of health care reform, in which the altruism of local communities replaced federal spending, was feasible. In addition to the wide range of sources employed in Chapter One, Chapter Two also relies on the GLBT Historical Society's Shanti Project archives.

As the first dedicated AIDS ward in the world, Ward 5B was a hub for the production and dissemination of knowledge. In that spirit, the nurses subjected their new model of healthcare to rigorous examination. Given the stakes of the experiment, both internal and external groups evaluated 5B, in the hopes of determining the merits of dedicated units in the treatment of AIDS. Researchers measured cost-effectiveness and length-of-stay, staff turnover and patient satisfaction. Of course, efficacy—given the climate of fear that

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34. Daniel M. Fox, "The Politics of Physicians' Responsibility in Epidemics: A Note on History," in AIDS: The Burdens of History*, ed. Elizabeth Fee and Daniel M. Fox (Berkeley: University of California Press, 1988), 316-344.*

necessitated the creation of 5B—was not enough. Safety was important too. The nurses submitted to regular blood tests, and with every negative result, undermined the many healthcare providers who were unwilling to treat PWAs, or would only do so in what are colloquially known as "space suits." Their role in occupational safety studies rendered them key actors in the fight against AIDSphobia in the medical profession.

Within months of opening, the results were clear: Ward 5B was exceeding all expectations, and its nurses remained healthy. The San Francisco model of AIDS Care was working. As the ward's reputation grew, so too grew the nursing staff's authority. Before long, many observers regarded them as the foremost experts in the care of PWAs. Given this success, the 5B nursing staff circulated their knowledge around the country and, to a lesser extent, around the globe. Nearly all of the ward's nurses evangelized the San Francisco model in one manner or another: through academic publishing, speaking tours, getting involved in nursing education, or becoming politically active in the AIDS Rights Movement. Chapter Three uses articles in professional publications, textbook contributions, media coverage, and interviews to examine the intellectual work the nurses did on behalf of their patients and for their profession, and the political nature of the "best practices" they advocated. Comparing their experiences with those of nursing staffs that implemented the SF model in other cities demonstrates that—innovative though the nurses were—much of 5B's success was the result of the social and political environment in which it was constructed.

CHAPTER ONE

"TO LAUGH IN THE FACE OF UNCERTAINTY AND DEATH": THE CREATION OF WARD 5B

By the time the year 1982 ended, the Centers for Disease Control (CDC) had reported 771 cases of AIDS and 618 deaths, the majority of which took place in San Francisco and New York City.[1] As the death toll grew, so too did the consensus among healthcare providers, public health officials, and scientific researchers that AIDS (so–named by the CDC that same year) was caused by an infectious agent. In fact, in November 1982 the Center for Disease Control's *Morbidity and Mortality Weekly Report* (MMWR) advised that hospital staff caring for people with AIDS use hepatitis B precautionary measures, a recommendation made on the assumption that the virus was blood-borne. By the end of the year, three major breakthroughs would confirm that hypothesis: (1) doctors identified the first case of seroconversion via blood transfusion; (2) the *MMWR* announced the diagnosis of three hemophiliacs with *pneumocystis carinii pneumonia* (PCP), one of the most common opportunistic infections suffered by people with AIDS; and (3) doctors presented four infants with unexplained immune deficiency in the *MMWR*, raising the possibility of pre- and perinatal transmission.[2] Early the following year (1983), the city of

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[1] "Thirty Years of HIV/AIDS: Snapshots of an Epidemic," amfAR, the Foundation for AIDS Research, accessed March 20, 2016, http://www.amfar.org/thirty-years-of-hiv/aids-snapshots-of-an-epidemic/.

[2] *The AIDS Epidemic in San Francisco: The Medical Response, 1981-1984, Volume II,* an oral history conducted in 1992-1993, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 1995, 155-156.

San Francisco distinguished itself through its financial and institutional response to the burgeoning epidemic. That same summer, San Francisco General Hospital opened Ward 5B.

In order to understand the significance of San Francisco General Hospital Ward 5B, and the political work performed by the nurses who staffed it, the ward must first be placed in its proper context. This chapter sketches the circumstances—medical and social, local and national—that necessitated the creation of the world's first dedicated AIDS ward, and explain how those circumstances made it possible for a small group of concerned nurses to mount a radical political response to the epidemic in a distant corner of San Francisco's public hospital. The fact of the ward's creation, and the intimate labor performed by the nurses of Ward 5B, was more than just an improvised response to a major public health crisis. The nurses, all of whom volunteered to work on the ward, were engaged in radical activism. In the context of a highly stigmatized epidemic, the staff's bodywork and nontraditional approach to patient relations were as much a form of political messaging as they were forms of care and empathy. Informed by a queer, feminist ethic, the ward was always and already a politicized space, as was (and is) the model of AIDS care its nurses pioneered.

Of course, the first and most important goal of the nurses' activities on the ward was improving the lives and deaths of San Francisco General Hospital patients with AIDS. That desire was not, in and of itself, radical. What made the unit radical was the nurses' work to ensure their efforts be seen and adopted around the country, and, indeed, around the world. The ward was constructed to serve as a rejoinder to AIDSphobia both within and beyond the boundaries of the San Francisco General Hospital. Insofar as homophobia was inextricable from the prejudice PWAs faced in the early 1980s, the ward was also a statement of gay and lesbian defiance in the face of bigotry. 5B was an unapologetic celebration of gay love, gay families, gay culture and gay liberation—an unexpectedly hopeful environment for a community under duress. The compassion on display challenged those suggesting the virus was a punishment from God. In the words of nurse George Jalbert, AIDS nursing expressed "a most joyous freedom—to laugh in the face of uncertainty and death."[3]

The space the nurses created—and the care they provided—was contingent on a homogeneous patient population, and, accordingly, representative of larger stratifications within the city of San Francisco. From the outset, the city's public health officials and medical practitioners coded AIDS as gay, and, to a lesser extent, white. The local government's response to the epidemic was a direct result of this framing. Identifying the disease as attacking a single, highly-influential voting bloc led city officials to mount a much more robust response to the epidemic than those seen in the virus' other urban epicenters. It also, however, meant that resources were allocated unevenly. As the demographic makeup of their patient population changed—a direct result of inadequate funding for support services in the broader community—the extent to which 5B's nursing staff was motivated by the politics of gay liberation became increasingly clear. The San Francisco model eventually adapted to better meet the needs of San Francisco's diverse patient population, but in the 1980s and early 1990s, the nurses were less effective in treating, and less *motivated* to treat, intravenous drug users (IVDUs).

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3. "Jalbert, George Chenille Crow," GLBT Historical Society Online Searchable Obituary Database, accessed June 10, 2017, http://obit.glbthistory.org/olo/display.jsp?name=19871029_Jalbert_George_Chenille_Crow.

The Politics of AIDS Care in San Francisco

Although San Francisco General Hospital is the subject of this study, it is important to note that The General was never, and could not be, the only hospital in the city admitting people with AIDS. In 1979 and 1980, people in San Francisco were dying of unusual diseases, but those deaths had not yet been ascribed to a single causative agent. Even once the virus *was* identified, people with AIDS (PWAs) did not present at hospitals *with* AIDS: they presented with opportunistic infections (OIs) *caused* by AIDS. Most PWAs were battling multiple OIs at the same time. For example, when writer Warren J. passed away, his death certificate noted his cause of death as respiratory arrest, herpes zoster, encephalitis, and AIDS; he also had chronic diarrhea caused by cryptosporidium, cryptococcal meningitis, and other opportunistic infections.[4] Medical professionals rarely saw many of the OIs common to AIDS, like *pneumocystis pneumonia*, *Kaposi's sarcoma*, *toxoplasmosis*, and cytomegalovirus, but not all PWAs presented with these conditions. The disease manifested itself in too many different ways to effectively screen out PWAs. The sheer number of patients, and the emergent nature of their OIs, made screening still harder. By the time the FDA licensed *ELISA* (the first commercial blood test for HIV) in 1985, over 12,000 people had already died of the disease.[5] Proportionally, San Francisco was the hardest hit city in the world**.**

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[4] Guenter Risse, *Mending Bodies, Saving Souls*, 658.

[5] Before ELISA (enzyme-linked immunosorbent assay), physicians used CD4 T cell—also known as "helper T cells"—counts to render diagnoses. In other words, doctors were using a symptom, compromised immunity, to make an inference. Blood tests were, therefore, always central to the AIDS evaluation process. ELISA was important because it was the first test that could identify HIV antibodies, and therefore definitively prove the

It is also important to remember that, along with the rising death toll came an increasing number of people *living* with AIDS, people who were not yet in a full-fledged medical crisis, or who were between hospitalizations and faring well. Refusing to care for PWAs, then, would not only have meant hospitals turning away people dying of *pneumocystis*; it *also* would have meant turning away trauma victims. It would have meant turning away people with broken bones, people who had been in car accidents, or people in the middle of acute medical crises, like a heart attack or stroke (all of which is illegal). Keeping PWAs out of private hospitals would have meant requiring all people seeking hospital admission to consent to blood testing, the constitutionality of which was, at best, contested—after all, testing positive could mean losing one's job, one's home, one's health insurance, everything.[6] Put simply, even if hospitals *had* been inclined to turn away all PWAs, discriminatory treatment on that level would have been costly, ineffective, controversial, and—as later cases would demonstrate—unconstitutional.

While San Francisco-area hospitals could not reasonably turn all PWAs away, structural inequalities in the American healthcare system did render some facilities more accessible than others from the very beginning of the epidemic. Even before the AIDS crisis,

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presence of the virus in the blood stream. ELISA is also commonly referred to as the "Western Blot Test." To learn more about the different techniques used to test for HIV and AIDS, see: Niel Constantine, "HIV Antibody Assays," HIVInSite, May 2006, accessed June 10, 2017, http://hivinsite.ucsf.edu/InSite.jsp?page=kb-02-02-01.

[6] There were activists—both at SFGH and around the country—committed to refusing or modifying services provided to PWAs. Among the most prominent spokespeople for this was Dr. Lorraine Day, the chief of orthopedic surgery at SFGH, who advocated testing of all non-emergency surgery patients. Those who tested positive would either (a) receive an alternative treatment, or (b) undergo surgery performed by surgeons wearing extra protective gear. Carol Pogash, *As Real as It Gets: The Life of a Hospital at the Center of the AIDS Epidemic* (New York: Plume Publishing Corporation, 1992), 58-64.

most regarded The General, San Francisco's only county hospital as a facility of last resort, and, accordingly, a natural repository for the city's most "undesirable" patients.

For all intents and purposes, there are two kinds of hospitals in the United States: public and private. There are far more of the former than the latter. Public hospitals tend to be larger and funded by federal, state, and local money, and, therefore, are not allowed to turn anybody away, regardless of their ability to pay for medical care.[7] Private hospitals, on the other hand, are more selective. While they are required by law to provide emergency services to all people, they have the right to refuse *admission* to anybody they believe will be unable to pay for their services. As a result, public hospitals are more crowded, have higher patient to care-provider ratios, and are less likely to offer the same kind of amenities available in private hospitals.[8] The two biggest medical facilities in San Francisco are San Francisco General Hospital (public) and The University of California, San Francisco Medical Center (private).

SFGH and UCSF had (and continue to have) a very unusual public-private partnership, which is important to consider in any discussion of the city's response to AIDS. UC San Francisco provides all of the medical and instructional staff at The General (e.g., doctors, residents, and interns)—and the city provides all nursing and support services. This arrangement is mutually beneficial. UCSF's support means SFGH can provide high-

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[7] This was not always the case. Hospitals were, in fact, allowed to run on a segregated basis via the Hill Burton Act, until the 1963 Simkins v. Cone ruling and the subsequent passage of the Civil Rights Act of 1964.

[8] "The Pros and Cons of Public vs. Private Hospitals," National Procedure Institute, accessed March 19, 2016, http://www.npinstitute.com/public-vs-private-hospitals-s/1852.htm.

quality medical care to underserved populations at minimal taxpayer expense. In return, UCSF's students get a rare opportunity to treat patients in both public and private institutions. Unsavory though it may sound to treat patients as "clinical material," access to a larger and more diverse patient population is also helpful for research.[9] While the SFGH-UCSF partnership was more tenuous in the early 1980s, it was still in place; that meant that all of the AIDS doctors at The General were university staff, while all the nurses were government-funded.

Both SFGH and UCSF mounted quick responses to the AIDS epidemic. The scope and character of those efforts, however, were vastly different, and indicative of their disparate funding structures and goals. Although SFGH became the most important AIDS research and treatment facility in the city, and indeed, the country, the UCSF Medical Center was the first institution to respond to the disease.[10] Dr. Marc Conant founded The KS Clinic (named for *Kaposi sarcoma*, a rare skin cancer and common opportunistic infection experienced by people with AIDS) in 1981. Housed in the Department of Dermatology and run on a shoestring budget, the weekly clinic facilitated the multidisciplinary study of patients. Very quickly, the clinic became a meeting place where California-based doctors and public health officials working on the front lines of the as-yet unknown epidemic exchanged information. The KS clinic had one nurse—Helen Schietinger—who was tasked first and foremost with collecting uniform and extensive medical histories of each patient. Her secondary task: providing comfort and aid to patients during what were undeniably

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[9] Risse, *Mending Bodies, Saving Souls*, 626.

[10] *Ibid*.

frightening and emotional appointments.[11] Because it was a once-a-week outpatient clinic, Schietinger's ability to interact with patients and dictate policy was limited. The clinic, vital though it may have been in the early years of the AIDS crisis, had neither the financial nor the institutional support to provide comprehensive care to PWAs. It was a once-a-week outpatient research enterprise, and its research subjects were, by and large, highly-educated (and well-insured) gay white men—the sorts of people who had the inclination and resources to seek medical attention when purple spots appeared on their skin.

Although UCSF (commonly referred to as Parnassus[12]) expressed initial support for Conant and the KS Clinic, records suggest that the institution balked at the prospect of expanding its AIDS services, despite the already limited number of PWAs for whom care at UCSF was financially feasible. Slowly but surely, policy decisions around treatment protocol began shifting responsibilities from UCSF doctors affiliated with the KS Clinic to SFGH doctors, who, administrators increasingly argued, had better infrastructure and support for their work on AIDS. Although this *was* increasingly becoming the case, many believed UCSF had ulterior motives for relinquishing its AIDS program to SFGH. By way of example, Dr. Don Abrams, one of the first doctors involved with the KS Clinic, believed he

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[11] Eventually, the clinic added a psychologist named Paul Dague to the team to support both the patients and the doctors, the majority of whom were young, and a great many of whom were gay themselves. Dague himself would die of AIDS within a few years. Marcus A. Conant, M.D., "Founding the KS Clinic and Continued AIDS Activism," oral history conducted in 1992 by Sally Smith Hughes, in *The AIDS Epidemic in San Francisco: The Medical Response 1981-1984*, *Volume II*, 99-102.

[12] Parnassus is a neighborhood located to the immediate north of Mount Sutro in the center of San Francisco. San Francisco General Hospital, meanwhile, straddles two much more urban neighborhoods: The Inner Mission District and Portrero Hill. These neighborhoods lie to the west of Parnassus, and sit at sea level.

lost a previously-guaranteed position as a clinical instructor at the UCSF Cancer Research Institute because his work with PWAs was politically untenable. His superiors reportedly told him they withdrew the offer of employment because he was found delinquent regarding the maintenance of patient charts; despite taking seemingly punitive action against the doctor, however, the administrators at the Cancer Research Institute also reportedly encouraged Abrams to move to SFGH, suggesting that the move would be beneficial to his career. According to Abrams, homophobia was a big part of the reason his career at UCSF came to an end, that "the concept of having all these gay men who were relatively healthy with this unknown disease sitting in the [oncology] waiting room around these patients with malignancies was disturbing [to them]."[13]

Dr. Mark Conant, who also worked at UCSF throughout the early AIDS crisis, was less charitable. "The leaders of the university would have just as soon never touched AIDS" he told the SF AIDS Oral History Project, adding that, from the hospital's perspective, "They viewed it as a disease 'those kinds of people' get: it's a sexually transmitted disease; 'nice' people don't get sexually transmitted diseases."[14] Conant argued that centralizing AIDS services at SFGH was never about size, space, or resources: it was that "people with STDs don't have any money and they ought to go to the county hospital and sit on a bench."[15] 5B

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13. Donald I. Abrams, M.D., "The KS Clinic, Lymphadenopathy and AIDS-Related Complex, and the County Community Consortium," oral history conducted by Sally Smith Hughes in *The AIDS Epidemic in San Francisco: The Medical Response 1981-1984*, *Volume II*, 31.

14. Conant oral history, 133.

15. *Ibid*.

founder, Nurse Clifford Morrison, concurred, referring to UCSF as “Parnassus on the hill.”[16] “That’s Heaven and God over there,” Morrison said, “Anything that is controversial, dirty, or beneath them goes to San Francisco General.”[17]

The *de facto* segregation of San Francisco’s healthcare system was the primary reason Abrams resisted moving his patients to The General. He reportedly told SFGH’s Dr. Paul Volberding that he “‘would not come work in that clinic with the graffiti in the elevator;’” Volberding reportedly responded by painting over the graffiti.[18] Abrams remained angry about the decision to make The General the locus for AIDS research and treatment in San Francisco. He explained his feelings on the subject in an interview, saying that he had not liked the idea of his patients—whom he described as “very sophisticated, intelligent people that have a high socioeconomic status”—being sent to the public hospital.[19] A gay man himself, he “just felt that this was a terrible affront to gay men to have to be herded to San Francisco General Hospital to wait for x-rays, sitting next to people that are chained and shackled and wearing orange prison uniforms. I thought that this was very, very bad.[20] Abram’s pre-5B opinion of The General demonstrates both the depth of the

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[16] Clifford Morrison, M.S., M.N., R.N., F.A.A.N., “Organizer of the AIDS Ward, San Francisco General Hospital,” oral history conducted by Sally Smith Hughes in *The AIDS Epidemic in San Francisco: The Response of the Nursing Profession, 1981-1984*, *Volume III*, 73.

[17] Morrison oral history, 73.

[18] Abrams oral history, 31-32.

[19] *Ibid.*, 30-31.

[20] *Ibid.*, 30-31.

inequality in healthcare provision and the tremendous political power that the gay community had amassed over the course of the 1970s.

Abrams ultimately discovered that most of his patients were more concerned about the doctor working with them than they were concerned about where that work took place. In fact, he later learned that his departure—and the loss of the patients who came along with him—had a considerable negative impact on the KS Clinic's finances.[21] The clinic closed in 1985, a few years after Dr. Abrams moved to San Francisco General Hospital. By that point the disease had outgrown the clinic's usefulness, and Ward 5B, not yet two years old, had already built a national reputation as a pioneer in AIDS care.

The changing nature of AIDS services at UCSF demonstrates that—while San Francisco's political response to the epidemic was undoubtedly the world's most robust—PWA services were never evenly distributed throughout the city. That almost half the money approved by the Board of Supervisors in 1983 to address the epidemic was allocated to San Francisco General Hospital demonstrates that within two years of AIDS' arrival, almost all related work had shifted away from UCSF. While the funding disparities and political implications of this shift were a source of consternation for doctors and nurses alike, this public vs. private dynamic was not unusual. There were several private hospitals operating in San Francisco during the AIDS crisis. Those hospitals, like the UCSF Medical Center, quietly admitted (insured) people with AIDS throughout the epidemic. For example, the Ralph K. Davies Medical Center, a private hospital located in the Castro district, routinely treated insured people with AIDS. They did not, however, conduct extensive research into the disease, or publicize the number of AIDS cases they saw, despite being

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[21] *Ibid.*, 33.

located in one of the country's first gay neighborhoods. As a nurse practitioner at SFGH explained, "[Davies had] all these other people who [were] paying, and they [didn't] want to scare them away with something queer and scary."[22]

The "queer and scary" nature of the new epidemic—and the lack of civil protections afforded to the emerging PWA population in the 1980s—meant that even in the cradle of the Gay Rights Movement, the sick faced circumscribed healthcare options. By understanding the larger sociopolitical climate in which they operated, the radical nature of the 5B nurses' efforts to establish a dedicated AIDS unit at San Francisco's public hospital becomes clearer. It also helps explain why their efforts attracted global attention.

AIDSphobia in the Early 1980s

On June 7, 1983, George Gallup wrote up the results of a Gallup survey on AIDS for *The Detroit Free Press*. According to that poll, 77 percent of Americans had heard or read about the disease—"a high percentage considering the disease was almost unknown to the public a few months ago."[23] Setting aside the problematic definition of "the public" that the report implies, the fact remains that the profile of AIDS was on the rise by 1983, and along with that awareness came fear not just of the virus, but also of the subgroups it supposedly targeted, namely: homosexuals, heroin addicts, hemophiliacs, and Haitians. [24]

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[22] Gary Stephen Carr, "Nurse Practitioner at the AIDS Clinic, San Francisco General Hospital," oral history conducted by Sally Smith Hughes, in *The AIDS Epidemic in San Francisco: The Response of the Nursing Profession, 1981-1984*, *Volume II*, 47.

[23] George Gallup, "Poll Shows AIDS Fear Spreading," *Detroit Free Press*, July 7, 1983, sec. B., 23.

[24] In 1982, The Centers for Disease Control announced that the mystery immunodeficiency they started tracking in 1981 had also been identified in a group of

Even before the Gallup poll came out, Associated Press reporter Jerry Schwartz was writing about AIDSphobia in urban America—especially in New York City and San Francisco, where two-thirds of all cases had been identified. By 1983, the same year 5B opened, New York prison guards had demanded that a prisoner with AIDS be segregated from the rest of the prison population, and that they be allowed to wear white surgical masks and gloves on the job, to protect against possible exposure to the virus. The Coronado, California Fire Department had cancelled a course on pulmonary resuscitation, lest the practice mannequins become a source of contagion. Members of television crews in both New York City and San Francisco likewise refused to share a studio with (much less interview) a PWA, with one anonymous cameraman pointedly asking Schwartz "[W]ould you go near these people, when you have kids at home?" Fear of and discrimination against

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Haitian men. This led many to refer to AIDS as the "4H Disease." The at-risk population—the 4H club—included homosexuals, hemophiliacs, Haitians, and heroin users. Of course, the disease's epidemiological track was never so restricted. For the purposes of this San Francisco-focused dissertation, it is especially important to note that IV-drug use was never confined to heroin. Many of the IVDUs identified in San Francisco in the beginning of the virus injected methamphetamines. To read more about the 4H Club and the problems that resulted from artificially narrowing the patient population, see: Sander L. Gilman, "AIDS and Syphilis: The Iconography of Disease," *October* 43 (Winter, 1987): 87-107, http://www.jstor.org/stable/3397566; Gerald M. Oppenheimer, "In the Eye of the Storm: The Epidemiological Construction of AIDS," in *AIDS: The Burdens of History*, eds. Elizabeth Fee and Daniel M. Fox (Berkeley: University of California Press, 1988): 267-292; Paula A. Treichler, *How to Have Theory in an Epidemic: Cultural Chronicles of AIDS* (Durham: Duke University Press, 1999); John Dececco and Michael Scarce, *Smearing the Queer: Medical Bias in the Health Care of Gay Men* (New York: Routledge, 1999); Michelle Cochrane, *When AIDS Began: San Francisco and the Making of an Epidemic* (New York: Routledge, 2004); and Jon Cohen, "Making Headway Under Hellacious Circumstances," *Science* 313, no. 5786 (July 28, 2006): 470-473, http://science.sciencemag.org/content/sci/313/5786/470.2.full.pdf.

To learn about activist efforts to expand the definition of AIDS, see: *How to Survive a Plague*, directed by David France (2013; United Kingdom: Network Releasing, 2014), DVD; *United in Anger: A History of ACT UP*, directed by Jim Hubbard, (2012; Los Angeles: The Film Collaborative, 2014), DVD; and David France, *How to Survive a Plague: The Inside Story of How Citizens and Science Tamed AIDS* (New York: Knopf, 2016).

people with AIDS continued even after they died: New York state morticians refused to offer embalming services for people who died of the disease, citing a lack of information about their cause of death.[25] A generous interpretation of these examples above might suggest that these individuals displayed an overabundance of caution (as opposed to outright paranoia), but AIDSphobia was never limited to persons who could reasonably expect to come into contact with a PWA. Despite the reassurance of public health officials around the country, the fear of AIDS began impacting the daily activities of American heterosexuals.[26] He quoted the coordinator of the AIDS Action Project at Howard Brown Memorial Clinic in Chicago about the kinds of calls they received at their office, calls from people "afraid of sharing laundry services in buildings where gays live… afraid of buying a house because it was occupied by a gay patient… afraid to work in the same office with gays, [and]… afraid they will get AIDS from mosquito bites.[27]

AIDSphobia and homophobia were imbricated to such an extent that—as in the quote above—sexual preference was sufficient to render an individual a medical risk to be avoided. This inaccurate perception stemmed from a far longer history of pathologizing sexual difference.[28] Indeed, the American Psychiatric Association had only removed

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[25] Jerry Shwartz, "The Public: AIDS Epidemic Spreading Fear," *The Galveston Daily News*, June 30, 1983, sec. C, 27.

For additional information on the death industry's response to the HIV/AIDS epidemic, see John Erik Troyer, "Technologies of the HIV/AIDS Corpse," *Mortality* 29, no. 2 (2010): 129-149.

[26] Shwartz, 27.

[27] *Ibid*.

[28] For more details on this rich, if troubling history, see: Ronald Bayer, *Homosexuality and American Psychiatry: The Politics of Diagnosis* (Princeton: Princeton University Press, 1987); Jennifer Terry, *An American Obsession: Science, Medicine, and*

homosexuality from the DSM III three years before the publication of Shwartz's article. While homosexuality was no longer officially recognized as a mental disorder, the 1981 emergence of AIDS provided a new (and arguably stronger) rationale for the medicalization and surveillance of queer desire.[29] In *When AIDS Began: San Francisco and the Making of an Epidemic*, medical geographer Michelle Cochrane notes that this prejudice was reinscribed through scientific and medical discourse which prioritized homosexuality to the exclusion of other risk factors in early San Francisco-based research, a point which will be discussed in greater detail later.[30]

While the impact of AIDSphobia was already visible in the early 1980s, it grew considerably in 1985, following the revelation that Rock Hudson was dying of AIDS. The "worried well," as therapists and counselors called them, came out of the woodwork, flooding volunteer AIDS hotlines with questions and concerns about the virus. Barry Davidson, the Director of Community Information at Gay Men's Health Crisis (GMHC), told *The Detroit Free Press*, "'The people who are at the lowest risk are the ones most obsessed.'" One might posit that the worried well were more "obsessed" with the prospect of contagion because those who *did* fit into major risk categories had dealt with the realities of the

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Homosexuality in Modern Society (Chicago: University of Chicago Press, 1999); Jack Drescher and Joseph P. Merlino, eds., *American Psychiatry and Homosexuality: An Oral History* (New York: Routledge, 2007); and Carolyn Herbst Lewis, *Prescription for Heterosexuality: Sexual Citizenship in the Cold War Era* (Chapel Hill: University of North Carolina Press, 2013).

[29] Gayle S. Rubin, "Thinking Sex: Notes for a Radical Theory of the Politics of Sexuality," in *Deviations*, ed. Gayle S. Rubin (Durham: Duke University Press, 2011), 170-171.

[30] Cochrane, *When AIDS Began*, XXII.

disease for four years already, and, accordingly, knew that one could not get AIDS by, for example, using a public toilet, or merely touching a PWA.[31] The AIDS panic of the early 1980s—and its attendant homophobia—rendered the choice to establish and work on a dedicated AIDS unit deeply political, a response to fear of and discrimination against a marginalized population. It was also a powerful condemnation of the federal government's inadequate response to the virus. At the time Ward 5B opened, the House of Representatives had only committed $2.6 million to AIDS Research through the Centers for Disease Control (CDC); the National Institutes of Health (NIH) offered another $2.5 million.[32] By that same time, the San Francisco Board of Supervisors had already allocated $2.1 million for AIDS programs, $1 million of which was earmarked for SFGH's in- and outpatient facilities.[33] While we know that the subject was frequently discussed in private, Ronald Reagan did not *publicly* address the AIDS crisis until May 31, 1987, by which time 36,058 Americans had been diagnosed with AIDS and 20,849 had died.[34]

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[31] Tamara Jones, "AIDS: A Mysterious Killer Stalks the Nation," *Santa Cruz Sentinel*, September 15, 1985, A1.

[32] *The AIDS Epidemic in San Francisco: The Medical Response, 1981-1984*, 156-157.

[33] *Ibid*.

[34] Jennifer Brier, *Infectious Ideas: U.S. Political Responses to the AIDS Crisis* (Chapel Hill: The University of North Carolina Press, 2011); Allen White, "Reagan's AIDS Legacy/Silence Equals Death," *SFGate*, June 8, 2004, accessed July 13, 2017, http://www.sfgate.com/opinion/openforum/article/Reagan-s-AIDS-Legacy-Silence-equals-death-2751030.php.

The Creation of Ward 5B

As Geunter Risse notes in “Caring for the Incurable: AIDS at San Francisco General Hospital,” the traditional organizational structure of the American hospital was ill-equipped to handle AIDS. Their architecture assumed a single cause of illness that could be cured by the ministrations of a single physician, not a panoply of illnesses requiring holistic care. Having patients scattered in myriad intensive care and isolation units throughout the hospital was not only inefficient and expensive, it impeded the unusual amount of communication required of doctors working with immunosuppressed patients.[35] Even more problematic, deathly-ill patients had to be transported all over the hospital to have their different medical conditions addressed and various tests run. This framework placed undue stress on physician, nurse, and patient alike.

Nursing Director Mary Anne McGuire turned to Nurse Clifford Morrison to bring order to the chaos. Within months of the virus’ emergence, Morrison established himself as a go-to authority on AIDS, almost by accident. He was working in the Department of Psychiatry when the epidemic began in 1981**.** A gay man himself, Morrison was drawn to learn more about AIDS out of a concern for his community, and, more specifically, for friends who he believed were at a high-risk of contracting the disease. [36] In the process, he became something of a culture broker at San Francisco General Hospital. Critical care units with PWA patients routinely consulted Morrison, because, in his words, “San Francisco had a reputation of being the gay mecca, but, in health care, we knew very little about the gay

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[35] Risse, *Mending Bodies, Saving Souls*, 660.

[36] Morrison oral history, 79.

lifestyle… [T]here wasn't a sensitivity to gay issues or [an understanding] that there might be a need to look at these issues in relationship to an individual's care: how it would impact him."[37] Increasingly, he devoted his time to serving as a medium between patients and their care providers, sensitizing both parties to be better attuned to the needs of the other.

Realizing that the changing demography of SFGH's patient population rendered Morrison indispensable, McGuire hired him to serve as their Inpatient AIDS Coordinator. That a single person was hired to address the needs of people with AIDS across the whole of San Francisco General Hospital, a five-hundred bed teaching hospital at the epicenter of the AIDS crisis, speaks to how quickly patient acuity—and the estimation of AIDS' impact—changed between 1981 and early 1983 in the city. It also speaks to the fact that McGuire was already thinking about creating an AIDS ward, for which she hoped Morrison would be responsible. While he agreed to serve as Inpatient AIDS Coordinator, Morrison had no interest in creating an AIDS ward at The General; in fact, he was actively opposed to the idea. As he explained to The San Francisco Oral History Project, "I remember telling my close friends—confidentially, of course—'I've taken this job because I'm going to ensure that we never have an AIDS unit at San Francisco General… it would be the worst thing in the world that could ever happen to our community, let alone to health care.'"[38] In order to understand why the prospect of an AIDS ward made Morrison so uncomfortable, one need only look at the longer history of both infectious disease treatment and homophobia in the United States.

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[37] *Ibid.*, 75.

[38] *Ibid.*, 93.

Numerous doctors, nurses, and hospital administrators expressed concern that segregating people with AIDS on a single ward would mean creating a "leper colony."[39] Fear was the order of the day, and Morrison saw that fear manifesting in conversations about patient care. "In 1982," he reminisced, "the whole discussion around units at that point was isolation: how to keep these patients away, how to protect staff, how to basically put them in the back of the hospital as far away from everything as possible."[40] The comparison to so-called "leper colonies," was neither hyperbolic nor unfounded. Indeed, there were still American citizens living in the Carville National Leprosarium in Carville, Louisiana, when 5B was under consideration. Carville was not the only healthcare institution famous for interning people with infectious diseases, the vast majority of whom also happened to exist on the margins of society.[41] North Brother Island, where "Typhoid Mary" Mallon lived out her days, is more famous than Carville, and its history even more fraught. Sanitariums, preventoriums, and other long-term quarantine facilities had

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[39] The term "leper"—which occurs throughout the 5A/5B archive, and in discourse around HIV/AIDS writ large—is considered deeply offensive to many people living with this condition, as is the historically and religiously fraught name of the condition. "Hansen's Disease" (HD) is the term those patients prefer, named for Gerhard Armauer Hansen, the Norwegian physician who discovered the bacillus responsible for leprosy in 1973. Many patients, accordingly, identify as having HD, or as "Hansenites"; see: Vanessa Buschschluter, "Living with Leprosy," BBC News, accessed June 21, 2017, http://news.bbc.co.uk/2/hi/8648725.stm.

[40] Morrison oral history, 78.

[41] The people living at Carville during the AIDS crisis were not forcibly interned, as had been the case only a few decades earlier. Having been segregated from society for most of their lives, these patients advocated for the right to live out their life in the institution, it being the closest thing to a home they had. For more information on the history of the Carville National Leprosarium, see "'We Are No Peculiar Breed of Femmes': Domesticity as Counter-Discourse for Women with Leprosy, 1940-1960," Andrea Milne's forthcoming article in *Frontiers Journal of Women's Studies*, publication date TBD.

vanished from the landscape of American public health, but the damage they had done was still front-of-mind, especially for healthcare professionals like Morrison.[42] By creating Ward 5B—a dedicated AIDS ward located at the far end of the hospital, isolated from the rest of the patient population—might he help bring these institutions back? Carol Pogash puts it simply in *As Real As it Gets*: "Creating an AIDS Ward would violate nearly every nursing concept Morrison had been taught in school."[43]

The history of infection control in the United States was sufficient in and of itself to suggest that an AIDS ward would do more harm than good, but Morrison's concerns were augmented still further by the way AIDS was changing the political climate around homosexuality. It bears remembering that the first reported cases of AIDS were known as Gay-Related Immune Deficiency (GRID), which underscores the fact that, as early as the drafting of the first *MMWR* report, epidemiologists and researchers alike treated AIDS as a theretofore unheard of sexually-discriminate disease. That characterization made it all the easier for leaders of the religious right like Jerry Falwell and Pat Roberston to attribute the

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[42] For more information, see: Judith Walzer Leavitt, *Typhoid Mary: Captive to the Public's Health* (New York: Beacon Press, 1997); Brad Byrom, "A Pupil and a Patient: Hospital-Schools in Progressive America," in *The New Disability History: American Perspectives*, eds. Paul K. Longmore and Lauri Umansky (New York: New York University Press, 2001), 133-156; Duane F. Stroman, *The Disability Rights Movement: From Deinstitutionalization to Self-Determination* (Lanham: University Press of America, 2002); Michelle T. Moran, *Colonizing Leprosy: Imperialism and the Politics of Public Health in the United States* (Chapel Hill: University of North Carolina Press, 2007); Cynthia A. Connolly, *Saving Sickly Children: The Tuberculosis Preventorium in American Life, 1909-1970* (New Brunswick: Rutgers University Press, 2008); and Gerald N. Grob, *From Asylum to Community: Mental Health Policy in Modern America* (Princeton: Princeton University Press, 2014).

[43] Pogash, *As Real as It Gets*, 104.

outbreak to God's wrath.[44] The parallels with Hansen's disease (leprosy) were undeniable. Would separating people with AIDS from The General patient population feed into the premise that PWAs were physically and spiritually unclean? Furthermore, how could anyone (but particularly a politically-active, gay healthcare provider) justify segregating people with AIDS from a general population that seemed entirely too happy to be rid of them and the gay lifestyle they were understood to represent?

As it turned out, many of the same reasons Morrison initially opposed the creation of an AIDS unit became reasons to pursue it: even in the comparatively liberal setting of a public hospital, few healthcare workers felt comfortable treating AIDS patients. The dramatic increase in PWA admissions to SFGH brought with it an uptick in abuse and neglect. As the Inpatient AIDS Coordinator, Morrison was responsible for interfacing with patients and staff all over The General, to solve problems unique to the care needs of people with AIDS. As the number of PWAs checking into the hospital increased, so did Morrison's workload. He reportedly began working fifteen to seventeen hour days, and working on the weekends, just to keep up. While overextension played a significant role in this change of heart, poignant experiences of staff prejudice were equally motivating.[45] He

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[44] For a more nuanced and capacious history of religion in the AIDS crisis, see: Thomas L. Long, *AIDS and American Apocalypticism: The Cultural Semiotics of an Epidemic* (Albany: State University of New York Press, 2005); Anthony M. Petro, *After the Wrath of God: AIDS, Sexuality, and American Religion* (Oxford: Oxford University Press, 2015); and Anthony M. Petro, "Ray Navarro's Jesus Camp, AIDS Activist Video, and the 'New Anti-Catholicism,'" *Journal of the American Academy of Religion*, advance article, published online May 4, 2017, https://doi.org/10.1093/jaarel/lfx011; Also look forward to Lynne Gerber's forthcoming book-length project, *A Church Alive: AIDS and the Metropolitan Community Church of San Francisco*.

[45] Morrison oral history, 97.

relayed several affecting stories to journalist Carol Pogash for her 1992 book *As Real As it Gets*. She wrote that, "Each day, as [Morrison] visited AIDS patients throughout the hospital, he was appalled by the treatment they received. He found trays of dried and rotting food piled in corners, floors unwashed and unswept and wastebaskets brimming over," that "Feverish young men with nightsweats were unable to find nurses to change their soaked sheets or to bring them Tylenol. When bed linens were removed, they were thrown out. Frightened staff were posting signs on patient's doors—CONTAMINATED AREA.[46]

According to Pogash, the final straw came when a deaf woman indicated to a nurse that she wanted last rites performed on her dying son, only to have the hospital priest refuse the request. His justification: that if the young man had "that gay disease," he had "brought it on himself." A group of Catholic nurses joined Morrison in performing the last rites in the priest's stead.[47] While Morrison did not relay this story in interviews with the San Francisco Oral History Project, he and other members of the nursing staff consistently described the environment at SFGH as profoundly homophobic. Sometimes this prejudice was overt, like when Nurse Diane Jones had to confront a physician who described a bronchoscopy to confirm PCP as "having to stick a tube down a fag's throat."[48] Equally often though, staffers' homophobia expressed itself more subtly, through what Jones described as a "blaming approach" to patients, or the exoticization of gay sex. Especially in the earliest

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[46] Pogash, 103.

[47] *Ibid*.

[48] Diane Jones, R.N., "First Wave of the Nursing Staff on the AIDS Ward, San Francisco General Hospital," oral history conducted by Sally Smith Hughes, in *The AIDS Epidemic in San Francisco: The Response of the Nursing Profession, 1981-1984*, *Volume III*I, 15.

years of the epidemic, taking a detailed medical history of a person with AIDS was understood to include the names of all their sex partners, the kinds of sexual practices in which the patient indulged with each partner, and other intimate details of their private lives, especially with regard to drug use. These voyeuristic documents were not just dubious in their utility, they were also poorly protected, resulting in regular violations of patient privacy.[49] The combination of fear, prejudice, neglect, and overwhelming need led Morrison to agree with McGuire that a dedicated AIDS unit might be in the best interests of AIDS patients at San Francisco General, at least until the stigma became more manageable, and hospital workers became more sensitive.

Morrison's assent, unsurprisingly, came with conditions. First and most important: any ward he designed would be run on a nursing model, an organizational and care modality which will be addressed later. Morrison expected, and received, tremendous latitude—from both McGuire and Head of the San Francisco Department of Public Health Dr. Merv Silverman—to design the world's first inpatient AIDS unit as he saw fit. Morrison believed that that latitude was more born of apathy than faith, "'mainly because they thought we wouldn't be able to accomplish anything.'"[50] Morrison took advantage of the creative freedom nevertheless, not only blending together a range of different healthcare models, but also bringing patients into the design process. According to Pogash, "Every day for three months, [Morrison] rounded up the AIDS patients well enough to leave their beds, gingerly lowering them into wheelchairs, and pushed them to an empty ward on the fifth

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[49] *Ibid*., 14.

[50] Pogash, As Real as It Gets, 104.

floor of the main hospital that would become the inpatient AIDS unit. Together, the dying men and the gay nurse designed the new facility."[51] The result was a patient-centered model of healthcare that, if inspired by a range of time-tested approaches, was itself decidedly new. That model is known to this day as The San Francisco model of AIDS Care, which—despite many changes over nearly three-and-a-half decades—remains the international gold standard in AIDS care, and San Francisco General Hospital's claim to fame. The ward officially opened on July 25, 1983. Four months later, the twelve-bed unit had already hosted one hundred patients.[52]

The 5B Nursing Staff

Nursing Director Mary Anne McGuire empowered Clifford Morrison to hire the ward staff himself, without administrative intervention. Because 5B was a direct response to issues of caregiver prejudice at SFGH, nurses volunteered for service on the ward. Morrison interviewed thirty-five candidates in order to find out why they were interested in joining the staff of the country's first AIDS ward, and ultimately hired twelve of them.[53] 5B nurse Diane Jones said of the process, "[Morrison] demanded a degree of self-reflection as to why you were doing what you were doing," that he scrutinized not only their motivations for working with people with AIDS, but also their expectations for the job.[54] As a result, the

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51. *Ibid*.

52. Risse, *Mending Bodies, Saving Souls*, 639.

53. *Ibid.*, 638.

54. Jones oral history, 32.

nursing team Morrison assembled agreed on what Jones characterized as a standard of "caring based on respect and empathy."[55] Morrison told the San Francisco Oral History Project that the nurses he believed best fit that standard made McGuire, uneasy. Upon hearing which nurses he had selected to staff the ward, she reportedly balked, asking Morrison 'Are you sure these are the people you want?" describing the group as a bunch of "rabble-rousers, troublemakers," who would 'make [Morrison's] life miserable,' not to mention hers."[56]

Unsurprisingly on a ward catering mostly to gay men, the political orientation of Ward 5B's founding nurses was very progressive, and their involvement in political activism high.[57] Morrison described himself as a "product of the sixties" forced out of the closet by Anita Bryant, whose homophobia he felt compelled to protest.[58] Diane Jones was a longtime political activist who Morrison hired on 80 percent–time to accommodate her other work around women's issues. George Jalbert and Bob Adrian were so enthusiastic about joining the ward that they applied for the position despite not yet having finished nursing school. They joined the staff as "orderly trainees," and were promoted upon

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55. *Ibid*., 33.

56. Morrison oral history, 125.

57. The same can be said of the healthcare providers with whom 5B's nurses collaborated. For more examples of AIDS care providers as activists, see: Ronald Bayer and Gerald M. Oppenheimer, *AIDS Doctors: Voices from the Epidemic, An Oral History* (Oxford: Oxford University Press, 2002); "Oral Histories on the AIDS Epidemic in San Francisco: The San Francisco AIDS Oral History Series, 1981-1984," Regional Oral History Office, last modified December 1, 2010, http://bancroft.berkeley.edu/ROHO/collections/subjectarea/sci_tech/aids.html.

58. Morrison oral history, 65-69.

earning their RNs and passing the state board exam.[59] Like Morrison, Jalbert was a product of the 1960s. He dropped out of seminary school to work in the Civil Rights Movement. A staunch opponent of the Vietnam War, he went to jail for resisting the draft. He later bought a farm that served as the staging ground for the 1976 "Faggots and Class Struggle" Conference.[60] That the 5B staff shared a strong commitment to social justice did not just make the ward more cohesive than average, it also made their interactions with the larger hospital staff, the community, and the media more effective.

Who were the nurses of Ward 5B? Of the thirteen people (including Morrison) who staffed Ward 5B at its inception, seven were men, and six were women. Their names were: Bob Adrian, Bill Barrick, Elissa Chandler, Charles Cloniger, Lorie Greer, George Jalbert, Diane Jones, Kathy Juristo, Steve Keith, Allison Moed, Bill Nelson, and Anne Steinlauf.[61] The demographic composition of the ward's staff—specifically with regard to gender, sexuality, health status and race—spoke to the political motivations of the volunteers, and the tensions around AIDS within both San Francisco General Hospital and the city writ large.

Gender and sexuality played a defining role on the ward. In a time when the percentage of male RNs hovered around four percent**,** a majority-male nursing unit was highly improbable, even in a city like San Francisco.[62] More improbable still, all seven of the

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[59] *Ibid*., 126.

[60] George Jalbert obituary.

[61] Jones oral history, 27.

[62] Liana Christin Landivar, "Men in Nursing Occupations: American Community Survey Highlight Report" (Washington, D.C.: U.S. Census Bureau, 2013), https://www.census.gov/ people/io/files/Men_in_Nursing_Occupations.pdf.

men working as nurses on 5B identified as gay, and several (though not all) of the female nurses identified as lesbian. The presence of lesbian women on staff is especially important to note; according to Morrison, the first volunteers to staff the ward were lesbian women, not gay men, to whom he posited the disease posed too significant a personal threat.[63] "[Lesbians] knew they weren't at risk, even at that point, but they saw it as a bigger issue," Morrison told the San Francisco Oral History Project, adding "I remember Diane [Jones] and others saying, 'Hey, this goes beyond being lesbian or gay male. This is an issue for us as a community... I have an obligation to step forward and do what I can for my gay brothers.'"[64] In this respect, the dynamic taking place on Ward 5B represented a microcosm of the San Francisco LGBT community's sociopolitical response to the AIDS crisis. According to Elizabeth A. Armstrong's 2004 book, *Forging Gay Identities: Organizing Sexuality in San Francisco 1950-1994*, the number of lesbian and gay nonprofits in San Francisco declined considerably in the 1980s, while the number of AIDS organizations in the city increased. While Armstrong interpreted these findings to mean the AIDS movement grew at the expense of the Gay Rights Movement—that gay identity politics were subordinated to avoid alienating potential donors and volunteers—recent scholarship by Elizabeth Clement demonstrates that the labor performed by lesbian nurses, if not always explicitly performed in service of LGBT rights, was motivated by the same ethos undergirding the gay and lesbian community groups of the 1970s.[65] Some of the

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[63] Morrison oral history, 122.

[64] *Ibid.*, 123.

[65] Elizabeth Clement, "AIDS and the Silent Majority," (keynote lecture, McMaster University Medical Humanities Program, Hamilton, Ontario, Canada, November 18, 2016).

nurses staffing Ward 5B had themselves provided community health services to women and gay men before the AIDS crisis began.[66] The unique composition of the ward staff shaped—and was shaped by—a queer and feminist ethic of care that gave the space its unique character.

Also crucial to Ward 5B's ethos was the presence of nurses who shared their patients' health status. When the ward opened in 1984, there was no test for AIDS, which meant none of the nurses working on the ward knew whether or not they were infected. However, two of the nurses—George Jalbert and Bob Adrian, the two nursing students—already had symptoms of ARC, or AIDS-related complex.[67] Both were dead by 1989. Before they died, though, the two nurses made an affirmative choice to work with patients whose suffering foreshadowed their own. In an article in *The Washington Post*, former 5B nurse Marcy Fraser described the experience of watching Jalbert work on the ward, taking naps in between lunch breaks to combat exhaustion. When the time came for Jalbert to become a patient himself, he reportedly asked Fraser to take him to San Francisco General Hospital,

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[66] Carr, 131. For more information on the gay health movement as a fundamental pillar of the larger gay liberation movement, see: Oppenheimer and Bayer, *AIDS Doctors*; Catherine P. Batza, "Before AIDS: Gay and Lesbian Community Health Activism in the 1970s" (PhD diss, University of Illinois–Chicago, 2012), xi; and Thomas R. Blair, "Safe Sex in the 1970s: Community Practitioners on the Eve of AIDS," *American Journal of Public Health* 107, no. 6 (June, 2017): 872-879.

[67] Per the National Library of Medicine, ARC is a "prodromal phase of infection with the human immunodeficiency virus (HIV)." In layman's terms, ARC was the diagnosis given to those who manifested symptoms of HIV infection, but whose condition had not yet progressed to AIDS, which requires one's T cell count to be less than or equal to 200. This diagnosis was especially important in the years before HIV testing, especially for practitioners of emergency medicine. The term faded from use at turn of the century, by which time laboratory medicine facilitated far more precise diagnoses. "AIDS-Related Complex: MeSH Descriptor Data 2017," National Institutes of Health—U.S. National Library of Medicine, http://www.nlm.nih.gov/cgi/ mesh/2009/MB_cgi?mode=&term=ARC.

specifically to the ward on which he had worked for the previous three years. She balked at the request, concerned about the emotional toll caring for one of their own would take on the nursing staff. Jalbert ultimately passed away in another hospital, as did Bob Adrian, a few years later.[68] That two of Ward 5B's founding staffers contended with their own diagnoses while caring for others speaks to the value the staff placed on both empathy and patients' voices.

If it is important to know who staffed Ward 5B, it is equally important to know who did not, as these absences speak to the way the hospital staff constructed power and authority on the unit, as well as the practices and tensions that power structure produced. While SFGH was a diverse hospital (a full forty percent of the nurses on inpatient units were Filipino), with the exception of an African American secretary, Ward 5B's first staff was entirely white.[69] Whether that demography was by accident or by design is a question the historical record leaves open. Morrison maintains that he sought racial diversity, only

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[68] Jane Meredith Adams, "Life and Death on Ward 5A," *Washington Post*, December 12, 1989, https://www.washingtonpost.com/archive/lifestyle/wellness/1989/12/12/life-and-death-on-ward-5-a/2039208c-fef9-4414-a930-10b1b1db735f/.

[69] The heavy Filipino/a presence on 5B was the result of a combination of factors. At a local level, even before the AIDS crisis, San Francisco was experiencing a major nursing shortage. Area hospitals explicitly recruited foreign-born nurses to fill the gap. Among the legacies of the colonial relationship between the United States and the Philippines was a deeply Americanized nursing professionalization apparatus that encouraged migration through English fluency programs and nurse-training opportunities abroad. While the Philippines was also experiencing a nursing shortage at the time, and nurses who stayed in the Philippines earned significantly more money than those who left, the brain drain persisted. By 1989, seventy-three percent of all foreign-born nursing students came from the Philippines. Many Filipinos fled to the West Coast during the Marcos dictatorship, which meant that there was a ready-made community in the Bay Area for this new wave of immigrant nurses to join. See: Jones oral history, 16. For a more nuanced discussion of Filipino/s nurses in the United States, see: Catherine Ceniza Choy, *Empire of Care: Nursing and Migration in Filipino American History* (Durham: Duke University Press, 2003).

to be stymied by a monochromatic applicant pool—but the archive is silent on those kinds of personnel issues. Intentions aside, having an all-white staff in an otherwise diverse hospital in a very diverse city meant rhetoric around ward and hospital-wide conflicts could easily become imbricated with racial prejudice. By way of example, a group of Filipino nurses staffing general medicine unit 5C developed a reputation for being overtly homophobic and AIDSphobic in their dealings with their PWA patients—a tendency 5B's nursing staff ascribed to cultural differences. The disrespect shown to AIDS patients, and the resulting conflict between the two nursing staffs, got ugly. When PWAs died on Ward 5C, some of the 5B nurses would quip that "the Filipino death squad struck again."[70] This in a city where Asians and Pacific Islanders constituted nearly a quarter of the population.[71]

Understanding who worked on Ward 5B is crucial to understanding the political labor performed on the ward, because the leadership structure on the unit was decidedly nontraditional. While Morrison crafted the care philosophy of the ward, he also tried to make it as egalitarian as possible, refusing to hire a medical director for the first several years and consistently referring to himself as a "Clinical Coordinator," not a "Head Nurse."[72] Per medical historian Geunter Risse, this decision reflected not only a desire to create a ward that eschewed hierarchism in favor of consensus-building, but also a reflection of the

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70. Guenter Risse, "Planning a New Hospital Ward: The San Francisco Model of AIDS Care" (presentation, London School of Hygiene and Tropical Medicine, London, May 24, 2000), 2.

71. "San Francisco City and County: 1970-1990," Bay Area Census, accessed June 10, 2017, http://www.bayareacensus.ca.gov/counties/SanFranciscoCounty70.htm.

72. Morrison oral history, 131.

culture of gay San Francisco at the time.[73] As Nurse Diane Jones told the SF Oral History Project, "[Morrison] set the orientation; he selected the staff, and then he turned it over to us and said, 'You all decide how you're going to run this thing, and what works for you.'"[74] Morrison understood his role on the ward as supportive in nature: his job would be to provide assistance to and lobby for the nurses doing the day-to-day work of patient care, as he (correctly) assumed that the high standard for patient care would be enforced by the nurses themselves.[75] This leadership structure, in addition to elevating the role of each caregiver on the unit, also facilitated the high level of intellectual, political, community, and media engagement for which the ward became known.

"The San Francisco Model of AIDS Care"

The San Francisco model of AIDS care blended several different healthcare models, two of which were relatively new in the United States: primary nursing and hospice. The primary nursing model—which was growing in popularity in the early 1980s, and a modified version of which is now *de rigueur* in hospitals around the country—saw a registered nurse coordinate all care provided to a patient or group of patients on a ward. This model replaced team nursing, which not only gave individual nurses less responsibility and accountability for patient outcomes, but also encouraged the use of para-

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[73] Risse, *Mending Bodies, Saving Souls*, 639.

[74] Jones oral history, 51.

[75] *Ibid*.

and nonprofessional nursing staff.[76] Morrison argued that providing quality care would require that only registered nurses work on the country's first AIDS ward. Director Mary Anne McGuire agreed with Morrison that an all-R.N. staff would be ideal, but told him "'We can't sell this, because it will cost too much… [T]his is a county hospital. We've got lots of L.V.N.'s [Licensed Vocational Nurses]. We've got lots of aides and orderlies. We can't promote something in this institution that doesn't include these other people. We'll be crucified for it.'"[77] McGuire's concerns were especially valid considering that 5B would already be the only non-critical care ward at SFGH with such a low nurse-to-patient ratio—an expensive proposition.[78] But Morrison persisted: apart from Jalbert and Adrian, the two nursing students on the ward, everybody on the inaugural staff had an RN. Morrison's hiring schema prioritized nurses who had worked in critical care or similarly intense medical nursing backgrounds, but *particularly* nurses who had worked in home or hospice care. Because his previous work on SFGH's psychiatric ward had been so important to his work as the Inpatient AIDS Coordinator, Morrison also made a point of prioritizing individuals with experience in mental health.[79]

Morrison's interest in hiring nurses with a home care or hospice background was highly unusual, and would be equally unusual today, as Eileen Boris and Jennifer Klein's 2015 book *Caring for America: Home Health Workers in the Shadow of the Welfare State*

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[76] Morrison oral history, 107.

[77] Morrison oral history, 108.

[78] The staff to patient ratio on 5B was 1:4. Compare this to a 1:7 or 1:10 ratio on other units. Risse, "Planning a New Hospital Ward," 4.

[79] *Ibid*.

makes abundantly clear. If non-profit care work has long been regarded as the responsibility of self-abnegating white women, these same services rendered for money are discursively constructed as the responsibility of unskilled black women, the moral value of whose toil is degraded by the compensation they receive.[80] (Should a man undertake the same labor, he experiences the "costs of racial feminization.")[81] Far from sanctified, a home-care worker's labor was (and is) often regarded as no more difficult than housekeeping. Indeed, the 1940 Fair Labor Standards Act categorized homecare workers and nurse-companions *not* as caregivers, but as domestic servants, who, coincidentally, were not eligible for the labor rights assured by the New Deal.[82] Homecare providers were seen not as trained professionals, but as hired help over whom the client could exert control. Considering that this climate persists to this day, Morrison's interest in hiring homecare workers placed him and Ward 5B well ahead of the curve.

The American hospice movement began in the late 1950s in response to a growing concern that the curative focus of modern medicine dehumanized and deprioritized the dying. In *The Inevitable Hour: Caring for Dying Patients in America*, Emily K. Abel points out that, at the time, not only were doctors inclined toward aggressive (and often painful) treatment of terminal illnesses, in some cases, those procedures were conducted against

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[80] Eileen Boris and Jennifer Klein, *Caring for America: Home Health Workers in the Shadow of the Welfare State* (New York: Oxford University Press, 2012).

[81] *Ibid.*, 8.

[82] *Ibid.*, 28.

the wishes of the patient.[83] Also problematic was longstanding medical wisdom, which encouraged medical professionals and families alike to hide bad news from patients, a tactic they thought helped keep patients' hope alive. Secrecy was so pervasive that even in the 1950s—the peak of heroic medicine—the majority of doctors *still* were not telling their patients when they were diagnosed with cancer. As a result of this combination of secrecy and medical aggressiveness, patients often died scared, isolated, and in pain.[84]

Discussions of the overtreatment and inattention to terminal patients—including Elisabeth Kübler-Ross' famous 1969 book *On Death and Dying*, which introduced the now familiar concept of the five stages of grief—led medical professionals to look to Europe for solutions.[85] The late 1960s and 1970s were a period of widespread social reform, and healthcare was no exception. The Black Panther's free health clinics, the women's health movement, and gay community health initiatives treated medical care as elemental to political empowerment.[86] The same moment saw the emergence of holistic medicine and

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[83] 83. Emily K. Abel, *The Inevitable Hour: A History of Caring for Dying Patients in America* (Baltimore: Johns Hopkins University Press, 2013), 167.

[84] 84. Abel, 93.

[85] 85. Cicely Saunders, a British doctor, nurse, social worker, and author, is widely regarded as the artificer of the hospice movement. Saunders made multiple trips to the United States over the course of the 1960s and early 1970s, during which time she gave lectures, toured extant institutions for the terminally ill, and, in 1974, opened the country's first hospice facility (The Connecticut Hospice Institute). See: Abel, 168-169.

[86] 86. To learn more about healthcare and other survival services provided by the Black Panther Party, see: Huey P. Newton, *The Black Panther Party: Service to the People Programs*, ed. David Hilliard (Albuquerque: University of New Mexico Press, 2008); Alondra Nelson, *Body and Soul: The Black Panther Party and the Fight Against Medical Discrimination* (Minneapolis: University of Minnesota Press, 2013); and Stephen Shames and Bobby Seale, *Power to the People: The World of the Black Panthers* (New York: Harry N. Abrams, 2016).

the self-care movements, which stressed not only focus on the whole patient, but also the centrality of patient experience to quality healthcare.[87] In this progressive atmosphere, the need for a new way of dying was especially pronounced. Lilian Wald opened the United States' first hospice in 1974. Within seven years, there were eight hundred hospice facilities running or under construction.[88]

The hospice movement encouraged doctors and patients alike to accept the inevitability of—and dignity in—death. The model is premised on the notion that alleviating a person's unnecessary suffering should be caregivers' end goal, not physical improvement. Accordingly, the primary form of care provided in a hospice environment is palliative in orientation. Palliative care is focused on easing the symptoms and pain of the dying patient, as well as attending to any psychic stress he or she may experience during

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For a detailed discussion of the women's health movement, see: Sandra Morgen, *Into Our Own Hands: The Women's Health Movement in the United States, 1969-1990* (New Brunswick: Rutgers University Press, 2002); Jennifer Nelson, *Women of Color and the Reproductive Rights Movement* (New York: New York University Press, 2003); and Jennifer Nelson, *More Than Medicine: A History of the Feminist Women's Health Movement* (New York: New York University Press, 2015).

To learn about the gay community health movement, see: Batza, "Before AIDS." See also Kevin Bentley's narrative, "My Clementina," which describes visits to the local VD clinic as romantic entanglements: Kevin Bentley, "My Clementina," POZ, January 1, 2003, https://www.poz.com/article/My-Clementina-493-5050.

87. Norman Cousins, *The Healing Heart: Antidotes to Panic and Helplessness* (New York: W.W. Norton & Company, 1983); Norman Cousins, *Head First: The Biology of Hope and the Healing Power of the Human Spirit* (New York: Penguin Books, 1990); Norman Cousins, *Anatomy of an Illness: As Perceived by the Patient* (New York: W.W. Norton & Company, 2005); and Nancy Tomes, "Norman Cousins and 'The Anatomy of an Illness,' (presentation, Inaugural Lecture in the History of Medicine, Huntington Library, San Marino, CA, March 25, 2015).

88. Abel, 169.

their dying process.[89] Helping patients to come to terms with their impending death is only possible in a paradigm of care in which power and information are shared between medical staff and care recipients.

The hospice movement began to take hold in the United States less than a decade before the AIDS crisis began. As it happened, Morrison was a strong proponent of hospice care even before founding 5B, having both read and communicated with Elisabeth Kübler-Ross many times. According to Morrison, "Nursing and some of the other disciplines were promoting hospice, but [it] had not taken off in this country in 1982-83. It was here, but we rarely talked about it. Nobody wanted to use it."[90] If not yet a popular healthcare choice, the hospice programs and facilities springing up around the country provided vital accommodations for the tens of thousands of people who would die of AIDS complications. Despite the fact that many 5B patients ultimately passed away in hospice and long-term care facilities, the fact remained—as Shilts wrote in *And the Band Played On*—that, "More people died in Ward 5B than in any other ward of the hospital; more diseases raged in a typical 5B patient's body than could be found in an entire ward in any other part of the hospital."[91] The exigencies of end-stage AIDS meant that hospice services needed to be integrated onto the ward, a subject to which we will return in Chapter Two.

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89. Hospice and palliative care, though similar, are not interchangeable. Palliative care is a healthcare modality that can be utilized in any number of venues, while hospice is a specific program to which one is admitted in the end stages of life.

90. Morrison oral history, 121.

91. Randy Shilts, *And the Band Played On: Politics, People, and the AIDS Epidemic* (New York: St. Martin's Griffin, 2007), 394.

The San Francisco model was and is as much (if not more) about principle as about process, and Morrison's patients-cum-consultants helped insure that the former consistently structured the latter. Control quickly emerged as a predominant theme in Morrison's discussions with PWAs. Unsurprisingly, these young men—dying before their time—wanted to regain some of the autonomy they had lost when they became sick. As a result, patient autonomy became the central organizing principle of the new ward. Nurses educated patients, and involved them in decision-making processes from which they had previously been excluded. Whenever possible, the patient dictated what would happen to them over the course of their hospitalization. Flipping the hierarchy of care, if very beneficial to the patient population, also posed a tremendous challenge to the 5B staff. Of patient-centered care, Morrison told the SF Oral History Project, "We know now that those are the patients that do the best. They're also the patients that can be the most difficult to deal with, because they're demanding." He added that "Physicians didn't like it; a lot of the nurses didn't either. They just weren't used to patients challenging them, and it was the first time that most of us had ever seen patients that knew more about their medications than we did.[92] A patient-centered paradigm also required a greater emotional investment from all parties involved. While the choice to keep patients informed about and engaged in their treatment meant conversations about diagnoses and medication, in the early days of AIDS, it also meant frank conversations about advance directives and funeral planning. Randy Shilts called attention to a statistically significant result of those discussions that bears elaboration.

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[92] Morrison oral history, 148.

When a patient experiences cardiopulmonary failure—a common result of *pneumocystis pneumonia*—the default response is to call a "code blue." Code-blue status, in addition to alerting medical staff that a life-and-death event is taking place, also communicates that hospital staff should take heroic measures to preserve the patients' life. In the case of individuals with *pneumocystis*, "heroic measures" usually meant being placed on a respirator. These machines require intubation, which, in addition to being very uncomfortable, renders speech impossible. In the first two years of the AIDS crisis, Shilts explained, SFGH doctors found that eighty-five percent of *pneumocystis* sufferers placed on a ventilator never regained the ability to breathe independently. In discussing treatment options with their patients, the nurses on Ward 5B routinely cited this statistic. As a result, most of their patients chose to wave code-blue status by having their doctors draw up a Do-Not-Resuscitate (DNR) order. According to Shilts, more patients made that choice on Ward 5B than on all other SFGH wards combined.[93]

At times, the nurses had to defend their patients' choices against their doctors' more aggressive impulses. Two 5B nurses and a Shanti Project counselor provided an example of this sort of patient advocacy work in an article they co-wrote for *RN* magazine, in which they described the case of a patient named John. In John's case, the doctors (following a negative bronchoscopy, the test used to test for *pneumocystis*) recommended an open-lung biopsy. They neglected to tell John that he almost certainly had pulmonary KS [*Kaposi's sarcoma*], or that the invasive diagnostic procedure would require general anesthesia and a chest tube. The likely result of these interventions: John would either be place on a ventilator, or spend the rest of his life in intensive care unit. The nurses "brought the

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[93] Shilts, *And the Band Played On*, 355.

physicians back in and asked them to explain exactly what would happen. After considering the new information John refused consent. We supported his decision."[94]

This anecdote is a powerful reminder that—especially in the face of a disease with no known cure—one of 5B nurses' most important functions was to provide and protect patient choice around death and dying. This work was as emotionally trying as it was necessary. 5B nurse Diane Jones has cautioned against romanticizing this labor, that necessary as their efforts were, "It was really horrible that twenty-five-year-olds had to make decisions about advance directives when they couldn't breathe. They were in the middle of a totally acute, life-threatening case of PCP, and we were asking them to make these decisions."[95] In an ideal world, she seemed to suggest, healthcare decisions of this magnitude would be discussed and formalized well before the need arose.

Efforts to put patients in control of another fraught topic—family time—were both very popular, and an example of the quotidian acts of resistance that built the character of the unit. Nurses granted patients on the country's first AIDS ward a privilege that remains unconventional in American healthcare to this day: they got to define their family for themselves. According to author Carol Pogash, the decision was the result of a disconcerting incident involving a patient on a ventilator. The patient in question had not seen or spoken to his (homophobic) mother in many years. When she unexpectedly arrived on the ward and, as his next-of-kin, declared that her son's lover and "'these homosexual

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[94] William J. Nelson, Linda Maxey, and Steve Keith, "Are We Abandoning the AIDS Patient?," *RN*, July 1984, San Francisco General Hospital AIDS Ward 5B/5A Archives, 1983-2003 (SFH 12), San Francisco History Center, San Francisco Public Library.

[95] Jones oral history, 44.

doctors and nurses'" were no longer allowed in the room, her son was physically unable to contradict her. The patient-centered family policy meant that upon arrival on the AIDS unit, new patients determined who could visit them, when, and for how long. Equally important to the success of the family policy was Morrison's decision to do away with visiting hours entirely; a patient's chosen family had the right to be on the ward whenever the patient desired their presence, which in some cases meant lovers practically lived on the ward. Anticipating that such a policy would meet with considerable administrative pushback, Nurse Morrison did not follow the traditional committee channels to get the plan approved; he made the announcement, and courted enough positive media coverage that revocation would be politically unpalatable.[96]

Hospitals around the country and around the world replicated and adapted the San Francisco model of AIDS Care to fit their needs, in no small part because 5B's nurses used their newfound expert status to promulgate their methodology. Certain components of their care paradigm, however, were harder to instrumentalize than others, *especially* 5B's radical empathy. The nurses' approach to AIDS care required that they routinely break standard codes of nursing conduct, demonstrate unusual emotion and vulnerability, and make their resistance to AIDSphobia quite literally tangible to their patients.

A Radical Touch: Intimate Labor as Activism on Ward 5B

The fact of Ward 5B's existence, and the commitments espoused by its all-volunteer staff, are in and of themselves evidence of an incipient political movement at San Francisco General Hospital. It is in the character of the nurses' interactions with the patient

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[96] Pogash, *As Real as It Gets*, 105.

population, however, that their radical contribution to the AIDS movement becomes most evident. Among the technologies of care that distinguished the 5B staff were: their expressions of empathy through touch, their commitment to relationship-building with patients, and their efforts to remember and mourn the dead. Of these approaches, the nurses' use of physical intimacy, or bodywork, was the most controversial—and arguably the most effective.

The term "bodywork" is traditionally employed to describe alternative medical and personal development techniques that focus on the body. These techniques, which range from massage therapy, to energy balancing, to yoga, all assume a body-mind connection in which physical wellbeing promotes spiritual wellbeing, and vice versa. Some historians of caregiving use the term simply to describe any labor a caregiver performs on the body of a patient.[97] "A Caring Disease" uses "bodywork" to describe the efforts of Ward 5B healthcare workers and volunteers because their accounts of their labor often centered on the importance of touching their patients. The nurses felt it was both politically and therapeutically important to have physical contact with their patients, because the stigma of an AIDS diagnosis often meant PWAs were isolated from their friends and loved ones. The nurses' dedication to the physical, emotional, and spiritual health of their patients meant providing and encouraging physical contact. Using the term "bodywork" to describe what happened on 5B, then, highlights the uniquely intimate quality of the care practices of

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97. Boris and Klein; see also: Rachel Parreñas and Eileen Boris, eds., *Intimate Labors: Cultures, Technologies, and the Politics of Care* (Stanford: Stanford Social Sciences, 2010); and Patricia D'Antonio, *American Nursing: A History of Knowledge, Authority, and the Meaning of Work* (Baltimore: Johns Hopkins University Press, 2010).

5B nurses, practices that in many cases required a lowering of personal and professional barriers.

Like most professions, the healthcare profession endeavored to limit the amount of physical contact staff had with patients to necessary procedures. According to Morrison, his nursing school particularly emphasized professionalism with male nurses, lest they be accused of sexual impropriety. However, the RN-only structure of 5B deliberately made that sort of distance impossible. The nurses—who, on most wards were confined to more bureaucratic work—found themselves doing physical tasks usually reserved for paraprofessional nursing staff, like attending to patient hygiene. These tasks, if consistent with the nursing staff's political ideals, were also physically exhausting.[98] The nurses cleaning and bathing their patients represented a return to an earlier form of nursing that emphasized healing over efficiency, a form of nursing heavily informed by Christian understandings of suffering and compassion. Historian Geunter Risse describes the 5B nurses' approach to care as related to that paradigm, but "[springing] from notions of secular humanism, holism, and individual autonomy."[99] The physical labor demanded of 5B nurses recalled an earlier era; so too did the nurses' unorthodox use of touch. Massage and touch therapy were an important part of the care schema implemented on 5B—as we will see in Chapter Two—but so too were physical demonstrations of affection. If both techniques were out of step with standard medical practice at the time, the latter was much more unusual, and much more controversial.

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[98] Risse, *Mending Bodies, Saving Souls*, 648.

[99] *Ibid*.

Morrison told the San Francisco AIDS Oral History Project that he "recognized right away, these were patients that were longing to be touched, that needed to be touched. They felt isolated, not only because of their illness but because of their lifestyle."[100] The AIDSphobia that characterized the early eighties meant that many of 5B's patients were living in relative isolation, touched only by rubber gloves in the moments when they were most vulnerable, most frightened. Morrison concluded that—despite continuing uncertainty as to how the virus spread—the nurses needed to engage their patients on a physical level. "I saw myself as a facilitator and a role model," Morrison said, "so I acted it out. Even when I was uncomfortable doing it, I did it, because I thought it was so important for people to see me doing it."[101]

The bodywork Morrison performed crossed myriad professional boundaries. He hugged his patients, held their hands, and sat on their beds while he talked to them. Sometimes he went still further. "Holding a patient sometimes means that you've got to actually get in bed, and lie down next to them, and cradle them, and hold them, because they're too sick to get out of bed. That's something that nobody had ever seen before," Morrison said, "and it created lots of problems in the institution. A lot of people, physicians and nurses, were very uncomfortable with it. They'd come in, '[tsk], Well, they're up in bed, god knows, having sex or whatever.' [laughter] This hadn't been done before.[102]

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[100] Morrison oral history, 158.

[101] *Ibid.*, 159.

[102] *Ibid.*, 159.

Perhaps even more surprising than the physical closeness with patients, Morrison also encouraged his nurses to address their emotions as they surfaced, even when that meant crying with their patients.[103] In some case, patients and nurses came out to each other, which was "a phenomenon of great emotional significance, especially for some volunteer staff members hitherto undecided about their own sexual orientation."[104] The level of physical and emotional connection between caregivers and their patients spoke to 5B nurses' different understanding of the nature of their work. In their estimation, nursing was about human understanding, and these physical interactions underscored the caregiver and patients' shared humanity.[105]

Carol Pogash wrote about 5B's unusual approach to patient care—and the complaints it drew from some hospital staffers, including nurses—in *As Real as It Gets*. She suggested that the nurses' bodywork could only take place because San Francisco health director Dr. Mervyn Silverman protected both Morrison and his unit from administrative rebuke.[106] Operating outside the boundaries dictated by traditional notions of professionalism, touch quickly became integral to the care provided by 5B's nurses. Pogash narrativized these practices in her book, describing one nurse's ministrations with a level of detail one might expect to see in the description of a sacred ritual. Pogash watched as

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[103] Leslie Lingaas and Andy Evangelista, "Death Teaches Lessons About Life," n.p., SFGH Scrapbook, Volume One, San Francisco General Hospital AIDS Ward 5B/5A Archives, 1983-2003 (SFH 12), San Francisco History Center, San Francisco Public Library.

[104] Risse, *Mending Bodies, Saving Souls*, 647.

[105] Ibid., 648.

[106] Pogash, *As Real as It Gets*, 105.

nurse Sue Kiely gave a particularly-sick patient a bed bath: "With a washcloth in her right hand she grasped the patient's thumb, and then his index finger, washing each finger as if he were her only patient. From the bony fingers, she moved to his whole hand and his wrist and then his forearm and elbow with the warm, silky water. As she went," Pogash wrote, "she massaged the muscles and she spoke softly to him. When she finished one limb, she patted it dry, covered it and moved on to another. And when she completed a side, she stuffed pillows up against the bed rail, rolled the patient on his side and tucked in clean sheets."[107] Pogash explained that the nurse benefitted as much from the ritual as the suffering patient did, that the intimate gesture "suited her and the unit. 'You feel like a little kid when you're sick. You want your momma,'" Nurse Kiely told her, "'You want someone to hold your head. That's how people feel when they're sick. I wouldn't imagine it's any different when you're sick with AIDS or when you're dying.'"[108]

The unabashed and highly-visible nature of the nurses' intimate caregiving offered a cultural alternative to the AIDSphobia (and homophobia) characteristic of both the popular and the clinical response to the epidemic. That the nurses made these gestures even before they knew definitively that they could do so *safely*, and persisted even (and especially) when doing so scared them, demonstrates their overarching commitment to cultural reform. In the early 1980s, hugging a person with AIDS was a deeply political act. It remained so for a long time, this despite fairly rapid scientific consensus that the virus did not spread through casual contact. In fact, several years after Ward 5B opened, in 1987, the

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[107] *Ibid.*, 102.

[108] *Ibid.*, 102.

National Institutes of Health (NIH) released a now-famous poster of a child's drawing challenging everyday Americans to do what the nurses had done for years. In the drawing, a little kid stands in a field of flowers, arms spread wide, telling the viewer "I HAVE AIDS/Please hug me/I can't make you sick."[109]

Nearly every patient who came through Ward 5B in the early years died of AIDS (the vast majority, national statistics would suggest, within two years of diagnosis), but patients *did* leave the ward on a fairly regular basis, when an opportunistic infection resolved itself, or they were admitted to a long-term care or hospice facility. When patients left 5B, the nurses frequently continued their personal relationships with them. The rationale for this practice was simple: 75 percent of all discharged 5B patients returned to the ward, often multiple times. In an article called "Death Teaches Lessons about Life," Morrison described throwing birthday parties for former patients, meeting with them for lunch… spending time with his patients in sickness and in (relative) health. Other sources reveal that nurses occasionally dated their patients.[110] While it took many different forms, Morrison and the rest of the 5B staff espoused a core philosophy that "We are connected with them until the end."[111]

Of course, that connection only magnified the toll that patients' deaths took on the 5B staff. As Diane Jones put it, "You die with every patient that touches you as a person."[112]

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[109] 109. Center for Attitudinal Healing, "I Have AIDS Please Hug Me," poster, 1987, viewable at https://profiles.nlm.nih.gov/ps/retrieve/ResourceMetadata/VCBBHD.

[110] 110. Risse, *Mending Bodies, Saving Souls*, 648.

[111] 111. Lingaas and Evagelista, "Death Teaches Lessons About Life."

[112] 112. Risse, *Mending Bodies, Saving Souls*, 654.

Physician and medical historian Guenter Risse wrote in 1999 that the nursing staff "showed clear signs of the traumatic stress syndrome commonly known as battle fatigue," a now-antiquated term that approximates post-traumatic stress disorder.[113] The combination of emotional and physical tension 5B nurses endured made furloughs and leaves of absence increasingly necessary to prevent burnout and injury.

In addition to facilitating time away from the ward, Morrison responded to concerns about the staff's mental health by building support systems into the AIDS care regimen, from support groups to team exercises "where everybody, including the housekeeper, was included."[114] These rituals evolved alongside—and were intrinsic to—the 5B patient care modality. Coming together to recognize and honor the deaths on the unit meant that that nurses could "let it go," and continue the emotional and physical work of connecting with patients.[115] One way that the 5B nurses processed their grief was by maintaining a detailed ward remembrance book, which included images, patient artwork, and thank you letters. Most striking, however, was the detailed necrology that comprised the books' first several pages.

The 5B necrology contained thousands of entries, written in increasingly small handwriting as the death toll increased. Each entry noted the name of the patient, the date of their death, and either: the location of their death—for example "@ home," "in room 27," at a local hospice facility or wherever they had relocated; the cause of death—"PCP" "E. Coli

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[113] *Ibid*.

[114] Lewis oral history, 158.

[115] *Ibid*.

of the lung," "Chose to discontinue treatment," "Took 0_2 mask off, found by friend,"; or a memorable detail about the patient—"Long haired, wanted to sell his motorcycle," "Lover murdered in 1983," "Continuous loud hiccups," "Thought of bombing the White House to increase AIDS funding," "Looked strikingly like mom."[116] The necrology testifies not only to the intimate and long-term relationships the nurses fostered with the patients, but also to their sense of personal responsibility for the memory of those they had cared for. Before the first entry in the necrology is a single, unattributed statement: "I don't want the names of the folks who have died on this ward to be forgotten."[117] That so many of the entries in the book are for patients who ultimately died *elsewhere* suggests a need to participate in rituals of remembrance above and beyond the desire for a historically-accurate archive of the facility.

The nurses' relative emotional freedom—expressed in the remembrance book, support group meetings, and daily acts of intimacy—seemed to effectively stave off burnout, at least for a while. 5B boasted incredibly low turnover; the unit did not lose a single nurse for four years, save George Jalbert, who left when he received his official AIDS diagnosis, and died a year later.[118] However, the impact of their intimate labor became more visible over time. Of the thirteen original 5B staffers, three died within its first decade of operation, and others found themselves battling severe physical and mental health

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116. SFGH Scrapbook, Volume One, San Francisco General Hospital AIDS Ward 5B/5A Archives, 1983-2003 (SFH 12), San Francisco History Center, San Francisco Public Library.

117. SFGH Scrapbook, Volume One.

118. Lewis oral history, 158.

issues. Morrison attributed the difficulties 5B nurses encountered in middle age to the lifestyle that their job promoted, saying, "Let's face it: if any of us didn't have a drinking problem when we started, we certainly picked it up later on, believe me. Whether it be smoking cigarettes or drinking alcohol or whatever, we all found whatever crutches we could to get through it."[119]

It perhaps goes without saying that certain components of the 5B care regime did not translate beyond the unit; crawling into bed to hold one's patients is not regarded as acceptable conduct any more now than it was in the early 1980s. However, Nurse Morrison told the SF AIDS Oral History Project that the extreme emotional stress of the AIDS crisis—and the leading role that "liberal," "kooky," "touchy-feely" San Francisco healthcare providers assumed—fundamentally changed the ethos of care in hospitals around the country. "In fact," he said, "probably the single most visible change that happened… is that health care providers show an emotional side of themselves that they never did before. We touch each other, and we touch our patients, and we touch our patients' families, and we hug people. Something we never did before."[120]

Whether or not the AIDS crisis had a lasting impact on nurse-patient interactions in the United States, the fact remains that the intimate bodywork 5B nurses performed (and the emotional connections that undergirded those labors) attracted national attention, almost all of which was positive. The technique was limited in its generalizability, but the care and concern 5B's nursing staff demonstrated for their patients was nevertheless a

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[119] Morrison oral history, 123.

[120] *Ibid.*, 173.

powerful, and political, rejoinder to the atmosphere of AIDSphobia in which the country at large was mired.

Mediating Ward 5B

Ward 5B was the first special-care unit for people with AIDS in the world, but its high profile was by no means a given. San Francisco General Hospital was a rundown county hospital that, in the years preceding 5B's debut, was plagued by problems so significant that it almost lost its accreditation. Even if the hospital's reputation had been better, it bears remembering that even those most-predisposed to following the AIDS crisis—the gay and lesbian community—had good reason to look askance at the medical establishment.[121] The combination of the hospital's poor reputation and the gay community's general distrust of the medical establishment (which had, up until the very recent past, understood homosexuality as a disease, and attempted to "treat" it with everything from aversion therapy and shock treatment to outright physical violence) meant that the ward staff had some significant public relations work to do if they wanted their work to be taken seriously.[122] They had still *more* work to do if they wanted to

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[121] 5B opened just ten years after homosexuality had been removed from the DSM II—replaced by a less-than-comfortable category of "sexual orientation disturbances." For more information on the mistreatment of LGBTQ individuals by the medical establishment, see: Batza, "Before AIDS"; Ronald Bayer, *Homosexuality and American Psychiatry: The Politics of Diagnosis* (Princeton: Princeton University Press, 1987); and Jay Hathaway, *The Gilded Age Roots of Modern American Homophobia* (New York: Palgrave Macmillan, 2003).

[122] Steven Vider and David S. Byers, "A Half-Century of Conflict Over Attempts to 'Cure' Gay People," *Time Magazine*, February 12, 2015, accessed July 13, 2017, http://time.com/3705745/history-therapy-hadden/.

educate the "general public," which was ignorant about the virus at best, and hostile to its sufferers at worst.

The media strategy around 5B seemed to be, if the ward failed, it should "fail big." Nurse Diane Jones recalled that—given the significant controversy around opening a dedicated AIDS unit—showcasing the facility seemed like the best available option. The hospital had a "huge" press conference on the day the unit opened, which all the major television networks attended. Physician and radio personality Dean Edell was also present.[123] Edell's syndicated show reached approximately 200 different media markets and over 2 million weekly listeners at the time it went off the air in 2010.[124] Thus began a courtship between San Francisco General Hospital and the media that continued into the 1990s.

Crucially, Ward 5B caught the attention of Randy Shilts. Best known for his award-winning 1987 tome *And The Band Played On: Politics, People, and the AIDS Epidemic*, Shilts was one of the first journalists to grasp the enormity of the public health crisis upon its dawning in 1981. He convinced his editor at *The San Francisco Chronicle* to let him report on AIDS full-time in the early 1980s—in other words, he became the beat reporter for the virus, the one journalist to whom all persons concerned about AIDS went for their news. Shilts made his first visit to San Francisco General Hospital in October 1983, three months after the ward opened. In the foreward to Carol Pogash's book *As Real As It Gets: The Life of*

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[123] Jones oral history, 55.

[124] Joe Garofoli, "Dr. Dean Edell Retiring as KGO-AM Radio Show Host," SFGate, December 2, 2010, accessed June 22, 2017, http://www.sfgate.com/politics/joegarofoli/article/Dr-Dean-Edell-retiring-as-KGO-AM-radio-show-host-2527447.php.

a Hospital at the Center of the AIDS Epidemic—which he wrote shortly before dying of AIDS himself—Shilts wrote that his first article on 5B was "[A]s grim as anything I had ever composed in my career to that point.[125]

The picture Shilts painted in that first article was poignant enough that he revisited it in *And The Band Played On*. Celebrated cabaret-singer Sharon McNight had rolled a piano onto the ward that October evening, and put on a performance for the patients as part of the ward's Halloween festivities.[126] She joked about the patients' "designer gowns" as they laughed and sipped champagne—all save the one man who sat motionless in his chair, dying of a brain infection that left him completely incapacitated. Despite the impending death of all the patients he interviewed, Shilts described the special care unit as "the most entertaining unit in the hospital," citing the gay nurses from all over the hospital who converged on 5B during their breaks, and the legion of volunteers and charity groups that turned out, especially during the holiday season, to support the patients.[127] He wrote in *As Real as It Gets* that when that first article went to press, he did not yet know anybody who had died of AIDS, though a few friends had taken ill. He certainly did not know that the same disease would take his life a decade later. Perhaps that's why, he wrote, the ward felt like such a positive space. The patients were optimistic that they would live long enough to see a cure. While he doubted 5B's current occupants would survive, even Shilts had not

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[125] Randy Shilts, forward to *As Real as It Gets: The Life of a Hospital at the Center of the AIDS Epidemic*, ed. Carol Pogash (New York: Plume, 1994), xi-xii.

[126] Please note McNight's surname is misspelled in *And The Band Played On*. This dissertation uses the spelling from the singer's web page.

[127] Shilts, *And the Band Played On*, 394.

fully grasped the enormity of the AIDS crisis. "[L]ike everyone else, I had this can-do attitude toward the disease," he said. "We could provide the best treatment, keep people alive, the cure would come, and then we could have another party to celebrate the end of AIDS. Sharon McKnight (*sic*) could sing then too.[128]

Hope in the face of death makes for great human-interest journalism, so it is little wonder that the media latched on to Ward 5B right around the same time Shilts did, and specifically to its hero-nurses. Indeed, the media became a fixture on the ward. A photographer from KRON-TV (San Francisco's channel-four news network) spent six weeks on the ward in 1984—one nurse recalled that he "practically lived with us." The station also sent film crews to the unit for six weeks to put together a television special called "In the Midst of Life."[129] In 1985, San Francisco General Hospital produced a documentary of its own called "AIDS: An Incredible Disease," that—in addition to providing a broad overview of the virus—showcased the hospital's response to the epidemic. In that documentary, now-famous AIDS doctor Paul Volberding described Ward 5B in the film as "a shining success."[130] In the 1990s, *60 Minutes'* Meredith Viera visited the unit; the resulting footage spotlighted the intimacy nurses cultivated on the ward, underscoring several times that the nurses' approach to AIDS care bucked cultural and professional expectations. At one point Viera asked a nurse if "there's a professor in nursing school

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[128] Shilts, forward to *As Real as It Gets*, xii.

[129] Jones oral history, 55.

[130] "1985 'AIDS: An Incredible Epidemic,' by San Francisco General Hospital," YouTube video, 18:45, posted by San Francisco Public Library, December 7, 2016, https://www.youtube.com/watch?v=cjDIoLlOWQo.

somewhere that would be wagging his or her finger at you…" to which the nurse offered her hypothetical reply: "I would look at them straight in the eye and say, 'And you're not here right now… you're not in my shoes."[131] Another nurse told Viera that—having never had children herself—her patients made her feel like a mother, so much so that she caught herself calling some of them "son." The political capital generated by sympathetic local and national media coverage accorded the 5B nursing staff attention and credibility they needed to advocate for political and professional change, but it also had many drawbacks.

Ward 5B's nursing staff had a love-hate relationship with the media. On the one hand, the media was the single most effective tool the nurses had for raising awareness of the virus, and the care paradigm they were creating. On the other hand, stories about 5B were often sensationalized or inaccurate, and time the nurses spent managing the media presence on the ward was time taken away from their patients. As is often the case, the sudden attention given to the ward also created—and exacerbated—personal problems for the ward's new stars.

The public interest in and coverage of San Francisco General Hospital's response to the virus had the greatest impact on 5B's founder, Clifford Morrison. In addition to occasionally overinflating his ego, his time in the media spotlight also bred conflict in the workplace. Morrison told the SF AIDS Oral History Project that the criticism he received from those "within the system" (the bureaucracy) did not bother him; after all, he did little that appealed to hospital administrators. What bothered, hurt, and preoccupied him was the offense occasionally taken by his colleagues on the nursing staff. "They felt they'd been

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[131] "Nurses at San Francisco General Hospital's AIDS Ward," *60 Minutes*, CBS, July 28, 1991.

slighted in some way," Morrison said. "'Why are you getting this attention?'" they'd ask him. "'It's taking away from our mission. You're spending more time playing to the media than you are doing your work. It's one thing if the mayor or the director of public health does it; it's another thing if you do it.'"[132] While his new-found fame ruffled feathers, that was not what ultimately led Morrison to step away from the media spotlight. He made that choice because his fame was eroding his private life. "I couldn't have a quiet dinner someplace without somebody coming up to me and complimenting me or castigating me or confronting me or something," Morrison told the SF AIDS Oral History Project, adding "I all of a sudden began to feel like, I can't get away from this stuff."[133]

The media was not the only outside presence on the ward that the nurses used to build their credibility (and which routinely interfered with their work). From the very beginning, guests toured 5B. Some of the visitors were doctors and nurses, others politicians… a great many were celebrities. As Nurse Diane Jones put it, "this was fishbowl nursing from the beginning."[134] At times, the sheer number of people on the ward became untenable. Particularly memorable to the staff was the day Nurse Elisa Chandler threw Merv Silverman (the Director of the San Francisco Department of Public Health) off the unit. Jones recalled that Silverman "showed up unannounced on a Saturday morning with a whole entourage of people. The floor was really busy and patients were really sick, and…

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132. Morrison oral history, 98.

133. *Ibid*.

134. Jones oral history, 55.

had been complaining that there had been too much activity going on."[135] While nursing was always the ultimate priority on 5B, it was important to indulge visitors as often as possible, in no small part because 50 percent of the *U.S. News and World Report*'s hospital scoring was based on reputation; showing off the ward built its reputation, and in so doing made it easier for the nursing staff to get resources their patients needed. The nursing staff of Ward 5B did their best to use the media without allowing the media to use them and their patients. While no political message survives mediation fully intact, their solicitous relationship with the press successfully raised the unit's profile, and allowed the nurses to bring a scared public to their patients' bedsides.

The Limits of Intimacy

Ward 5B's mere existence—and the intimate care modality with which it was run—should be seen as radical AIDS activism in the early 1980s, an example that, to echo Jennifer Brier in *Infectious Ideas*, troubles the limiting boundary between service and activism that has long characterized the literature on HIV/AIDS.[136] But questions remain; after all, empathy, however radical, is a finite resource, always unevenly distributed. Which patients were on the losing side of that equation? The answer (insofar as any answer is available, given the problematic nature of the sources) speaks to larger exclusions at work in both gay San Francisco and the scientific community.

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[135] *Ibid*.

[136] Jennifer Brier, *Infectious Ideas*, 4.

Medical geographer Michelle Cochrane's 2004 monograph *When AIDS Began: San Francisco and the Making of an Epidemic* examines the first AIDS cases to appear in San Francisco, arguing that public health officials overemphasized the role of homosexuality in the spread of the disease, while overlooking structural injustice and other causes of the virus' spread.[137] By way of example she deconstructs the medical records of one of the city's first AIDS patients, a friendly twenty two year-old bathhouse attendant with a "down-home" Southern accent—or so he was remembered by Dr. Paul Volberding in Shilts' *And The Band Played On*.[138] The patient's medical records, however, offer a very different, and far less romantic, perspective. The patient "was homeless, had only sporadic employment as a dishwasher or janitor… was 'sickly from birth,' suffered from Marfan's syndrome… and had a history of MDA ("ecstasy") and intravenous amphetamine use which the patient himself correlated with the emergence of his "purple spots."[139] This example is presented as something of a proviso: while the available sources present a fairly-unified portrait of the epidemic's track through the city—and accordingly, an archetypal 5B patient—there is legitimate reason to question this narrative. What follows then, is a circumscribed story that should raise as many questions as it answers.

In New York City, the initial outbreak of AIDS affected a diverse community, and that diversity was reflected in the city's public hospitals. The same cannot be said of San

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137. The author raises some very controversial questions, and some of her larger arguments about the virus itself remain far outside the mainstream, but her analysis holds strong regarding the representation of the earliest AIDS patients.

138. Cochrane, *When AIDS Began*, 12; Shilts, *And the Band Played On*, 75-76.

139. Cochrane, *When AIDS Began*, 28.

Francisco, or of the 5B patient population. In the early 1980s, the overwhelming majority of 5B's patients were young (mostly white) men. In 1984, 91 percent of PWAs in San Francisco were white, and the majority of those admitted to being gay.[140] Later that same decade, conventional narratives posit that the demographics of San Francisco's epidemic shifted, increasingly including women and IV drug users (IVDU).[141] Recent scholarship has demonstrated that the idea that the virus hit in a series of waves is inaccurate—that the shifting patient demographics had more to do with changing reporting practices, access to care, and other factors.[142] Michelle Cochrane's research found that as many as six of the first twenty-four cases of AIDS reported in San Francisco were identified as cases of homosexual transmission *despite* self-reported use of injected amphetamines, which suggests that any demographic data that *does* exist to support such a claim is likely inaccurate. What is certain is that the gay-identified, non-IVDU PWA population dwarfed

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[140] Risse's footnote in *Mending Bodies, Saving Souls* (footnote 180) indicates that he determined this information by consulting the City and County of San Francisco, SFGH Quarterly AIDS Surveillance Report. Risse further suggests consulting the San Francisco Department of Public Health Annual Reports and San Francisco Controller Reports. As of this writing the author is unable to independently confirm the demographic breakdown of non-white PWAs. One imagines, though, that these statistics are only partially accurate, as there were probably many people living with AIDS who—for one reason or another—did not receive health care. Risse, *Mending Bodies, Saving Souls*, 659.

[141] Gayling Gee, R.N., M.S., "Head Nurse at the AIDS Clinic, San Francisco General Hospital," oral history conducted by Sally Smith Hughes, in *The AIDS Epidemic in San Francisco: The Response of the Nursing Profession, 1981-1984*, *Volume IV*, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 1999, 29-30.

[142] Daniel M. Fox, "AIDS and the American Health Polity: The History and Prospects of a Crisis of Authority," in *AIDS: The Burdens of History*, eds. Elizabeth Fee and Daniel M. Fox (Berkeley: University of California Press, 1988), 316-340; Guenter B. Risse and Michael J. Balboni, "Shifting Hospital-Hospice Boundaries: Historical Perspectives on the Institutional Care of the Dying," *American Journal of Hospice and Palliative Medicines* 30, no. 4 (June, 2013): 325-330, https://doi.org/10.1177/1049909112452336.

the heterosexual, IV-drug-addicted, PWA patient population in San Francisco, and that the latter experienced Ward 5B differently than the former.

The rise in 5B's IVDU patient population attracted special attention from the local media. In July of 1989 a Sunday publication affiliated with the *San Francisco Examiner* ran an article titled "Addicts on the AIDS Ward," which endeavored to communicate the difficulties born of 5B's growing population of heroin-users. When they founded the unit in 1983, nurses described the patient population as comprised exclusively of gay men. When "Addicts on the AIDS Ward" hit the presses six years later, they reported that between twenty and twenty-five percent of the patients in their care were IV drug users.[143] 5B nurse Kathleen O'Leary was blunt:

> People are on the ward to take care of AIDS patients… But really, we're on the ward to take care of gay AIDS patients. It has been very gratifying dealing with gay patients... [but with IV drug users] It's a constant taking from us. It's not the fun type of nursing where we're able to care for each other. It's not holistic type nursing… We know this is the reality of the epidemic. Deep down inside, we know we should be unconditionally accepting of everyone. It's hard… We want it to be like it was, with patients we can have fun with and care for.[144]

The nurses interviewed for the San Francisco AIDS Oral History Project were less explicit in their analysis of the changing patient population, but the sense of their diminished satisfaction with, and commitment to the treatment of, the changing patient

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[143] It also bears mentioning that the paradigm O'Leary sketched above foreclosed the possibility of a gay AIDS patient also using intravenous drugs, which—the 22 year old bathhouse attendant from When AIDS Began demonstrates—could, and did, happen. See: Cochrane, *When AIDS Began*.

[144] Carol Pogash, "Addicts on the AIDS Ward," San Francisco Examiner, July 16, 1986, San Francisco General Hospital AIDS Ward 5B/5A Archives, 1983-2003 (SFH 12), San Francisco History Center, San Francisco Public Library.

population was consistent across multiple sources. Interestingly, the changing demographics of Ward 5B were not the result of the epidemic—they were the result of a municipal response that prioritized gay men's health over the health of other at-risk populations.

According to the available sources, the changing demographics of Ward 5B did *not* represent a major shift in the track of the AIDS epidemic in San Francisco—AIDS was still very much a disease of gay men, especially compared to the virus' other urban epicenters. Per "Addicts on the AIDS Ward," approximately 150 IV drug users were diagnosed with AIDS per year, compared to approximately 6,000 gay men. The disproportionate representation of addicts on the ward, then, reflected the inadequacies and the biases of substance abuse treatment facilities in San Francisco at the time. At a practical level, People with AIDS often required resources and medical treatments that these facilities were unable to provide—for example, a private shower for a patient with a leg lesion. At a personal level, according to SFGH Doctor Eric Goosby, the staff of substance abuse treatment centers were "not homophobic… [just] genuinely scared of AIDS."[145] If 5B's nurses were less enthusiastic about caring for IV drug-users with AIDS, drug-treatment facilities were ill-equipped and unprepared to handle their healthcare needs. The problem was compounded further because many residential programs into which 5B patients were typically discharged—nursing homes, hospice facilities, etc.—did not accept IVDUs. The nurses' experiences with and biases against drug addicts, then, were (at least partially) the result of broader structural inequality in the city. By failing to attend to IV drug users with

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[145] *Ibid*.

AIDS' unique healthcare needs, San Francisco relegated a frequently-noncompliant swathe of the patient population to long-term residence on 5B.

Traditional narratives of the AIDS Rights Movement tend to distinguish between medical facilities, service delivery organizations, and AIDS activist organizations. Close examination of the intimate labor performed by the nurses on the country's first AIDS ward demonstrates just how impoverishing that analytic framework is. The nurses' labor straddled all three of these spheres, and underscored the radical political potential inherent to all three. Treating 5B's nursing staff as political actors troubles the standard chronology of AIDS activism, which posits a transition from the service-delivery work of organizations like Gay Men's Health Crisis (GMHC) to radical street activism in 1987, with the formation of the AIDS Coalition to Unleash Power (ACT UP). The same ideas that inspired ACT UP members to take to the streets in the later 1980s and early 1990s inspired nurses at San Francisco General Hospital to create Ward 5B many years previous. Just like their counterparts in militant groups like ACT UP—the nurses' execution of their ideas was imperfect, and at times perpetuated the very inequalities they sought to ameliorate. When we allow for a more capacious definition of activism, one that includes paid—indeed, state-funded—intimate labor, the nurses of 5B and the political space they built at San Francisco General Hospital become an early and essential component of the AIDS Rights Movement.

As the nurses who originated and practiced the SF model became nationally and internationally known as the preeminent experts on AIDS care, the epidemic continued to worsen. In *And the Band Played On*, Shilts wrote that this combination of contingencies "created an unheard-of situation at the county hospital: well-heeled respectable gay men clamored to get in."[146] Ward 5B comprised twelve (and later, twenty) private rooms. Staffing shortages meant occasionally reducing patient loads to sixteen. Under the best of circumstances, neither the space nor the nursing corps was sufficient to address the ever-growing number of PWAs crossing the threshold of San Francisco General Hospital. Indeed, by late 1984 and early 1985, up to twenty-five percent of the patients at the five-hundred bed facility were AIDS patients.[147] Thus, the staff of 5B, carefully selected and guided by commonly-held political and philosophical principles, increasingly used their expertise to set hospital policy, train caregivers, and monitor the treatment of PWAs on other units.

As the ward's profile and the number of PWAs housed at SFGH continued to grow, so did community interest in the enterprise. Morrison and the rest of the 5B staff capitalized on that public interest by building a support structure for the ward that guaranteed the patients were never isolated from the rest of the city. The following chapter will detail the social benefits—and political drawbacks—to public engagement on and with the AIDS ward.

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[146] 146. Shilts, *And the Band Played On*, 395.

[147] 147. Diane Miller, "AIDS Policy and Administration at San Francisco General Hospital," oral history conducted by Sally Smith Hughes, in *The AIDS Epidemic in San Francisco: The Response of the Nursing Profession, 1981-1984*, *Volume IV*, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 1999.

CHAPTER TWO

"ALMOST LIKE ONE OF THE STAFF": THE PRACTICE AND PARADOX OF COMMUNITY CARE

As the AIDS crisis unfolded in San Francisco, hospitals became a *de facto* extension of the city's gay community. Journalist Michael Helquist, who lost a partner to AIDS in 1983, described SF-area hospital cafeterias as a social gathering point for gay people. Friends and loved ones visiting PWAs would drop into the cafeteria for coffee or a meal, "and there were all those other gay men and lesbians also taking a break. And you got to know some of the other people who were going through the same thing, which certainly helped for support, as well as just meeting other people."[1] San Francisco General Hospital was the only hospital in the Bay Area publicizing its efforts to study and treat AIDS, and the only hospital in the area that provided non-emergent care services for the uninsured. It also represented the forefront of AIDS research and treatment efforts in the United States. Suffice it to say, if all area hospitals became extensions of the city's gay community, SFGH's AIDS ward became a veritable cultural institution.

Despite its inherent tragedy, 5B was never just a place where people went to commiserate. It was also a hub of gay activity. Gay nurses from all over the hospital took their breaks on Ward 5B, visiting with patients and each other. Patients who were well enough to leave their rooms socialized in the Elizabeth Taylor Lounge, a room named in

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[1] 1. Michael J. Helquist, "Journalist of the Early AIDS Epidemic in San Francisco," in *The AIDS Epidemic in San Francisco: The Response of the Nursing Profession, 1981-1984, Volume I,* Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 1999. 40.

honor of the gay icon, who reportedly made numerous clandestine visits to the unit.[2] The San Francisco Gay Men's Choir gave regular performances, as did cabaret singer Sharon McNight. 5B's nursing staff showed up to work in drag at least once, with some of the nurses impersonating each other.[3] The ward also held multiple wedding ceremonies that—while not legally recognized at the time—were nevertheless well appointed and attended. The ward was knit into the fabric of gay life in the early 1980s by necessity, and—as we will see in this chapter—by design.

Nurse Coordinator Clifford Morrison recognized from the outset that accepting, and further developing, the relationship between the medical and gay communities would improve the quality of the Ward 5B (and the SFGH) patient experience.[4] Correctly framed, it could also be a valuable public-health intervention—in other words, everybody in the hospital, save those hostile to gays and PWAs, stood to benefit. By empowering individuals and institutions unaffiliated with the hospital to contribute material, emotional, and practical support to the ward, the nurses of 5B, to quote renowned AIDS doctor Donald

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[2] Carol Pogash, *As Real as It Gets: The Life of a Hospital at the Center of the AIDS Epidemic* (New York: Plume Publishing Corporation, 1992), 103.

[3] SFGH Scrapbook, Volume One, San Francisco General Hospital AIDS Ward 5B/5A Archives, 1983-2003 (SFH 12), San Francisco History Center, San Francisco Public Library.

[4] San Francisco boasted a large gay and lesbian medical community, evidenced by robust community outreach efforts by groups like the Bay Area Physicians for Human Rights. Especially in the 1970s, particular doctors were known in the Bay Area for being gay-friendly (or gay themselves). There were also a number of free clinics for gay men in 1970s San Francisco staffed by volunteer doctors and nurses; the proliferation was at least partially in response to the rising tide of sexually-transmitted infections, which had by the also attracted the attention of the San Francisco Department of Public Health.

Abrams, "provided a target for the gay community to show their support and their care for their brothers who were sick."[5]

Even before the ward opened, Nurse Morrison sought out the support of individuals and organizations operating outside the purview of the San Francisco Department of Public Health, and, in many cases, outside the medical establishment completely. The integration of "non-experts" and community-based groups onto the ward was central to the success of the San Francisco Model. Involving the community in AIDS care was so crucial to Ward 5B's success, in fact, that Clifford Morrison included a section on establishing volunteer programs in a textbook chapter. Not only, he argued, did a robust volunteer program build community trust and promote AIDS awareness and education—it also made good business sense.[6]

There are several reasons that integrating the San Francisco community onto the ward was a radical intervention. Affiliation with San Francisco General Hospital—and, in some cases, state funding—legitimized gay and lesbian organizations that might have otherwise gone unrecognized. The nurses did not just court the gay community: they *were* the gay community. From facilitating weddings to marching in gay pride parades, to doing their rounds in drag, the majority-gay-and-lesbian nursing staff went out of its way to

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[5] Donald I. Abrams, M.D., "The KS Clinic, Lymphadenopathy and AIDS-Related Complex, and the County Community Consortium," an oral history conducted in 1992 by Sally Smith Hughes in *The AIDS Epidemic in San Francisco: The Medical Response 1981-1984, Volume II*, an oral history conducted in 1992-1993, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 1996. 34.

[6] Clifford Morrison, "Establishing a Therapeutic Environment: Institutional Resources," in *The Person with AIDS: Nursing Perspectives*, ed. Jerry Durham and Felissa Cohen (New York: Springer Publishing Company, 1987), 121.

identify 5B with the Gay Liberation Movement.[7] At a more abstract level, bringing outsiders onto the ward helped ameliorate disparity among patients, and ensure—insofar as such a thing is ever possible—that no patient fell through the cracks.[8]

The kind of community care the nurses organized on Ward 5B was a radical political expression that—if central to the success of the San Francisco model of AIDS care—also created complex political and labor dynamics worthy of scrutiny. In elevating the status of the ward's volunteers, 5B's nursing staff inherently devalued the labor of paraprofessional caregivers, destabilizing the hierarchies of knowledge and authority on which nursing is built. It also birthed another major political contradiction. That Ward 5B was so reliant on community altruism for its success was at once a powerful expression of the staffs' support for queer, feminist reform of the healthcare industry, *and* consistent with the Reagan-era values they opposed. Examining 5B's novel approach to community care lays bare important tensions and inconsistencies between the nurses' politics and praxis. The shared political ideology of the nurses who built the country's first AIDS ward, if crucial to building the ward into a vibrant, queer-affirming community space, also made it a space of contradictions.

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[7] 5B marriages were not recognized as such by the state, as gay marriage was illegal at the time, but the archive demonstrates that the nurses nevertheless called the ceremonies "weddings," and memorialized them in their scrapbook with extra panache. SFGH Scrapbook, Volume One.

[8] The following examples—all invented, but drawn from the historical record—illustrate this point. Patient X may have lacked family support, but he had a guaranteed practical and emotional support system in his Shanti counselor. Patient Y was homeless, but the money and in-kind donations to 5B meant she would had new bathrobe, access to a television, and all the food she could eat while recovering from pnuemocystis. Patient Z may be on a ventilator, but regular visits and massages from members of the 5B volunteer program ensured they would not go through the pain of dying in isolation.

This chapter interrogates a few representative examples of community integration on the ward: the 5B Volunteer Program, The Shanti Project, and the ad hoc volunteerism of Rita Rocket and Mary Rathbun. Some of these support systems were formalized, and some were not, but all brought "the outside world" onto a critical care unit in a substantive way. Despite the political conflicts and contradictions illuminated here, all of the efforts described here have been, rightly, remembered as successes. One could argue that the San Francisco model, as it exists today, does an even better (if different) job engaging the community. However, the model, as originally conceived, was only broadly generalizable to other urban settings, and had to change itself considerably over time in accordance with the contingencies of the epidemic. It is in examining the flaws and unintended consequences of the SF model's first iteration that the improbability of its creation—and the political labor central to its maintenance—become clear. In other words, by placing voluntarism at its center, this chapter attests to the nurses' political investment in community care, and the additional organizational labor they took on to realize that vision.

Contextualizing Community Care

The notion that communities should be directly involved in healthcare dates to the early twentieth century, and is attributable to a wide-range of Progressive Era healthcare reformers including Lilian Wald, Dorothea Dix, Margaret Sanger, and the less-celebrated but no-less-important African American anti-TB activists throughout the American South. [9]

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[9] Meg Muckenhopt, *Dorothea Dix: Advocate for Mental Health Care* (New York: Oxford University Press, 2003); Jean H. Baker, *Margaret Sanger: A Life of Passion* (New York: Hill and Wang, 2011); Doris Groshen Daniels, *Always a Sister: The Life of Lillian D. Wald* (New York: The Feminist Press at CUNY, 1985); Samuel Kelton Roberts, Jr., *Infectious Fear: Politics, Disease, and the Health Effects of Segregation* (Chapel Hill: UNC Press, 2009).

The community healthcare models that had the most direct impact on 5B's nursing staff, however, were those connected to the Civil Rights Movement. Some of the 5B nurses participated directly in the Civil Rights Movement, while others grew up with—and internalized—both its messages and the contemporaneous backlash against them. In "The Long Civil Rights Movement and the Political Uses of the Past," Jacqueline Dowd Hall writes that the civil rights movement was broader in both size and scope and duration than historical production around it might suggest. While African Americans struggled for the right to vote and the end of segregation (one might go so far as to call it legal personhood), they also sought equality in other spheres, like labor, healthcare, and education.[10]

5B's historical antecedents include the group of predominantly young, white, and male physicians that formed the Medical Committee for Civil Rights (later known as the Medical Committee for Human Rights) in the mid-1960s. The group—which referred to itself as "the voice of humanist medicine"—provided medical services to civil rights activists during events like the March from Selma to Montgomery. The group grew increasingly radical over time. Recognizing that health inequality, like racial inequality, affected a wide range of people far beyond the boundaries of the American South, they created the National Health Crusade to spread their message and engage a wide range of publics. They staffed free health clinics around the country, confronted local healthcare workers, educated healthcare consumers in schools and neighborhoods, and engaged in street-level political activism. A 1971 article in *Science*, said of the MCHR that

> Each new step of political advocacy… has led to the attrition of some of the doctor-members who thought the action to be 'unprofessional,' with the

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[10] Jacquelyn Dowd Hall, "The Long Civil Rights Movement and Political Uses of the Past," *The Journal of American History* 91, no. 4 (2005): 1233-1263.

> result that MCHR now [seven years after its founding] consists largely of house staff, medical students, and young middle-level health professionals such as nurses and laboratory technicians. And in its current national crusade MCHR hopes to recruit an increasing percentage of nonprofessional health care critics.[11]

The "nonprofessional health care critics" the *Science* writer was referring to were patients. "The radicals," as the author called them, "[sought] primarily to give the recipient of health care a voice in controlling the institutions that deliver health care."[12] While the MCHR advocated for patient-centered care, other organizations—including a few right in San Francisco General's backyard—were focusing on creating a non-judgmental environment for indigent and otherwise-underprivileged individuals to seek care.[13] The most famous of these San Francisco institutions was The Haight-Ashbury Free Medical Clinic.

The Haight-Ashbury Free Medical Clinic opened in 1967, during the "Summer of Love."[14] The facility (which is still operating today) was only a ten-minute drive from The General—indeed, when it opened, the Haight-Ashbury Clinic ran primarily on the volunteer labor of healthcare workers from UCSF, SFGH, and Stanford. One of the early volunteers, Mark Conant, M.D., went on to found the Kaposi Sarcoma Clinic

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[11] Robert J. Bazell, "Health Radicals: Crusade to Shift Medical Power to the People," *Science* 173, no. 3996 (August 6, 1971): 506.

[12] *Ibid*.

[13] For more information on the MCHR, see John Dittmer, *The Good Doctors: The Medical Committee for Human Rights and the Struggle for Social Justice in Health Care* (New York: Bloomsbury Press, 2009).

[14] Mark Harris, "The Flowering of the Hippies," *The Atlantic*, September, 1967. Accessed April 20, 2017 https://www.theatlantic.com/magazine/archive/1967/09/the-flowering-of-the-hippies/306619/?utm_source=twb.

at UCSF.[15] The 24-hour facility's operating budget was $25,000, all of which went to the salary of the only full-time staff member: a nurse. Many of the Haight-Ashbury Clinics' patients were veterans who returned from Vietnam addicted to drugs, isolated from the rest of society, and, in many cases, suffering from post-traumatic stress. The clinic provided a range of services, including comprehensive medical care (complete with "guerilla pharmacy" to fill prescriptions on the spot); detox and drug counseling programs; a "bad trip room"; and a mobile "overdose team," that saved Janice Joplin's life at least once.[16] While they do not enjoy the same popular memory, The Berkeley Free Clinic and The National Transgender Counseling Unit (NTCU) opened contemporaneously, providing community-based care to poor and to transgender populations, respectively. [17]

The NTCU was the first transgender-specific clinic, but it was part of a far larger wave of gay health activism starting in the late 1960s, which was itself part of an

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[15] Mark Conant is not the only SFGH AIDS healthcare worker the archive suggests volunteered in community health programs. Ward 86 nurse Gary Carr volunteered and served on the board of the St. Mark's Community Clinic on the Lower East Side of New York before coming to San Francisco. Gary Stephen Carr, "Nurse Practitioner at the AIDS Clinic, San Francisco General Hospital," oral history conducted by Sally Smith Hughes, in *The AIDS Epidemic in San Francisco: The Response of the Nursing Profession, 1981-1984*, *Volume II*, 47. 10-14; Marcus A. Conant, M.D., "Founding the KS Clinic and Continued AIDS Activism," oral history conducted in 1992 by Sally Smith Hughes, in *The AIDS Epidemic in San Francisco: The Medical Response 1981-1984*, *Volume II*, 86-87.

[16] Laurie Udesky, "Haight Ashbury's Free Health Clinic: Middle-Aged and Still Groovy," NPR, last modified January 22, 2017, http://www.npr.org/sections/health-shots/2017/01/22/510622207/haight-ashburys-free-health-clinic-middle-aged-and-still-groovy?utm_campaign=storyshare&utm_source=twitter.com&utm_medium=social.

[17] "History," The Berkeley Free Clinic, accessed June 22, 2017, http://www.berkeleyfreeclinic.org/clinic-history/; Susan Stryker, *Transgender History* (Berkeley: Seal Press, 2008), 78.

increasingly radical Gay Liberation Movement. From the Riot at Compton's Cafeteria in the Tenderloin District of San Francisco, to the Black Cat Riots in Los Angeles—and, later, the better-remembered Stonewall Riots in Greenwich Village—the late 1960's were marked by a departure from the respectability politics of the homophile movement.[18] In her dissertation, *Before AIDS: Gay and Lesbian Health Activism in the 1970s*, historian Catherine Batza argues that the gay community health services that arose during the 1970s were a direct result of two seemingly-oppositional forces: the militancy of the gay rights movement in the late 1960s, and concomitant state efforts to serve underprivileged communities, and, in so doing, stem the rising tide of poverty (The Great Society).[19] As ended up being the case regarding California's response to the AIDS epidemic, Batza finds that "the state emerge[d] as an unlikely, and often unintentional, benefactor of gay and lesbian health services… not only allowing for creation of these services, but also shaping their growth."[20] Other marginalized social groups used Great Society funds to create community health clinics too, but in the case of the LGBT community, state funding for

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[18] *Screaming Queens: The Riot at Compton's Cafeteria*, directed by Victor Silverman and Susan Stryker, (2005; San Francisco, CA: Frameline); Hailey Branson-Potts, "Before Stonewall, There Was the Black Cat; LGBTQ Leaders to Mark 50th Anniversary of Protests at Silver Lake Tavern," *Los Angeles Times*, February 8, 2017, accessed June 22, 2017, http://www.latimes.com/local/lanow/la-me-ln-silver-lake-black-cat-lgbtq-20170208-story.html; David Carter, *Stonewall: The Riots That Sparked the Gay Revolution*, (New York: St. Martin's Press, 2004); John D'Emilio, *Sexual Politics, Sexual Communities: The Making of a Homosexual Minority in the United States, 1940-1970*, (Chicago: University of Chicago Press, 1998); Elizabeth A. Armstrong, *Forging Gay Identities: Organizing Sexuality in San Francisco, 1950-1994* (Chicago: University of Chicago Press, 2002).

[19] Batza, "Before AIDS," xi.

[20] *Ibid*., xi-xii.

healthcare opened and legitimized a whole new theater of civil rights activism.[21] As you will see in this chapter, by integrating gay organizations like The Shanti Project onto the ward, 5B's nursing staff helped them to gain professional legitimacy, state funding, and community support.

The above is a pale sketch of the community healthcare as a facet of the Civil Rights Movement. It is by no means complete. The reproductive rights movement fought for women's right to terminate a pregnancy, and—in the case of women of color—for the right to *have* children.[22] The Black Panther Party's Survival Programs included community health clinics, free sickle-cell testing, dental care, and ambulance services; there were over sixty Survival Programs total, providing everything from coats and shoes to police

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[21] It is also important to note that the need for LGBTQ health services became especially acute in the 1970s. Venereal disease disproportionately impacted gay men, to the extent that, by the late 1970s, gonorrhea and syphilis were two times more common in gay men than they were in the rest of the population. Hepatitis B was a full-fledged epidemic among gay men. The twin stigmas—an STI diagnosis and homosexual identity—prevented gay men from getting the medical care they needed. Batza, "Before AIDS," 18.

Batza cites the following documents regarding venereal disease rates among homosexual men in the 1970s: Education Department of Health, and Welfare Center for Disease Control, "Figures and Tables for "Profile of the Gay STD Patient," 1976, Walter Lear Personal Collection, Philadelphia; Alfred Baker, "Chronic Type B Hepatitis in Gay Men: Experience with Patients Referred from the Howard Brown Memorial Clinic to the University of Chicago," *Journal of Homosexuality* 5, no. 3 (1980); Marshall Schreeder et al, "Epidemiology of Hepatitis B Infection in Gay Men," *Journal of Homosexuality* 5, no. 3 (1980); William W. Darrow et al, "The Gay Report on Sexually Transmitted Diseases," *American Journal of Public Health* 71, no. 9 (1981).

[22] Jennifer Nelson, *More Than Medicine: A History of the Feminist Women's Health Movement* (New York: New York University Press, 2015); Jennifer Nelson, *Women of Color and the Reproductive Rights Movement* (New York: New York University Press, 2003); Sandra Morgen, *Into Our Own Hands: The Women's Health Movement in the United States, 1969-1990* (New Brunswick, NJ: Rutgers University Press, 2002).

patrols.[23] During this same time, people with disabilities and people living in institutions fought for the right to make their own healthcare decisions—indeed, they fought for the right to be regarded *as* people—with mixed results.[24] These and so many other community health initiatives laid the groundwork for 5B's nursing staff to bring "nonprofessionals" to the bedsides of San Francisco General Hospital's PWA population.

A Crisis of Authority in Healthcare

To understand the improbability of the SF model's creation one must first understand the political and cultural climate in which the nurses conceived it. The 1980s were a tumultuous time for the healthcare industry, and, in turn, for the nursing profession. For the purposes of this chapter, the most important force impacting institutional responses to AIDS was the corporatization of American healthcare. Historian Rosemary

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[23] "A Huey P. Newton Story: Community Survival Programs," PBS, accessed June 22, 2017, http://www.pbs.org/hueypnewton/actions/actions_survival.html; Alondra Nelson, *Body and Soul: The Black Panther Party and the Fight against Medical Discrimination* (Minneapolis: University of Minnesota Press, 2013); David Hilliard, ed. *The Black Panther Party: Service to the People Programs* (Albuquerque: University of New Mexico Press, 2008).

[24] Doris Fleicher, *The Disability Rights Movement: From Charity to Confrontation*, (Philadelphia: Temple University Press, 2011); Kim E. Nielsen, *A Disability History of the United States: ReVisioning American History*, (Boston: Beacon Press, 2012); Sharon N. Barnartt and Richard K. Scotch, *Disability Protests: Contentious Politics 1970-1999* (Washington, DC: Gallaudet University Press, 2001); Paul K. Longmore and Lauri Umansky, *The New Disability History: American Perspectives* (New York: New York University Press, 2001); Gerald N. Grob, *From Asylum to Community: Mental Health Policy in Modern America*, (Princeton, NJ: Princeton University Press, 1991); also see Andrea Milne's article "'We Are No Peculiar Breed of Femmes': Domesticity as Counter-Discourse for Women with Leprosy, 1940-1960," forthcoming in *Frontiers Journal of Women's Studies* (date TBD).

Stevens puts it simply when she writes that “Economic power shifted in the 1980s from those who provide health services to the organizations that pay for them.”[25]

The early 1980s saw the healthcare industry reeling from the impact of supply side economics and New Federalism. The passage of the Omnibus Budget Reconciliation Act of 1981 had the dual effect of initiating sweeping changes to the structure and economy of healthcare and hamstringing the federal response to HIV/AIDS, as Randy Shilts so capably demonstrated in *And the Band Played On*.[26] The Reagan budget cut $266 billion in health spending over a three-year period, and reduced block and categorical grant budgets by an average of 20 percent. Perhaps most detrimental to the day-to-day functioning of American medicine writ large were the massive cuts in federal entitlement programs, including Aid to Families with Dependent Children (AFDC), Medicare, and Medicaid. The latter two programs saw a $3.5 billion reduction in federal spending; as a result, patients saw their benefits go down, and their copayments and deductibles increase.[27] In a 1985 essay titled “‘Reaganomics’: Health Policy and Politics,” Patricia Anne Jones—the chief executive officer of Professional Nurse Associates, Inc. and former Director of the American Nurses

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[25] Rosemary Stevens, “Medicare and the Transformation of the Medical Economy,” in *Major Problems in the History of American Medicine and Public Health: Documents and Essays*, eds. John Harley Warner and Janet A. Tighe (Boston: Houghton Mifflin, 2001), 485-488.

[26] Randy Shilts, *And the Band Played On: Politics, People, and the AIDS Epidemic* (New York: St. Martin’s Griffin, 2007).

[27] People with AIDS were especially impacted by the rise of “managed care” specialists, people who looked for ways to make caring for high-risk patients more cost-effective. For more information on this topic, see Rosemary Stevens, “Medicare and the Transformation of the Medical Economy.” Also see Rosemary Stevens, *Welfare Medicine in America: A Case Study of Medicaid* (New Brunswick: Routledge, 2003).

Association's Washington Office and Center for Governmental Affairs—detailed some of the many impacts for healthcare financing, service, and delivery that nurses were bracing for in the early 1980s. Among those impacts were: the promotion of competitive healthcare plans; the elimination of health planning; legal questions arising from cuts to government entitlements; the elimination of professional standard review organizations; and a phasing out of health professions training programs.[28]

The scope and scale of the changes on the healthcare horizon constituted a major threat to the nursing profession in particular. Nursing budgets accounted for approximately fifty percent of total hospital budgets at this time, and hospitals suddenly faced both new regulations and severe capital shortages. A 1983 study showed that 25 percent of the nation's hospitals were in debt, and another 25 percent saw profit margins under 3 percent.[29] In a 1983 issue of *Hospitals*, R.L. Johnson estimated that three thousand hospitals would close by the end of the decade, many of them community hospitals. In most cases, he suggested, the hospitals would be bought out by either an investor-owned or religious national chain.[30] The 1985 edited volume *Power, Politics, and Policy in Nursing*

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[28] Patricia Anne Jones, "Reaganomics: Heath Policy and Politics," in *Power, Politics, and Policy in Nursing*, ed. Rita Wieczorek (New York: Springer, 1985), 29-30.

[29] C.K. Davis. National Legislation and Regulatory Action (Unpublished speech presented at the Biennial Convention of the National League for Nursing, Philadelphia, PA, June 3, 1983); cited in Franklin A. Shaffer, "'Prospective Payment': A Strategic Plan for Nursing Power" in *Power, Politics, and Policy in Nursing*, ed. Rita Wieczorek (New York: Springer, 1985).

[30] R.L. Johnson, "Era of Responsibility: Competition Challenges CEOs to Be Tough-Minded and to Take Risks," *Hospitals*, June 16, 1983. Cited in Franklin A. Shaffer, "'Prospective Payment': A Strategic Plan for Nursing Power" in *Power, Politics, and Policy in Nursing*, ed. Rita Wieczorek (New York: Springer, 1985), 39-40.

featured numerous essays about "selling" the merits of the profession to financial stakeholders. They needed to explain, for example, why it made sense to hire an R.N. over a less-expensive L.V.N. They needed to be able to make a compelling case for smaller nurse-patient ratios, or risk losing staff. For the profession to survive, it seemed, a re-branding was in order.[31] As one author put it, "Power in nursing is based upon expertise. Nursing can be system-smart in the allocation of scarce resources."[32] Put differently, in the face of competition, nurses started thinking about ways to fit into the new model of healthcare as business: defining their product, analyzing "customer" behavior, building public relations campaigns, and establishing continuous feedback and quality control measures.[33] Placing a premium on expertise, efficiency, and quality care all at once (and while cutting resources) was, at best, an exceedingly tall order, and would require that nurses make uncomfortable compromises.

In elevating the role of community in healthcare—as radical health activists had done before them, and were continuing to do alongside them—the 5B nursing staff made the political statement that healthcare was a human right, that in the face of government apathy the LGBT community would integrate into, and reshape, the healthcare system by force. Indeed, they would do so *with state funding*. As a guiding philosophy, community involvement was a rejection of Reagan-era individualism. In practice, their efforts to

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[31] Christiana Gomboschi Wasserman, "Marketing: A Strategy for Power in Arenas of Competition" in *Power, Politics, and Policy in Nursing*, ed. Rita Wieczorek (New York: Springer, 1985).

[32] Shaffer, 45.

[33] Wasserman.

mitigate care disparities allowed the Reagan administration to continue its studious negligence of the AIDS crisis

The Ward 5B Volunteer Program

The Ward 5B Volunteer Program, like so many of the community-based programs on the AIDS unit, began idiosyncratically. The first volunteer was a PWA named Marty Cox, who—according to the volunteer training handbook developed by staff Nurse Steve Keith—was "Not one for going through 'appropriate channels'" in his efforts to create positive change.[34] Cox, who had himself already weathered multiple hospitalizations, began appearing on the ward every single morning to deliver newspapers to patients, who looked to him as a welcome source of both companionship and insight.[35] He started soliciting donations from the community to augment his daily deliveries. The local Mrs. Field's donated all the cookies remaining at the end of the day, and other businesses began following suit. Individuals and organizations also started contributing money, which the nurses used to pay the television rental fees for all of the patients."[36]

Marty Cox, who Nurse Keith described as having become "almost like one of the staff," passed away two years after the founding of 5B, in 1985. He lived long enough to see a full-fledged volunteer program established on the ward, the purpose of which was to

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[34] Volunteer Training Handbook, 1987, San Francisco General Hospital AIDS Ward 5B/5A Archives, 1983-2003 (SFH 12), San Francisco History Center, San Francisco Public Library, 6.

[35] *Ibid*.

[36] *Ibid*.

make the lives of patients more comfortable and ease nurses' workloads. [37] Given 5B's status as the first AIDS ward in the country—and given the myriad needs end-stage AIDS patients exhibited—the 5B-volunteer experience was a far cry from candy striping. As scholar and physician Thomas Blair put it in a personal conversation, these were not the kind of volunteers who stopped by for three hours on Christmas. This was something new.[38]

Because of the way the disease presented in the early 1980s—not as a chronic illness but as an acute immunodeficiency—all of the patients on Ward 5B had AIDS, and were somewhere in the process of dying. In many cases, they spent their final days, weeks, or months in isolation. Even those patients who weren't yet critical found themselves in dire straits. These were predominantly young people, many uninsured, and in need of highly specialized care. Even patients who recovered from the acute illnesses that brought them to 5B oftentimes found they had nowhere else to go, and no means of financial support.[39] Because health insurance was tied to employment, even PWAs who had insurance lost it when they lost their jobs. Among the most important role volunteers played on 5B, then, was keeping the atmosphere light, and offering "some caring, some acceptance, some love" to patients who lacked companionship or needed practical

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[37] *Ibid*.

[38] Thomas Blair, personal conversation, May 23, 2017.

[39] Ward 5B had discharge planning rounds between one and three times a week, during which patients were interviewed, their discharge needs assessed, and referrals executed. Discharge planning is designed to determine and facilitate care transitions, be the transition back to one's home, long-term care, to rehab or transitional housing, or—as was all-too-often the case PWAs during this time—to a hospice facility.

support.[40] The emotional toll of the work was significant enough that, when the program first started, the nursing staff mandated support group attendance for all volunteers.[41] Although the staff eventually relaxed this policy, they did so in recognition that not all people process grief the same way, not because the need for such processing diminished.

The 5B Volunteer Communication Book suggests a roughly even split between men and women volunteering on the unit, and reveals complex networks of care in which many women were involved. Especially among the female volunteers, it seems their work with AIDS patients often extended beyond time they put in on the ward. Several women indicated that they also worked as home healthcare workers, though, in many cases, that labor seems to have been for friends, and largely unpaid.[42] One of the most prolific volunteers, Irene Smith, offered workshops for her fellow volunteers on therapeutic touch and massage, served as facilitator for the volunteers' support group meeting, and simultaneously cared for a roommate with end-stage AIDS until his death on February 23, 1985.[43]

Most of the men volunteering on Ward 5B identified as gay. Like Marty Cox before them, many had had prior experiences on the floor, either as a patient or as a visitor. One volunteer, identified only as Peter, began volunteering a week after accompanying his best

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[40] Volunteer Training Handbook, 1987, 10.

[41] Volunteer Communication Book, San Francisco General Hospital AIDS Ward 5B/5A Archives, 1983-2003 (SFH 12), San Francisco History Center, San Francisco Public Library.

[42] Volunteer Communication Book, 31-67.

[43] *Ibid.*, 106.

friend, newly diagnosed with AIDS-Related Complex (ARC), on a visit to the unit.[44] People with AIDS—and, in the early years of the epidemic, persons with an ARC diagnosis—underwent different health screening procedures than other volunteers, but, like Bob Adrian and George Jalbert, were nevertheless welcome on the ward when they were well enough to work.

Given the epidemic's devastating impact on San Francisco, most of 5B's volunteers came to the ward having already endured some manner of loss. While the interest form filled out by prospective volunteers asked whether they were actively grieving at the time of their application, the volunteer communication book makes clear that bereavement was not an exclusionary criterion. Not only had many of the individuals accepted into the program recently lost loved ones, several lost loved ones *during* their time volunteering, only to return to the ward within a few weeks. Many found themselves caring for newly-diagnosed friends.

Although the 5B volunteers played a big role in establishing the caring (and relatively jovial) character of the unit, their presence was not without controversy. In what was, at the time, a highly unionized city, some regarded the sheer amount of unpaid labor performed on 5B as threatening.[45] The volunteer program empowered community members with minimal training to perform labor—answering patient call lights, front-desk

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[44] *Ibid*., 114.

[45] Clifford Morrison, M.S., M.N., R.N., F.A.A.N., "Organizer of the AIDS Ward, San Francisco General Hospital," an oral history conducted in 1995 and 1996 by Sally Smith Hughes in *The AIDS Epidemic in San Francisco: The Response of the Nursing Profession, 1981-1984*, *Volume III,* Regional Oral History Office. The Bancroft Library, University of California, Berkeley, 1999, 121.

coverage, assisting with baths and other daily hygiene tasks, transporting patients to other areas of the hospital, and other tasks that *could* have been performed for remuneration by a Licensed Practical Nurse (L.P.N.) or Certified Nursing Assistant (C.N.A.).[46] Unpaid labor concerns were likely magnified by the additional *unofficial* tasks performed by volunteers. Some offered haircuts, manicures, and even facials to patients, while others ran weekly delivery routes and completed small cleaning and repair jobs around the unit.[47] According to the 1990 iteration of the Volunteer Handbook, there were at least three volunteers on the ward every morning, afternoon, and evening, seven days a week; on an average shift, then, there were almost as many volunteers on the unit as there were nurses.[48] This is a surprising ratio, especially on a unit dedicated exclusively to the care of critically ill patients. 5B's nurses were over-extended as a result of staff shortages, making the volunteers' labor (intimate labor included) vital to maintaining the ward. The heavy reliance on unpaid workers also helped keep costs down.[49]

It is also important to note the volunteer program's benefit to the broader community. Setting aside the satisfaction volunteer work provides, and the healing potential that working on 5B offered a city in crisis, the more people 5B's nurses had regular contact with, the more people they could educate about AIDS, and engage in

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[46] Volunteer Training Handbook, 1987, 9.

[47] Volunteer Communication Book.

[48] Volunteer Training Handbook, 1988, San Francisco General Hospital AIDS Ward 5B/5A Archives, 1983-2003 (SFH 12), San Francisco History Center, San Francisco Public Library, 7.

[49] Morrison oral history, 121.

conversations about safe sex, infection control, and healthcare reform. The nurses could casually monitor the health of their volunteers with AIDS/ARC, which would improve the chances of identifying and treating their opportunistic infections early. Creating an informal labor force on the ward also meant more members of the community—and, in turn, their friends and loved ones—would claim a sense of ownership of the ward and its political work. Finally, in integrating volunteers onto the ward, the nurses built an informal public relations team, which meant that the ward's reputation for quality and compassion could spread all the faster throughout the Bay Area.

While the choice to create a volunteer program on 5B made sense from a political, a practical, and a public health standpoint, it also caused problems. One of the biggest issues was the blurring of volunteers' personal and pseudo-professional boundaries. That such a blurring took place is unsurprising given the nature of the work 5B volunteers performed. The notes left in the Communication Book suggest that volunteers devoted most of their time to affective labor. 5B volunteers' self-reports of their activities and the Volunteer Training Handbook alike suggest visiting, holding, and conversing with patients was their most important duty. The psychosocial[50] component of volunteer-patient interactions was significant enough that Nurse Keith arranged at least one in-service[51] on the subject of communicating with dying people.

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[50] Per the Gale Encyclopedia of Medicine "Psychosocial" is "A term referring to the mind's ability to, consciously or unconsciously, adjust and relate the body to its social enivornment." Examples of psychosocial health factors include: marital status, age, and education. "Psychosocial," Gale Encyclopedia of Medicine (2008), accessed September 25, 2016, http://medical-dictionary.thefreedictionary.com/psychosocial.

[51] Per the McGraw Hill Concise Dictionary of Modern Medicine, the term "in-service" is used to describe "any form of on-the-job training." "In-Service," McGraw Hill

5B's Volunteer Training Manual underscored the importance of physical contact with PWAs; one of the rules enumerated in the manual read "Hugs are mandatory."[52] If beneficial to the patients, and elemental to the nursing staff's politics, volunteers were equally invested in intimate labor. A volunteer named Daniella described the experience of comforting a crying patient to her peers, saying that "It was very beautiful for me because I got to hug him and hold him and I just felt very close and loving toward him."[53] She later added that "It feels good to be here and to write in this book and to feel the volunteers as one group holding hands in a circle of love around this ward."[54] Ward volunteers clearly shared the nurses' belief in the clinical and psychosocial efficacy of physically engaging patients.

If volunteers devoted the majority of their time to talking with patients, they devoted almost as much time to massaging them. Nurses encouraged volunteers to massage patients for two primary reasons. First, massages provide temporary relief of symptoms experienced by many PWA's, including severe muscle-spasms, cramps, edema, inflammation, and generalized tension. Second, massages improve psychosocial functioning by reducing stress, anxiety, and depression. While these were in and of themselves important reasons to provide 5B patients with regular massages, recent research suggests that massage may also boost white and natural killer cell counts, thereby enhancing the

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Concise Dictionary of Modern Medicine (2002), accessed September 25, 2016, http://medical-dictionary.thefreedictionary.com/in-service.

[52] Volunteer Training Handbook, 1987, 10.

[53] Volunteer Communication Book, 73.

[54] *Ibid*.

patient's immune system.[55] Most volunteers underwent special training in massage therapy; nurses authorized those who did not undergo training to provide light hand and foot massages. For patients to have such regular access to massage therapy—albeit amateur massage therapy—was and still is highly unusual, even within integrated care models. 5B volunteers, then, played a *very* significant role in patient palliative care. That they were trained in the provision of such care underscores their importance to the unit, and the economic benefit of their presence.

Ward 5B volunteers found talk and touch to be the most rewarding elements of their work. Few entries detail administrative and other quotidian work, though that work clearly took place. Also absent from the record is any evidence of volunteers retreating *into* administrative work to cope with the difficulties of caring for PWAs. Indeed, entries like the following, dated August 6, 1985, suggest that volunteers were enthusiastic about the emotional engagement working on the unit required. A volunteer identified only as Pam wrote that, "Hi all—I just had a very special experience that I want to share. Dean in #3 was to have a bronchoscopy this A.M. and was terrified. Last time he had one he ended up in ICU! I've spent the last 4 hours with him! He relaxes easily—just needs someone to help him keep focused." [56] She continued, "I went with him to the bronchoscopy and held his hand & talked to him throughout it. It was fascinating—both physically and spiritually. I'm high as a kite! He did <u>really</u> well. I didn't get anything else done here, but it really felt good

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[55] 55. Miguel A. Diego et al, "HIV Adolescents Show Improved Immune Function Following Massage Therapy," *International Journal of Neuroscience* 106, no. 1-2 (2001): 35-45.

[56] 56. Volunteer Communication Book, 186.

to help Dean. Looking forward to seeing you all next Tues."[57] In spending four hours with a scared patient, and seeing him through an invasive medical procedure, Pam played a role usually reserved for friends and family. The nurses expected volunteers to divide their time between multiple patients and a wide range of other duties, but—as the entry above suggests—the opportunity to create intimate connections with patients (healthy or not, expected or not) was, sometimes, too powerful to resist.

There is considerable evidence to suggest that, however necessary it may have been to attend to the psychosocial needs of patients, the weighty interactions between 5B volunteers and 5B patients also blurred boundaries, creating significant conflicts of authority on the ward. The nursing staff expressed concern about the amount of time some of the volunteers spent counseling patients. They also noticed preferential treatment given to patients with whom volunteers shared a rapport. These and similar instances of unprofessional behavior led the nursing staff to place restrictions on the time and activities in which unpaid laborers were allowed to engage.

The 5B policy around visitation and medical guardianship privileged patients' chosen families over their biological families in cases of conflict, and in so doing validated and facilitated queer kinship structures. While the nurses never imposed visiting hours on actual visitors, the hospital staff *did* impose a 10 PM curfew for volunteers. The nurses took this action in response to administrator concerns that volunteers were becoming too involved with patients, this in direct response to some volunteers spending the night on the

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[57] Volunteer Communication Book, 186.

unit.[58] Later, in response to concerns voiced by multiple nurses, Nurse Keith wrote the following reminder in the Volunteer Communication Book: "[Y]ours is not a counseling role. Half of your responsibility is for the comfort of <u>all</u> the patients and half is for the assistance of the nursing staff."[59] The nurses removed at least one volunteer from the unit. They allowed him to return later with strict guidelines in place regarding time on the unit and permissible forms of patient interaction, and a strong suggestion from the head nurse that he "maintain some means of ongoing emotional support for himself."[60]

If the boundaries between volunteers and patients were occasionally too permeable, far more problematic was the blurring of boundaries between volunteers and nurses. For legal reasons, hospital volunteers were not (and never are) supposed to engage in activities that could be reasonably be described as "medical care." Massage—which volunteers had to undergo training to perform—straddled that line, given how central bodywork of that kind was for the care of PWAs. Although the 5B volunteers were not authorized to write in patient's charts, this topic appears to have been a subject of some contention, appearing in meeting minutes as part of a "weekly dos and don'ts" list in the mid-1990s, approximately a decade into the life of the unit. Also mentioned on that list was picking up controlled substances from the pharmacy, and manipulating IVAC equipment controls.[61] That the

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[58] *Ibid.*, 193

[59] *Ibid.*, 395

[60] San Francisco General Hospital AIDS Ward 5B/5A Archives, 1983-2003 (SFH 12), San Francisco History Center, San Francisco Public Library. Box 9, Folder 115.

[61] An IVAC is a trademarked pump that electronically dispenses intravenous fluids, including pain medication.

nursing staff had to repeatedly remind volunteers that they were not authorized to handle patient charts or controlled substances raises two possibilities: (1) that unit volunteers occasionally empowered themselves to play a role in patient care well above and beyond that outlined by both the nursing staff and the law, or (2) that there were drug-seekers among the volunteers. The truth is probably a combination of the two.

The contributions that volunteers made on the ward and in the lives of patients were crucial to the success of 5B, a fact Clifford Morrison shared broadly. In addition to building community trust—a necessary process given the historic injustices committed against lesbians, gays, and people of color, among others—Morrison wrote in a journal article that involving volunteer groups could "lead to better education of the community concerning the issues around AIDS… [and] can also contain costs and maintain quality care."[62] As other institutions tried to replicate the program, 5B granted reprint rights (with acknowledgement) for their Volunteer Training Book.[63] As of August 1988, the handbook had been shared with over 400 hospitals around the United States.[64] From a patient-centered perspective, the success of this community-integration experiment outweighed its ethical drawbacks.

As important as the volunteer program was, it was not the only program on the ward providing care and companionship. The Shanti Project also maintained a daily presence on the unit, helping people with AIDS, their families, their friends, and those

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[62] Clifford Morrison, "Establishing a Therapeutic Environment," 121.

[63] Volunteer Communication Book, ii.

[64] Cathy Sears, "Volunteers: How to Get Them, Train Then, and Keep Them," *AIDS Patient Care* 2, no. 4 (August 1988): 20.

charged with caring for them to process the difficult emotions that came with diagnosis, decline, and death. While 5B volunteers did this work in an informal capacity, The Shanti Project formalized their relationship with the ward at the outset, once again troubling the usual distinction between medical, activist, and service organizations (ASOs).

The Shanti Project

The Shanti Project was unique among AIDS service-delivery organizations involved with San Francisco General Hospital because it predated—and continues to exist beyond—the first wave of the AIDS crisis. While *primarily* a community-based, volunteer organization, Shanti provided Ward 5B several full-time licensed counselors to aid in psychosocial patient care. Dr. Charles Garfield founded The Shanti Project in 1974 to provide emotional and practical support to people with terminal illnesses, especially cancer.[65] The emergence of HIV, however, coincided with a moment of major internal upheaval that shifted the organization's focus. During the early 1980s The Shanti Project's executive board attempted to dissolve the non-profit entirely. At that time, Shanti volunteers—who various sources intimate were mostly white, gay men—took over the executive board, and changed the orientation of the group to focus specifically on PWAs.[66]

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[65] "The Shanti Project," accessed May 24, 2015, http://www.shanti.org.

[66] Helen K. Schietinger, R.N., M.S., F.A.A.N., "Nurse Coordinator of UCSF's First AIDS Clinic," an oral history conducted in 1995 and 1996 by Sally Smith Hughes in *The AIDS Epidemic in San Francisco: The Response of the Nursing Profession, 1981-1984*, *Volume I*, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 1999. 133.

Dr. Paul Volberding, an oncologist and one of the developers of the AIDS clinic attributes much of the "gay spin" to Jim Geary's ascendance to the executive directorship.

The organization only began catering to other critically ill populations again after the worst of San Francisco's AIDS crisis was over, in the late 1990s and early 2000s.

The use of the word "Shanti"[67] in the organization's title is a testament to its bent toward New Age philosophy, as is its logo, which "represents a sun in eclipse, the passage from light to darkness and back to light."[68] It also, of course, represents a benign orientalist impulse endemic to New Age medicine.[69] Problematic name aside, the organization attributes its national reputation and success to the Shanti Model of Peer Support™, which the current website describes as "a way of being with another person that frees both parties to be fully who they are and communicate their feelings to one another. It is a way of being which allows two persons to meet as equals. It is a way of relating to others that is characterized by certain values and attitudes."[70] Those values include honesty, empathy, mutual respect, and patient empowerment, among others. Deeply spiritual but unaffiliated with any organized religion, Shanti volunteers served (and continue to serve) as

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Paul A. Volberding, M.D., "Oncologist and Developer of the AIDS Clinic, San Francisco," an oral history conducted in 1992 and 1993 by Sally Smith Hughes, Ph.D., in *The AIDS Epidemic in San Francisco: The Medical Response, 1981-1984*, *Volume III*, Regional Oral History Office, The Bancroft Library, University of California, Berkeley. 119.

67. "Shanti" (शान्ति) is a Sanskrit word that roughly translates to "inner peace."

68. Shanti Training Manual, Shanti Records, 2006-02, The Gay, Lesbian, Bisexual, Transgender Historical Society.

69. Nazrul Islam, "New Age Orientalism: Ayurvedic 'Wellness and Spa Culture,'" *Health Sociology Review* 21, no. 2 (January 1, 2012): 220–31.

70. "The Shanti Model," accessed May 24, 2015, http://www.shanti.org/pages/shanti-model.html.

compassionate companions for their clients during the myriad emotional transitions that accompany death and dying.

The Shanti Project's nondenominational approach to death and dying made the organization especially compelling at the outset of the AIDS epidemic. Beyond traditional counseling, Shanti's emotional support volunteers were also trained "to be open to various approaches, including pain control, visualization and relaxation exercises, and [were] familiar with both traditional and alternative therapies."[71] Shanti volunteers attended not only to patients, but also to their (biological and chosen) families, and were trained to handle a myriad of difficult situations caregivers faced in interacting with PWAs, including dementia and suicidal ideation.

The Shanti Project, if innovative in some elements of its ideology and practice, should be understood as continuing the longstanding quest for a modified "good death" chronicled in Hallen et al.'s *Beyond the Body: Death and Social Indentity*, James Green's *Beyond the Good Death: The Anthropology of Modern Dying*, and Drew Gilpin Faust's *This Republic of Suffering.*[72] The concept of the good death inhered in the fifteenth-century religious notion that the manner of one's death spoke to the material and spiritual quality of one's life, but has long since transcended its theological framework. To die well was (and for many, still is) an art, a process requiring preparation, whether it be by reading texts like the *Ars Moriendi*

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[71] Shanti Training Manual.

[72] Elizabeth Hallam, Jenny Hockey, and Glennys Howarth, *Beyond the Body: Death and Social Identity* (London: Routledge, 1999); James W. Green, *Beyond the Good Death: The Anthropology of Modern Dying* (Philadelphia: University of Pennsylvania Press, 2012); Drew Gilpin Faust*, This Republic of Suffering: Death and the American Civil War* (New York: Alfred A. Knopf, 2008).

(*The Art of Dying*), or putting one's financial affairs in order.[73] Throughout history, assuring a good death has frequently required improvisation. By way of example, in *This Republic of Suffering*, Faust demonstrates that Civil War soldiers adopted a series of practices in the hopes of approximating a good death despite the exigencies of war. These modifications to the *ars moriendi* made the salvation of a generation of young men killed in new and previously inconceivable ways conceivable, easing the preoccupations of the dying and the bereaved alike. AIDS is too-often compared to war,[74] but the impact of the two catastrophes on death-ways is nevertheless instructive for understanding the benefit Shanti provided patients on 5B. Like war, disease makes the unthinkable not only thinkable, but tangible. The AIDS epidemic was characterized by the death of previously vigorous young men, many of whom (as a result of homophobia and resulting gay migration to major metropolitan areas) were physically and emotionally alienated from their own families. Gay and straight PWAs alike were often estranged from the religious institutions in which they were raised. For those raised in the Judeo-Christian tradition, the idea of dying of a "gay plague" raised the specter of eternal damnation and public shame. Former Shanti Project counselor Ed Wolff articulated this dynamic in the 2011 documentary, *We Were Here*, saying that,

> I would stand in the hallway, a gay man myself, in my mid-thirties, visiting and talking to a mother and father who are just stepped out of a room, just found out that their son has pneumocystis and had, 3 months to live, or whatever. And the father would stand there and go "You know, it's harder for

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[73] Aries describes this process as "The Tame Death." Philippe Aries, *The Hour of Our Death: The Classic History of Western Attitudes Toward Death over the Last One Thousand Years*, trans. Helen Weaver (New York: Vintage Books, 2008).

[74] Susan Sontag, *Illness as Metaphor and AIDS and Its Metaphors* (New York: Picador, 2001).

> me to find out that my son is a fag than to find out that he's going to be dying soon." And there I would be, trying to comfort him.[75]

The realities of AIDS, like the realities of war, bred innovative practices intended to facilitate a good death. The Shanti Model™ was just one of many practices adopted to ease the existential crises that usually accompanied a diagnosis. The Shanti approach to dying well gained traction at the outset of the AIDS crisis, because, as journalist Michael Helquist recalled, the demographic the virus initially struck—young men, isolated from families and faith communities—were unfamiliar with (and emotionally unprepared for) tragedy on this scale. He described the services Shanti offered as "mostly appropriate for the time. That *is* what was happening: people *were* dying. It was difficult dying, so here was a response to it."[76]

In addition to providing emotional support through the process of dying, Shanti volunteers also assisted their clients with the oftentimes complicated business of living. Volunteers attended to a wide range of practical concerns, from meal preparation and housework, to hospital advocacy and making funeral arrangements. By addressing both patient's spiritual and quotidian concerns, Shanti volunteers provided a calming influence in the lives of many San Francisco PWAs.

Multiple people working on AIDS at The General knew of The Shanti Project, felt the organization was doing important, principled work, and wanted that work to happen on 5B, with Clifford Morrison being Shanti's strongest advocate. Morrison felt that the New Age ethos of the organization—if often a subject of ridicule—also made it a natural fit for a

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[75] David Weissman and Bill Weber, *We Were Here* (Weissman Projects, LLC, 2011).

[76] Helquist oral history, 33.

unit dedicated to challenging the healthcare status quo. Nurse Morrison's involvement with The Shanti Project began in 1982, before he had even been tapped to serve as organizer of Ward 5B. He became involved after attending a talk given by Helen Schietinger, the nurse and counselor at the UCSF Kaposi Sarcoma Clinic. After hearing her stories about the AIDS crisis, Morrison asked her how he might be of service to PWAs; Schietinger responded by suggesting he sign up for a Shanti Project volunteer training, which he began in December of 1982. Later, when he was empowered to design Ward 5B, Morrison quickly determined that, to be effective, the unit needed psychosocial support far beyond what the nurses, psychiatrists, and social workers would be able to offer.[77] "The nurses were going to be busy taking care of the physical needs of the patients," he said, "and [although] I wanted them to have an ability to recognize and deal with the psychosocial issues… they were not going to be able to handle all that."[78]

Although Morrison thought that bringing The Shanti Project onto Ward 5B would be "the logical solution" to his manpower needs, he also realized that nothing of that sort had ever been done before.[79] This was taking community caregiving to a level that—for a variety of reasons, including patient privacy and security—would be difficult to sell to an

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[77] When Ward 5B first opened, it only had one social worker on staff. Her primary responsibilities involved discharge planning, which Nurse Diane Jones indicated was a point of contention. Diane Jones, R.N., "First Wave of the Nursing Staff on the AIDS Ward, San Francisco General Hospital," an oral history conducted in 1995 and 1996 by Sally Smith Hughes in *The AIDS Epidemic in San Francisco: The Response of the Nursing Profession, 1981-1984*, *Volume III*, Regional Oral History Office. The Bancroft Library, University of California, Berkeley, 1999. 28-30.

[78] Morrison oral history, 133.

[79] *Ibid*., 132.

administrator. The unit was already controversial at The General (according to Morrison, "there was already this rumbling that I was creating my own little dynasty,"[80]), so Morrison concluded that a proposal coming from him would likely be unsuccessful. Instead, he coached James Geary, then-director of The Shanti Project, on the process of writing and submitting a proposal to the Department of Public Health. As he expected, the proposal was unpopular with SFGH's administrative and house staff alike.[81] The primary concern—enunciated by department heads around the hospital, was that the "hare-brained" scheme would grant unprecedented access and power to an outside organization—a gay-identified outside organization.[82] Morrison remembered his response to the concern that allowing "those people" to join Ward 5B would upset people accordingly: "Well, this is a public hospital, and my take on… the role of this institution is that it should be working with the community. You've done it with other groups, not that well, but you've done it. I think now is the time to do it with this group… you've got a lot of P.R. to do, because the gay community does not trust this facility, and never will."[83] As he had done in the past, Dr. Mervyn Silverman (then-San Francisco Director of Health), agreed with Morrison, and cleared the way for Shanti to join the ward—over the objections of the Executive Administrator, the Chief of Medical Services, and several department heads.

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[80] *Ibid.*, 133.

[81] *Ibid.*, 133.

[82] *Ibid.*, 134.

[83] *Ibid.*, 93-94.

Shanti recruited three *professional* counselors to join the staff of San Francisco General Hospital. The timing of the contract meant that The Shanti Project was a part of Ward 5B from its inception; indeed, the work of Shanti founder Charles Garfield and Swiss-American psychiatrist Elisabeth Kübler-Ross figured prominently in the staff-training program.[84] SFGH's Shanti staff grew over time; by the spring of 1989 there were seven people serving as "counselor, advocate, educator, hand-holder, masseur, facilitator and mediator all rolled into one" both on Ward 5B and in other areas of the hospital.[85] The Shanti Project writ large, meanwhile, still did the majority of its work outside the hospital connecting volunteers to community members in need. As such, Shanti volunteers often made regular appearances on the ward to visit hospitalized clients. To be clear, as demonstrated in the chart below, The Shanti Project was the only organization that contributed to patient care in both a professional *and* a volunteer capacity.

Table 1. Paid vs. Unpaid Labor on Ward 5B

Paid Employees	Volunteers
• Ward 5B nurses, physicians, house and clinical staff. • 5B social worker(s) • 5B Shanti Project counselors	• 5B Volunteer Program participants • Shanti volunteers (visiting individual clients) • Ad-hoc volunteers (i.e. Rita Rockett, Mary Rathbun)

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[84] Jones oral history, 29.

[85] *Ecclipse*, Spring 1989, Shanti Records, 2006-02, Box 1, Folders 1:47, The Gay, Lesbian, Bisexual, Transgender Historical Society. 1.

This constituted a significant elevation of the predominantly-gay, community-based organization. Through its formal affiliation with 5B and the financial support of the San Francisco Department of Public Health, Shanti gained visibility and legitimacy. Morrison's advocacy work enabled state endorsement of queer community enterprises like Shanti; as a result, care was more accessible to San Franciscans living with AIDS, and the medical hierarchy at SFGH destabilized.

The alliance between 5B and the professional Shanti Project staff was not just ideological and contractual. It was also social. According to Morrison, the nursing staff and the Shanti staff partied together frequently, which helped all involved to deal with the stress and grief of their job. They also shared a Communication Book, and took collective responsibility for maintaining the ward necrology.[86] These processes of collective mourning were central to group cohesion. In fact, the Shanti staff occasionally used their counseling techniques for the benefit of their Ward 5B colleagues. Throughout the San Francisco Oral History Project AIDS Series on the response of the nursing profession, there are multiple references to a death visualization exercise Shanti counselors conducted in staff training sessions, all of which suggest the experience was deeply affecting.[87] When a 5B nurse committed suicide in the early 1990s, Shanti Project Counselors "sat with" the nurses, providing the crucial support services necessary for the continued functioning of

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[86] *Ecclipse,* Spring 1989, 6.

[87] *The AIDS Epidemic In San Francisco: The Response of the Nursing Profession, 1981-1984*, *Volume I-IV*, an oral history conducted in 1995 and 1996, Regional Oral History Office, The Bancroft Library, University of California, Berkeley. 1999.

the Ward.[88] That 5B integrated professional counselors from an outside organization, despite already having clinical therapists and social workers on the ward, could easily have read as an indictment of their peers—and the occasional squabble did indeed take place between the different stakeholders on the unit. However, the sheer magnitude of the AIDS crisis, its attendant losses, and the community ethic of the ward went a long way toward easing professional tensions where they existed. The practical and political ends that the alliance between 5B and Shanti served superseded day-to-day power struggles.

In addition to their shared political beliefs, the mutual respect between hospital staff and Shanti counselors was likely a result of the organizations' longstanding presence in San Francisco, and the fact that many of Shanti's unpaid volunteers were nurses, doctors, and patients. UCSF nurse turned "AIDS Poster Boy" Bobby Campbell raised the organization's profile in much the same way he raised the profile of the disease: he became an unofficial spokesman. Because of his strong ties to the gay, activist, and medical communities—not to mention the local and national media—Campbell's involvement in Shanti allowed it to grow rapidly, and also attracted other medical professionals to the organization.[89] Though undoubtedly Shanti's most famous volunteer, he was just one of the many members of the San Francisco medical community that worked with the group. Like Clifford Morrison, UCSF Kaposi's Sarcoma Clinic Psychologist Paul Dague was deeply invested in Shanti, and Ward 86 Head Nurse Gayling Gee held multiple positions on the Executive Board in the late

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[88] February 14, 1995 letter from Diane Jones, R.N. Box 9, Folder 107, San Francisco General Hospital AIDS Ward 5B/5A Archives, 1983-2003 (SFH 12), San Francisco History Center, San Francisco Public Library.

[89] Helquist oral history, 33.

eighties and early nineties.[90] Shanti's ranks included doctors, nurses, even laboratory researchers at The General. Isabel Gaston, for example, worked in the lab, and—not knowing anybody with AIDS herself—decided to join The Shanti Project.[91]

Though usually a harmonious pairing, integrating a community-based psychosocial support service onto 5B did occasionally breed tension. Although SFGH's Shanti staff (unlike most members of The Shanti Project) were both licensed and compensated for their labor, oral histories suggest they were often referred to as "volunteers" by their co-workers. If perhaps an honest mistake, it is also evidence of what 5B nurse Diane Jones referred to as an on-again off-again "turf war" between nurses, social workers, and the Shanti staff.[92] While interviews suggest that all involved recognized the profundity of the psychosocial issues 5B patients faced, the nurses' willingness to relinquish responsibility for their patient's mental and emotional health was not always absolute—after all, they were *also* trained to manage such issues themselves. Especially in such an emotionally-charged workplace, one can easily imagine nurses occasionally regretting the choice to cede responsibility to outsiders.[93] Territorial squabbles aside, the relationship between the Shanti counselors and the 5B staff was a central pillar of the San Francisco model, and equally central to public memory of the ward.

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[90] Paul Lorch, "KS Takes Paul Dague: Former OC Director Loses Two-Year Battle," Bay Area Reporter, Jan 26 1984. Ecclipse, February/March/April 1992, Box 1, Folder 1:47, Shanti Records, 2006-02, The Gay, Lesbian, Bisexual, Transgender Historical Society.

[91] Carol Pogash, As Real as It Gets, 80.

[92] Jones oral history, 31.

[93] Ibid., 30.

The Shanti Project was foundational in establishing the famously queer, hospitable ethos of Ward 5B, and their methodology informed both the practical and the emotional work that took place on the unit from the very beginning. Despite its integral role on the ward, and the wide-spread support of nursing staff, however, The Shanti Project's affiliation with 5B ended before the hospital's need for their services did. The SF Department of Public Health terminated Shanti's contract a couple years after a financial scandal rocked the organization. That scandal, which broke in the spring of 1993, also led to Executive Director Jim Geary's resignation. Some people—including Michael Botkin of the *Bay Area Reporter* and author Benjamin Heim Shepard—saw Shanti's loss of state support event as heralding the death of the San Francisco model.[94] In fact, community-hospital integration was successful enough, and popular enough, to persist, but that culture-brokers were thinking about the organization's fall from grace in such terms is telling.

Shanti's financial problems came at a very inopportune time. The early and mid-nineties were a period of dismay for people and organizations leading the response to AIDS. Despite their efforts, a full decade after HIV's emergence, the death toll continued to climb, the federal government's indifference held fast, and the much hoped-for cure was nowhere in sight. In the autumn 1992 edition of *Eclipse* (The Shanti Project's official newsletter), Executive Director Eric E. Rofes expressed these frustrations to Shanti supporters, writing that "Many of us thought this epidemic would be over by now… We are

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[94] Michael C. Botkin, "SF Model—R.I.P.," *The Bay Area Reporter*, June 29, 1995; Benjamin Heim Shepard, *White Nights and Ascending Shadows: An Oral History of the San Francisco AIDS Epidemic* (London: Cassell, 1997).

overwhelmed by the amount of death we've witnessed and the volume of fear which cycles through us. We are anxious and angry. And we are exhausted."[95]

During this time, the AIDS movement began to fracture. While in some cases organizations grew both their budgets and their reputations through professionalization, in other cases, the groups turned their critiques of power inward, effectively cannibalizing themselves. The Shanti Project was one of the service-delivery groups that, with volunteers in the thousands, seemed to be on the road to professionalization. By 1993, the organization's budget had expanded to over $5 million.[96]

What happened next lent credence to the concerns hospital administrators had enunciated from the start. In the same moment that Shanti was experiencing unprecedented financial success, San Francisco General Hospital workers were becoming dissatisfied with the Shanti staff's professionalism. According to Ward 86 Nurse Practitioner Stephen Carr, the quality of the paid counselors working on the outpatient unit went down considerably over time. Counselors dated Carr's patients, at least one was suspected of coming to work under the influence of drugs, and others reportedly expressed an unprofessional degree of militancy around "dying the Shanti way."[97] The broader community also questioned the merits of the organization's approach. According to Gayling Gee, who chaired The Shanti Project Executive Board at the time the contract was revoked, "People would say 'This is like a cult. What are you doing with these volunteers in terms of

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[95] *Ecclipse*, August/September/October 1992, Box 1, Folder 1:47, GLBT Historical Society, Shanti Project Collection 2006-02.

[96] Shepard, 222.

[97] Carr oral history, 73-74.

training? What do you expect patients to give to you?' Some of the training was perceived as not being as therapeutic as it could be."[98]

It was in this already embattled atmosphere that city officials discovered Shanti owed $500,000 in expenses that were not covered by contracts. All of the expenses in question were reportedly used to provide direct services to people with AIDS.[99] This gives some purchase to Benjamin Heim Shepard's argument in *White Nights and Ascending Shadows* that the scandal was a "streak of bad luck," wherein "combinations of innuendo, carnivorous political moods and dyslexic accounting made casual appropriations of funds take on the nuances of embezzlement."[100] Shepard's text included selections from an interview with Shanti Activities Coordinator Richard Chavez, who described the "nuances of embezzlement" as the result of incompetent accountants and inattentiveness to documentation on the part of some of the organization's directors.[101]

Although The Shanti Project paid back all of the money owed to the city, and audits by Cooper & Lynbrand found no misuse of funds occurred, the damage to the organization's

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98. Gayling Gee, R.N., M.S., "Head Nurse at the AIDS Clinic, San Francisco General Hospital," an oral history conducted in 1995 and 1996 by Sally Smith Hughes in *The AIDS Epidemic in San Francisco: The Response of the Nursing Profession, 1981-1984*, *Volume IV*, Regional Oral History Office, The Bancroft Library, University of California, Berkeley. 1999. 59.

99. "Shanti Project Audits Find no Misuse of Funds; Agency's Probation To Be Removed," Press Release. Box 1, Folder 44, Shanti Records, 2006-02, The Gay, Lesbian, Bisexual, Transgender Historical Society.

100. Shepard, 220.

101. *Ibid*., 222.

reputation had already been done.[102] The Department of Public Health terminated its contract with Shanti when it came up for renewal in 1995 because their history of financial mismanagement, intentional or not, made further support from the city of San Francisco untenable.[103] While the organization still exists to this day—and, indeed, has expanded into Los Angeles, Laguna Beach, and Seattle—it is not formally affiliated with any major-medical institutions.

It may be true that Shanti "got way too big for its britches," but documentation by 5B staff regarding the counselor's departure suggests the nurses were upset to see them go, and believed the organization's net effect on SFGH patients was positive.[104] One might say that the same informality that caused political and financial problems for The Shanti Project also facilitated an award-winning patient care experience. Of Shanti counseling, Carr explained that "There was… an availability about it that's not the same thing as psychiatry or therapy, and that the nurses don't have time to do."[105] No other organization stepped in to fill the void left by The Shanti Project.

Although the group's departure was at one time characterized as the death knell of the San Francisco model, that analysis failed to account for the changing nature of the epidemic. Even if The Shanti Project *had* maintained its contact with SFGH, the exigencies of the AIDS crisis meant that their efforts within the hospital would have almost certainly

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[102] "Shanti Project Audits Find no Misuse of Funds."

[103] Carr oral history, 74.

[104] *Ibid*., 73-74.

[105] *Ibid*., 74.

contracted with time. Indeed, in many respects, the ward's community outreach initiatives were victims of their own success. Take, for example, the change in admission and duration-of-stay statistics over the first decade of the AIDS crisis. HIV testing began in 1985; before that time, many of the patients who arrived on Ward 5B never left, so acute was their condition. Outpatient support services were limited. PWAs often lived on the ward for weeks, sometimes months, and, accordingly, required the sort of psychosocial care and companionship Shanti's SFGH counselors offered. By the mid 1990s, however, the average length of a hospital stay was only six and a half days. PWAs on the unit were there because of an acute medical need that could not be accommodated at home; as a result, the atmosphere on the ward shifted. According to Nurse Diane Jones, the drama on Ward 5B became similar to the drama nurses experience on a labor and delivery ward: short-lived, but intense.[106] The reduction in hospital stays led to a prioritization of medical over psychosocial issues within the boundaries of the hospital. Even if The Shanti Project had retained its contract with SFGH, the changing manifestations of the illness reduced the holistic care needs of 5B patients. Because The Shanti Project was founded as a peer-to-peer support service, where volunteers met clients in their homes and communities, it is unlikely that the organization's relationship with the PWA community was as deeply impacted by the shift out of the hospital setting as it was by the reputational damage it endured in the 1990s.

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[106] Jones oral history, 42.

Though it rarely gets much attention in academic histories of the AIDS crisis, The Shanti Project looms large in San Francisco's popular memory.[107] One could even argue that Shanti's legacy has been more enduring than 5B's. While many different people (nurses, doctors, social workers, and volunteers of all kinds) attended to the practical and psychosocial needs of PWAs, the improbability of the Shanti counselors' presence at SFGH rendered their narrative extremely compelling. The sheer numbers of people who volunteered for the organization (thousands), and the staggering amount of money the organization raised through fundraisers and bequests (millions), only deepened the mark it made on the first wave of the epidemic. Additionally, several Shanti volunteers—like Bobby Campbell before them—have become part of the public face of San Francisco AIDS history. Of these individuals, Ed Wolf is arguably the best known today, and the best represented in The Shanti Project's archives.

A former 5B staff counselor, David Weissman featured Wolf in his 2011 documentary *We Were Here.* In the film, Wolf discussed a myriad of experiences from his time as a counselor on the ward, including the bereavement fatigue that ultimately forced him to leave the ward. "We have a local paper here in San Francisco called *The Bay Area Reporter*, and there was one issue, they decided to just run all the photos of all the people that had died in the last year,"[108] he said. When he looked at the paper, "It was just page after page, after page, after page of all these primarily gay men who had died on the unit. I

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[107] While not mentioned by name, Cindy Patton critiques organizations like Shanti in Inventing AIDS. Most other conversations about the organization have been confined to medical and public health scholarship. Cindy Patton, *Inventing AIDS*, (New York: Routledge, 1990).

[108] *We Were Here*.

just felt something, like, right here, [*points to chest*] it was a physical, like 'click,' because I saw all these faces, and I was stunned by how many of them I knew from working on the unit. And I realized, you know, I realized I couldn't. I just couldn't do it anymore.[109]

In discussing the happier moments on Ward 5B, Wolf reminisced about one woman in particular, affectionately known as "Rita Rocket." Although she was, at one time, something of a service celebrity, Rita Rocket and her "brunch bunch"—and the many other ad hoc community groups that sprang up in support of 5B—have been largely overlooked by the literature on San Francisco's response to the AIDS crisis.[110] The same informality that has allowed those groups to slip under the historiographical radar, however, underscores the communal quality of the healthcare environment established by Ward 5B's nursing staff, and the degree to which their interactions with volunteers reflected their political commitments.

Rita Rocket's Brunch Bunch and Other Community Ventures

> When I woke up this morning, I thought, "Today is the day I'm going to eat a home-cooked meal." –Richard Roberts (Ward 5B patient, aged 34)[111]

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[109] *Ibid*.

[110] Guenter Risse is the only academic who has ever mentioned Rita Rocket's work; she was mentioned as contributing to the character of the unit. All substantial accounts of Rocket's work to date have come from journalists. Guenter Risse, "Planning a New Hospital Ward: The San Francisco Model of AIDS Care" (presentation, London School of Hygiene and Tropical Medicine, London, May 24, 2000), 5.

[111] Laura Paull-Borja, "Rita Rockett's Really Cooking on Ward 5A," *SF Examiner*, March 15, 1986, sec. zA. Box 9, Folder 103, San Francisco General Hospital AIDS Ward 5B/5A Archives, 1983-2003 (SFH 12), San Francisco History Center, San Francisco Public Library.

In 1984, travel agent Rita Berger—along with friends Lee Harrington and Terry Scott—decided to throw an Easter brunch for a friend on Ward 5B named Larry Beach. Beach passed away before the holiday, but by that time, Berger, Harrington, and Scott had become familiar enough with the other patients residing on the unit that they decided to throw the brunch anyway. The brunches became a bi-monthly event on the unit, and yet another source of volunteer labor on the ward; by 1994, Berger estimated she and her fellow volunteers had prepared and served over 10,000 meals on 5B.[112] She served meals for another six years thereafter, raising that total still higher. By welcoming the efforts of well-intentioned community members like Rocket, the 5B nurses saved money, raised their public profile, and demonstrated that one need not have extensive medical training to make an impact on the sick.

Berger did more than just nourish 5B's patients, she also provided entertainment. A former tap dancer, she gave choreographed performances in a hallway crowded with patients and hospital staff—usually dressed as a cocktail waitress or Playboy bunny. Sometimes she even brought backup dancers. The patients dubbed her "Rita Rocket" in honor of her fancy footwork, and the Sunday brunch spectacular quickly took on the same name, its volunteers referred to as members of the "Rita Rocket Brunch Bunch." Berger's assumed name became so embedded in 5B culture that at least one article about *The San Francisco Chronicle* neglected to identify Rocket by her given name at all. For the sake of

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[112] Pamela Burdman, "An Easter to Celebrate for All Reasons," *San Francisco Chronicle*, date and page unknown, Box 9, Folder 103, San Francisco General Hospital AIDS Ward 5B/5A Archives, 1983-2003 (SFH 12), San Francisco History Center, San Francisco Public Library.

clarity, then, Rita Berger will henceforth be referred to as Rita Rocket, the name that appears with the greatest frequency in archival sources.

Food provision for PWAs was, and remains, one of the most important services provided by community volunteers. Wasting is a common symptom of HIV/AIDS, a result of poor appetite, food intolerance, nausea, diarrhea, and adverse reactions to drugs. Because proper nutrition is vital to maintaining both a healthy body weight *and* fighting off infection, Ward 5B nurses encouraged significant others to bring appealing foods "from the outside," to help patients muster the enthusiasm to eat. Rita Rocket and other food delivery services like hers were therefore crucial to the nutrition of patients who lacked a support system. Physical benefits aside, Rita Rocket and similar service-delivery groups around the country (groups like God's Love We Deliver and Project Open Hand, for example) also recognized the *psychosocial* benefit patients derived from their special deliveries. As 5B patient Rod Meth told the *San Francisco Examiner*, "As good as it is, Rita's food is just a sideline… Rita has the supreme ability to lift people out of themselves. When she comes, everybody gets happy."[113]

"The Tap-Dancing Florence Nightingale"[114] became a local celebrity quickly after starting her brunch bunch, winning a Langton Humanitarian Award and a San Francisco Cable Car Award within her first two years of service.[115] In the brunch's early years, she

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[113] Paull-Borja.

[114] Unidentified Magazine Clipping, Box 9, Folder 103, San Francisco General Hospital AIDS Ward 5B/5A Archives, 1983-2003 (SFH 12), San Francisco History Center, San Francisco Public Library.

[115] Paull-Borja.

paid for the sixty-person meals—which cost about $200 on average—with tips she received working as a cocktail waitress at the Castro Station. Community donations later subsidized her efforts, the result of extensive press coverage of her bi-weekly buffets.

Like many Ward 5B and Shanti Project volunteers, Rita Rocket began serving the PWA community while grieving her own losses. Rocket came to San Francisco a divorcee and newly-bereaved mother of a three-and-a-half-year-old daughter. She told *The San Francisco Examiner* that she saw her volunteer work as a way of repaying the kindness shown to her by the gay community during those trying times. "'They're all my babies… my poor babies'" she said, adding that "'When I came here, I didn't know no one. The gay guys took me in, protected me. They're like my brothers.'"[116] The maternalism evidenced here—and demonstrated by volunteers throughout the archive, speaks to the way the nurses of 5B both validated and facilitated nontraditional kinship structures at the local and community level. Coming from a large midwestern family, Rocket articulated her commitment in terms of traditional family values: "Whenever there is something wrong, you take food."[117]

Rocket vowed to continue serving 5B patients until the epidemic ended and the ward closed, a promise that highlights just how improbable the epidemic's endurance seemed, even to those most engaged with its sufferers. After sixteen years and two children, however, Rocket left San Francisco to care for ailing family members. Though

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[116] *Ibid*.

[117] Sabin Russell, "Pioneering S.F. AIDS Ward Celebrates Its First 20 Years/It's Become An International Model for Compassionate Care," SFGate, July 26, 2003, Accessed June 23, 2017, http://www.sfgate.com/health/article/Pioneering-S-F-AIDS-ward-celebrates-its-first-20-2600024.php.

volunteers and ward staff put plans in place to continue the brunch tradition in her absence, the archive is unclear as to the success of that venture."[118] Upon Rocket's departure, the San Francisco Health Commission formally recognized her service at an awards ceremony in her honor.

Rita Rocket was not the only celebrated AIDS volunteer to carve out a niche role on 5B. As Carol Pogash wrote in *As Real As it Gets*, SFGH's reputation for AIDS care drew "nontraditional volunteers who give the hospital a warmth and character lacking in other institutions. Among those volunteers was Mary Rathbun, "the volunteer patron saint of Ward 86." Rathbun's eccentric brand of service demonstrates how the nursing staff's permissive attitude toward individualized volunteerism reflected their political commitments, both to patient care and to broader left-wing politics.[119]

A retired waitress, Mary Rathbun—also known as "the cookie lady" or "Brownie Mary"—would arrive at SFGH each week festooned with pins and patches in support of the legalization of marijuana. She would also have hundreds of cookies in tow.[120] Already a well-known personality in San Francisco during the 1970s, a 1981 arrest for selling an "Alice B. Toklas brownie" to an undercover cop turned Rathbun into a national news story. After completing her court-mandated community service, the sixty-six year old ex-con

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[118] "Thanks for Everything, Rita!" *Bay Area Reporter*, June 22, 2000. Box 8, Folder 103, San Francisco General Hospital AIDS Ward 5B/5A Archives, 1983-2003 (SFH 12), San Francisco History Center, San Francisco Public Library.

[119] Pogash, *As Real as It Gets*, 162.

[120] *Ibid*., 167-168.

became a volunteer "runner" on Ward 86.[121] She joined the volunteer staff because at least half of the customers she had once sold marijuana to, and counted among her friends, were gay. She explained the demographics of her clientele crudely; her customers were gay "because I live in the faggot zip code. Some people can say that. Some people can't. I can. …This epidemic came along and so many of my friends were gay, lesbian, bisexual or who cares? …I've watched a hundred thousand of them deteriorate and die."[122] In response to the destruction of her community, she turned what had once been a business into a charity venture, a one-woman (illegal) service-delivery organization—and she did so with the support (or, at the very least, the benign neglect) of the 5B nursing staff. Not everybody was as content to ignore Brownie Mary's charity work as 5B's nursing staff was. The police arrested Rathbun again in 1992, during a Drug Enforcement Administration raid on her home. At the time, she was in the process of baking twenty-dozen marijuana brownies, eighteen dozen of which she had planned to deliver, free of charge, to AIDS patients.

Marijuana—which is both an analgesic and an appetite stimulator—is beneficial to patients fighting "wasting syndrome." At the time, it was also a schedule I substance in California. Mary Rathbun told the media multiple times that she was willing to go to jail for distributing her baked goods because she believed that "her kids" needed access to the drug.[123] A *Modern Maturity* article titled "Proud Mary," quoted a defiant Rathbun saying of marijuana that "It gives 'em the munchies and relaxes them… I have a half of [a marijuana

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[121] Pogash, *As Real as It Gets*, 169.

[122] *Ibid*.

[123] *Ibid*.

brownie or cookie] myself before I go to General. Keeps me going."[124] The nursing staff's willingness to look the other way while Brownie Mary dispensed pot-laced baked goods on the unit demonstrates the political ethic informing patient care on the ward, a political ethic shared by many San Franciscans beyond the boundaries of the hospital. Not only did the state eventually drop all charges against Rathbun, the San Francisco Board of Commissioners named August 25, 1992 Mary Rathbun Day.[125]

While especially captivating, Rita Rocket and Mary Rathbun are only two of many examples of ad hoc community engagement on Ward 5B. Also highly visible on the unit were gay-identified affinity groups unaffiliated with AIDS, among them the San Francisco Gay Men's Chorus (SFGMC), the Bay Area Lawyers for Individual Freedom (BALIF), and the Metropolitan Community Church of San Francisco (MCC). For-profit organizations also maintained a presence on the unit. Numerous gay-owned businesses gave regular donations to the ward, from weekly donations of ice cream, to videos, to satin robes for every patient. The quality and extent of the community's involvement with Ward 5B was a direct result of the political strategies of San Francisco's gay rights movement, which facilitated the explosive growth of gay commerce—and the emergence of the Castro as a "gay neighborhood"—in the 1970s.[126] Nurse Morrison himself recognized the importance of the economic and political power amassed by the gay community for the construction,

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[124] R. Atcheson and D. Mathison, "Proud Mary," Modern Maturity, 1995. Box 13, Folder 145, San Francisco General Hospital AIDS Ward 5B/5A Archives, 1983-2003 (SFH 12), San Francisco History Center, San Francisco Public Library.

[125] Pogash, *As Real as It Gets*, 247.

[126] Elizabeth A. Armstrong, *Forging Gay Identities: Organizing Sexuality in San Francisco, 1950-1994* (Chicago: University Of Chicago Press, 2002), 120-123.

growth, and survival of 5B, saying that, “Gay people flocked here, built a community here, sought political power here, for reasons that, while they couldn’t anticipate the epidemic, were really about the same thing.” “They were about stigma and oppression and not having equal access,” he said, adding, “there was a context and preexisting structure that could incorporate and deal with [the AIDS epidemic].”[127] Morrison and the rest of the 5B nursing staff exploited that preexisting structure, all to the benefit of their patients.

The significance of the San Francisco community’s donation of time, money, and labor to the unit—and the significance of the nursing staff’s encouragement of those efforts—was neither inevitable, nor can it be underestimated. The nurses’ choice to accommodate a willing public on the crowded unit, sometimes against the wishes of hospital administrators, was central to the ward’s success: it kept the costs associated with the unit down, and built community trust in a crucial political moment. It also lent a façade of efficacy to a central pillar of Ronald Reagan’s vision for the American healthcare system. While intended as a repudiation of an uncaring federal government, the politics and culture that structured Ward 5B unintentionally lent support to a community care model being advanced by the Reagan Administration. San Franciscans effectively did with voluntarism and charity what the federal government would not: support people with AIDS.

While community integration on the ward was central to its success, the community—the family—that gay San Francisco built on Ward 5B yielded unintended exclusions and political paradoxes. Ward 5B was such an unabashedly queer space that PWAs who were not out-of-the-closet, or did not fit the archetype of the San Francisco PWA

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[127] Morrison oral history, 47.

might not be comfortable receiving care there. And, of course, it was precisely that archetype that motivated so much of the volunteer work for which 5B became famous. For understandable reasons, volunteers' intimate labor was culturally and politically motivated. Political mobilization is always contingent and transitory; people could get tired of volunteering, or stop contributing to the ward when they stopped seeing themselves in the patients. For this reason the San Francisco model of AIDS care was only ever generalizable in the abstract; the queer and feminist ethics with which healthcare providers established the unit were mirrored and amplified by the civilians supporting them, but such voluntarism is hardly reliable. Similarly frustrating was the reality that the gay community was providing SFGH with much-needed support at the same time that the Reagan Administration was calling for altruism to take the place of government services. An honest analysis of this case study would conclude that reliance on such altruism is at best a temporary solution to a problem for which the federal government must claim ultimate responsibility.

The goal of community integration onto Ward 5B produced many challenges, opportunities, and unintended consequences. The nurses interest in a community-based model of care was of a piece with the larger radical health movement, but the sociopolitical context in which they instantiated it was very different. The rise of right-wing conservatism coincided with multiple existential crises in the nursing profession in the early 1980s. Giving up power was something the profession on the whole was loathe to do, but that is precisely what 5B nurses did in allowing the volunteer program, The Shanti Project, and other ad hoc service projects to shape the character and daily life of the unit. The political labor of 5B's nurses created and sustained a model that was as successful as it was politically and culturally contingent. It also laid bare the tensions between radical health praxis and the progressive values that inspired them.

In a 1998 article in the *Journal of the Association of Nurses in AIDS Care*, Clifford Morrison wrote that using volunteer labor to raise money, provide support, and provide "basic services" was one of the guiding philosophies of Ward 5B. The strategy quickly gained media attention, which, Morrison argued, was a good thing. "[They] did some of the first positive reporting on the epidemic the country had experienced," he wrote. He understood the positive press coverage as a boon to the gay community, writing that they "began to be viewed as taking responsibility and some level of control of the situation, as well as working within the system to improve care and conditions for people with AIDS."[128]

The media was one of the mechanisms 5B's nurses used to gain a national reputation as the foremost experts in AIDS care, but it was not the only one. In fact, nurses engaged in multiple forms of intellectual labor. They promoted, and, later, leveraged, the success of the San Francisco Model to raise awareness and share their knowledge, but they also used their platform to advocate for major reforms of the nursing profession.

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[128] Clifford Morrison, "HIV/AIDS Units: Is There Still a Need?" *Journal of the Association of Nurses in AIDS Care* 9, no. 6 (November-December 1998): 17.

While is beyond the scope of this project, it is important to note that this opinion was (and remains) very controversial. To learn more about the trope of gay responsibility, see Deborah Gould, *Moving Politics: Emotion and ACT UP's Fight against AIDS*, (Chicago: University of Chicago Press, 2009), 85-90; David M. Halperin and Valerie Traub, eds., *Gay Shame* (Chicago: University Of Chicago Press, 2016), 237.

CHAPTER THREE

SEX, DEATH, STIGMA, & THE MAKING OF AIDS NURSING

> Issues and concerns related to the AIDS epidemic require innovative approaches. The AIDS epidemic tests nurses' ability to overcome biases and prejudices and to provide the highest level of care possible to persons affected by this disease. AIDS is a test of nurses' compassion, understanding, humanity, and love for each other. If nurses pass this test, society will be better for it. Nurses will feel better about themselves and their work.
> –Clifford Morrison[1]

When Ward 5B came into being in 1983, all parties involved understood it as a temporary solution to a temporary problem—a test of the medical professions' ability to adapt to the exigencies of an epidemic that, like even the most grueling tests, would eventually come to an end. The "end" envisioned in the case of AIDS was twofold: one, that researchers would identify and cure the disease quickly; and two, that the social stigma associated with the disease would diminish with every new scientific discovery. These hopes went largely unrealized. Instead, the expertise cultivated by 5B's nurses became more salient over time, the fears of the "general public" (and even some medical professionals) greater, and the need to replicate 5B's successes more urgent. This chapter will demonstrate that the nurses fully embraced their new status as authorities, and used that status to advocate for radical procedural, professional, and political change. As a result of their efforts, there were forty dedicated AIDS units across the United States by 1988.[2]

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[1] Clifford Morrison, "Establishing a Therapeutic Environment: Institutional Resources," in *The Person with AIDS: Nursing Perspectives*, ed. Jerry Durham and Felissa Cohen (New York, NY: Springer Publishing Company, 1987), 123-124.

[2] Linda H. Aiken et al, "Organization and Outcomes of Inpatient AIDS Care," *Medical Care* 37, no. 8 (August 1999): 760.

In addition to the regular evaluations one might expect to see conducted in a hospital, 5B's nursing staff submitted their new patient care modality to external review. They also became research subjects themselves, undergoing regular testing in the hopes of proving that AIDS posed no risk to healthcare workers. (Initial testing seemed to bear out the nurses' position. Years later, the nurses would learn that the virus *did* in fact pose a threat to medical professionals, and that—in their quest to lead by example—they had been dangerously cavalier with their own health). Armed with proof of concept, the nurses shared their model with the rest of the country through speaking tours, training programs, academic publishing, and a range of other professional and political activities.

Advocating for the adoption of the San Francisco model of AIDS care meant advocating for an expansion of nurses' role in patient care writ large. It is important to remember that nursing looked different on Ward 5B than it did in other parts of San Francisco General Hospital. The 5B nurses performed physical tasks that would usually be handled by paraprofessional staff (like bathing, bloodwork, and toileting).[3] Discharge planning was, by necessity, more complex, requiring that nurses provide resources and support services traditionally understood as the province of social workers. Effective discharge planning required that the nurses broach subjects, like safe IV-drug use, that they likely were not trained to discuss. 5B's nurses also doubled as community facilitators, coordinating volunteers and events to keep the patients happy and visible, and building relationships with organizations that could support them post-discharge. The 5B staff also advocated for nurses becoming more politically active, directly engaging (and educating)

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[3] Guenter Risse, *Mending Bodies, Saving Souls: A History of Hospitals* (Oxford: Oxford University Press, 1999), 648.

their communities and their government about AIDS. To do less, they suggested, would be to betray the values and diminish the reputation of their already-embattled profession.

5B's nursing staff created and circulated knowledge that was intrinsically political. In the process of promulgating the San Francisco model of AIDS care, they advocated for a wide range of progressive causes, and forced ethical conversations that the conservative nursing establishment had long overlooked. This chapter is organized into four sections. The first examines the status quo ante in the nursing profession, a status quo the San Francisco model of AIDS care and its advocates sought to disrupt. The second section discusses the model, and the nurses themselves, as research subjects. The third section interrogates the ways 5B's nurses promulgated their care modality. The final section examines the mixed results these efforts yielded, and once again underscores the extent to which the SF model of AIDS care was (and is) socially and politically contingent.

AIDS (Non)Coverage in the *American Journal of Nursing*

One can only understand the intellectual labor performed by 5B's nursing staff as radical when juxtaposed with the institutional response to AIDS that it challenged. Having already examined the atmosphere of prejudice that necessitated a dedicated ward at SFGH, we will now interrogate the representation of AIDS and AIDS nursing in the *American Journal of Nursing* (*AJN*). The *AJN*—the oldest and largest-circulating nursing journal in the world—published its first story on AIDS in November 1982, over a year after the virus entered medical consciousness, and shortly before Ward 5B opened at San Francisco General.

The authors of the article, Jeanne Allen and Grace Mellin, worked directly with PWAs in their capacity as staff nurses at St. Luke's Roosevelt Hospital Center in New York City; they were not members of the *AJN* staff. Allen and Mellin's article, "The New Epidemic: Immune Deficiency, Opportunistic Infections, and Kaposi's Sarcoma" was long by *AJN* standards: five pages. Substantial though it was, it was also the *only* major article to appear in the first three years of the epidemic. By the time the virus was next mentioned in the *AJN* over 25,000 people had died and another 590,000 were infected worldwide. The mainstream media's (and especially the *New York Times'*) failure to cover AIDS is a well-known facet of the early crisis; the *AJN*'s silence, however, has gone unremarked upon in the historical literature.[4]

Allen and Mellin's medical/surgical unit saw eleven people with AIDS between June 1981—when the virus first caught the attention of the Centers for Disease Control (CDC)—and November 1982. To give a sense of scale, by the end of 1981, there were 270 reported cases of AIDS, and 121 of those individuals had already died. Allen and Mellin were rare nurses, then, because they had not only cared for PWAs, they were sufficiently concerned about the condition to write up their experiences for the foremost journal in their

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[4] David W. Dunlap, "1983 | Having Claimed 558 Lives, AIDS Finally Made It to the Front Page," *The New York Times*, October 30, 2014, accessed June 24, 2017, https://www.nytimes.com/times-insider/2014/10/30/1983-having-claimed-558-lives-aids-finally-made-it-to-the-front-page/; "The AIDS Epidemic: 1981-1987," *The New York Times*, accessed June 24, 2017, https://partners.nytimes.com/library/national/science/aids/timeline80-87.html; "When Gay Journalists Were Closeted: A History of AIDS Coverage at 'The Times,'" *Columbia News*, November 23, 2015, accessed June 24, 2017, http://news.columbia.edu/content/when-gay-journalists-were-closeted-history-aids-coverage-times; Trevor Cullen, "HIV/AIDS: 20 Years of Press Coverage," *Australian Studies in Journalism* 12 (2013): 64-82; Cathy Cohen, *The Boundaries of Blackness: AIDS and the Breakdown of Black Politics* (Chicago: University of Chicago Press, 1999), 149-185.

discipline.[5] Their article had two primary goals: first, to share their knowledge of the disease with uninitiated nurses (read: most nurses in the early 1980s); and second, to relay their experiences treating PWAs. Their article demonstrates that the status and notoriety achieved by 5B's nursing staff were by no means a foregone conclusion. Medical institutions around the country (specifically in New York City and Los Angeles) were similarly inundated with PWAs, and trying to mount a streamlined response to the epidemic.

Allen and Mellin's attempts to forge the kind of interdepartmental coordination for which 5B later became famous reveal that, even at the new epidemic's epicenter, communication and education were limited.[6] They wrote that within their institution, "[T]here were separate outreach/support and immunologic research projects underway, each without knowledge of the other, although directed at the same patient population. Nursing information generated on our unit was poorly communicated to other units." [7] They added that, "When we called other hospitals about AIDS patients, no one seemed to know who the appropriate resource person was, or even who might direct us to that person. At one hospital where a conference had been held on AIDS, even those who might have been interested in participating seemed to know little about it."[8] San Francisco

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[5] "A Timeline of HIV and AIDS," accessed June 24, 2017, https://www.hiv.gov/hiv-basics/overview/history/hiv-and-aids-timeline.

[6] Jeanne Allen, and Grace Mellin, "The New Epidemic: Immune Deficiency Opportunistic Infections and Kaposi's Sarcoma," *American Journal of Nursing* 82, no. 11 (November 1982): 1721.

[7] Allen and Mellin, 1722.

[8] *Ibid*.

General had started addressing communication gaps of this sort even before 5B opened. (Assuming *AJN*, as a medical journal, has a comparatively short time-to-publication, Morrison was already serving as SFGH's Inpatient AIDS Coordinator at the time the article came out.)[9]

The two most illuminating portions of the article were an infographic documenting the case of Mr. N, and another infographic dedicated to patient Q&A. The former would have been many nurses' first exposure to the clinical course of the AIDS virus, and the trauma both patient and caregiver experienced during the process. Their case history is an accurate representation of best practices circa 1982—they responded to AIDS patients without prejudice, and in a manner consistent with their training. Juxtaposing Mr. N's case history with the policies Clifford Morrison was drafting (with the aid of his patients) for Ward 5B, however, demonstrates how significantly the San Francisco Model altered the landscape of AIDS nursing. "On January 7," they wrote, "Mr. N's chest x-ray showed almost complete whiteout of both lung fields, and he was transferred to ICU and put on a respirator. Mr. N was alert, oriented, and terrified about what was happening to him." The nurses responded to his fear by "[trying] to spend more time with him and make him as comfortable as possible. The nurses in ICU relaxed the visiting regulations and allowed his family and friends to be with Mr. N whenever possible."[10]

These notes—paired with the later revelation that Mr. N only died after "resuscitation from two respiratory arrests"[11]—indicate multiple ways that the 5B nursing

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[9] *Ibid*.

[10] *Ibid*.

[11] *Ibid*.

staff's approach to AIDS care was groundbreaking compared to those at other equally-besieged institutions. If the St. Luke's ICU nursing staff felt moved to relax visitation hours out of compassion for Mr. N, 5B nurses rejected the concept of visiting hours altogether… without bothering to ask hospital administrators for permission first. If nurses at St. Luke's encouraged families to decorate their loved ones' hospital rooms and bring home cooked food to stimulate patient's appetites, 5B encouraged the same from individuals and businesses in San Francisco's gay and lesbian community, arranging for patients to have catered brunches, bathrobes, and even the occasional pot brownie. If the nurses caring for Mr. N arranged a visit with a Catholic priest to help him come to terms with his impending death, 5B had Shanti counselors available on the ward at all times, and encouraged routine visits from religious leaders and community groups like the San Francisco Gay Men's Choir. If Mr. N's death was something out of a nightmare (in addition to being on a ventilator, it bears remembering that resuscitation efforts usually result in broken ribs) Ward 5B's nurses discussed the statistics around ventilator use with their patients upon arrival; as a result of those conversations, the vast majority of 5B patients waved code-blue status, preferring not to be resuscitated.[12]

It is crucially important to examine the absences in Allen and Millen's 1982 *American Journal of Nursing* article on AIDS, because those absences make the overtly-political nature of the 5B nurses' innovations all the clearer. At no point in the Allen and Millen article were fears of contagion discussed, except for a brief mention that no evidence existed to suggest healthcare workers were at risk of contracting the mystery disease. In

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[12] Randy Shilts, *And the Band Played On: Politics, People, and the AIDS Epidemic* (New York: St. Martin's Griffin, 2007), 355.

other words, where contagion was mentioned at all, it was framed as a workplace safety issue. The article did not detail the discrimination PWA patients faced in hospitals around the country.

The article was similarly circumspect regarding issues on which 5B's nurses were explicit: sex, death, and stigma. In their article Allen and Mellin noted the aggressive clinical course of the opportunistic infections experienced by PWAs, and the similarly grim fatality ratios for *pneumocystic carinii pneumonia* in both homo- and heterosexual men diagnosed with AIDS. For example, if non-AIDS-related KS had an average survival time of eight-to-thirteen years post-diagnosis, one study put the mean survival rate for U.S. cases at only fifteen months.[13] Three of the authors' eleven patients at St. Luke's had already died of PCP, and several were—at the time of writing—readmitted to the hospital with "progressively deteriorating conditions."[14] The infographic dedicated to patient Q&A, however, encouraged nurses to be cagey about questions of death and dying.

Instead of using "Am I going to die?" as a sample question, the nurses went with "Once I am diagnosed as having AIDS, will I always have it?" Instead of training nurse-readers to be frank about the high mortality rate associated with the condition, Allen and Mellin suggested telling patients that "… it is difficult to determine the long-term course of the disease. At this time, those with AIDS should be treated as if they were permanently immunodeficient."[15] This standard of care only partially addressed patients' psychosocial

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[13] Jeanne Allen and Grace Mellin, 1719.

[14] *Ibid*., 1721.

[15] *Ibid*., 1720.

needs, and could leave them and their loved ones in legal jeopardy regarding everything from final wishes to asset allocation.

Discussions of sex were similarly clinical, and lacked necessary cultural context. The uninitiated reader, for example, would be justifiably confused by their mention of the (now debunked) theory that amyl nitrites (popularly known as "poppers") contributed to AIDS. Allen and Mellin described the drug as commonly used by "young, sexually active homosexuals," but failed to articulate what the drug was, what it did, or why it was particularly popular in the gay male subculture.[16] (The drug was popular in the gay community because it allowed for faster relaxation of the anal sphincter, thereby reducing the need for foreplay and improving the orgasm of men engaging in casual anal sex.) Not only did the article fail to explain what poppers were or why patients might use them, it exclusively referred to the drug by its clinical name. Their patient Q&A made clear that nurses would be expected to offer counseling on safe sex practices, but Allen and Mellin's article failed to provide the background information essential to correctly perform that task.

The article also did not address the impact of homophobia on PWAs. While explicit about the demographics of the virus and its possible modes of transmission (including anal sex) the nurses failed to articulate the impact of being diagnosed with what the *New York Times* referred to earlier that same year as "Homosexuals' Precancer Syndrome."[17] In a

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[16] *Ibid*., 1719.

[17] Lawrence Altman, "Clue Found on Homosexuals' Precancer Syndrome," *The New York Times*, June 18, 1982, accessed June 24, 2017, http://www.nytimes.com/1982/06/18/us/clue-found-on-homosexuals-precancer-syndrome.html.

paragraph on assessing patients' emotional needs, for example, the nurses discuss a patient who, over the course of multiple hospital admissions, had grown increasingly accepting of his prognosis. The nurses wrote that he "had also accomplished the difficult task of informing family and friends about his illness and the possibility of his shortened life expectancy," adding that, "This patient found that he relied for his major support on a select group of his closest friends, rather than on relatives or an organized support system."[18] While there may be other reasons for the man's "finding," the reality of family rejection hangs heavy over the sentence.

A review of all AIDS articles published in the *American Journal of Nursing* between 1981 and 1984—in addition to revealing a disturbing lack of attention to the virus—suggests that Allen and Millen's abstraction of stigma, sex, and death may well have been an editorial decision. Indeed, their contribution was the most straightforward and comprehensive discussion of AIDS in the journal until September 1985. That article—a five-page "epidemiology update"—is conspicuous for its publication date: two months after Rock Hudson's AIDS diagnosis became public, one month before his death, and the same month that Ronald Reagan first publicly addressed the crisis.[19] The *American Journal of Nursing*, the longest-running and most widely-read publication in the profession, it seems, reflected the anxieties—and priorities—of the time. During the period from 1981 to 1985, when AIDS was popularly understood as a disease affecting persons outside the "general

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[18] 18. Jeanne Allen and Grace Mellin, 1722.

[19] 19. "A Timeline of HIV/AIDS."

population," the virus only received three other mentions in the journal.[20] By the end of 1984 there had been 7,239 cases of AIDS reported, and 5,596 deaths, but only one *AJN* article had described what the virus was, and how to care for its sufferers.[21] Instead, the *AJN* articles demonstrate a preoccupation with occupational safety. For the above to comprise all the coverage the *American Journal of Nursing* gave to HIV/AIDS in the first three years of the crisis speaks to the conservativism 5B's nurses (and their allies) fought against in the profession writ large, and the reasons so many members of the nursing staff took on the additional labor of publishing, speaking, and teaching while working on the unit. It also goes a long way to explaining why they were so cavalier about their *own* occupational safety.

While the *American Journal of Nursing*'s publication record is a powerful example of conservatism in the profession, it is by no means the only example. UCSF Nurse Educator Angie Lewis offered the San Francisco AIDS Oral History Project an anecdote from the time she and "AIDS Poster Boy" Bobbi Campbell presented on AIDS at a meeting of the American Nursing Association. She said that the two nurses (both of whom were involved with, but did not directly serve on, 5B) submitted a proposal, and did not hear back. "We assumed that nothing was going to happen, and then got an invitation days before we were supposed to go," she said, "So it obviously was something that the ANA wasn't clear that

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[20] "Serum Marker May Identify Potential AIDS Victims," *American Journal of Nursing* 84, no. 2 (February 1984): 177; "Newscaps," *American Journal of Nursing* 84, no. 7 (July 1984): 944; "Newscaps," *American Journal of Nursing* 84, no. 12 (December 1984): 1535.

[21] "Thirty Years of HIV/AIDS: Snapshots of an Epidemic," The Foundation for AIDS Research, accessed April 3, 2017, http://www.amfar.org/thirty-years-of-hiv/aids-snapshots-of-an-epidemic/.

they wanted to do." Based on anonymous evaluations, the overall response to the pair's presentation was positive. There were, however, a few audience members who were upset that "the ANA invited queers."[22] AIDS was clearly a fraught topic in the nursing community, one that both professional journals and professional associations struggled to address, when they addressed it at all.

Establishing Proof of Concept

The caregiving that took place on Ward 5B was unconventional, but it still needed to meet certain quantitative metrics of success if the model—and the nurses who authored it—were to secure their position as the leading authorities on AIDS care. The hospital's internal research into cost effectiveness and length-of stay was compelling from the first, but by 1987, when the National Public Health and Hospital Institute conducted a national survey of 623 acute-care hospitals treating PWAs, the results were definitive: San Francisco General Hospital had the strongest inpatient AIDS program in the country. The average PWA spent twenty-six days in the hospital in a given year, with each individual stay averaging about seventeen days, by 1987 5B patients' average length of stay was twelve days.[23] SFGH and Johns Hopkins (which boasted the third AIDS ward in the country) were in a near dead-heat regarding cost-of-hospitalization, with the average 5B stay costing

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[22] 22. Angie Lewis, R.N., M.S. "Nurse Educator in the San Francisco AIDS Epidemic," an oral history conducted by Sally Smith Hughes in *The AIDS Epidemic in San Francisco: The Response of the Nursing Profession 1981-1984*, *Volume II*, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 1999. 129-130.

[23] 23. Eileen McCaffrey, "Setting Up an AIDS Unit: The Johns Hopkins Experience," *AIDS Patient Care* 1, no. 1 (June 1987): 6-8; Dennis P Andrulia et al, "The 1987 U.S. Hospital AIDS Survey," *Journal of the American Medical Association* 262, no. 6 (Aug 11, 1989): 784.

$9,204, compared to (an estimated) $8,560 at Hopkins. Meanwhile, Boston hospitals were averaging $14,289, and Los Angeles County hospitals a striking $21,000.[24]

5B's nurses also offered up their bodies for research. In a 1985 article in the *New England Journal of Medicine* (*NEJM*), Julie Gerberding, M.D., M.P.H—then an Assistant Professor at the University of California, San Francisco—shared the results of a prospective study of hospital staff at San Francisco General Hospital.[25] She had followed 160 individuals, including doctors, nurses, and laboratory workers; collectively, the group had attended to approximately 500 PWAs. Approximately one-third of the healthcare workers Gerberding followed reported needlestick injuries or skin contamination with infected blood between 1981 and 1985, with no resulting seroconversions.[26] Gerberding would continue studying healthcare workers well into the future, expanding her focus to include eight-hundred at The General alone.[27] Parallel studies by the World Health Organization (WHO) and Britain's Communicable Disease Surveillance Centre suggested that healthcare workers' risk of HIV (then referred to as human T cell lymphotrophic virus type three, or HTLV-III) transmission was exceedingly low.[28]

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[24] McCaffrey, 7.

[25] J.L. Gerberding et al, "Transmission of Hepatitis B Without Transmission of AIDS by Accidental Needlestick," *New England Journal of Medicine* 312, no. 1 (1985): 56.

[26] Alasdair Geddes, "Risk of Aids to Health Care Workers," *British Medical Journal* 292, no. 6522 (Mar. 15, 1986): 711-712.

[27] Carol Pogash, *As Real as It Gets: The Life of a Hospital at the Center of the AIDS Epidemic* (New York: Plume Publishing Corporation, 1992), 45.

[28] There were a few reports/studies that suggested healthcare workers may have been infected on the job, but in most cases the nurse in question was also a homosexual man who had engaged in unprotected anal sex. Therefore, while there was some evidence to suggest a risk of HIV infection by accidental needlestick, room remained for doubt.

One imagines 5B's nursing staff was especially thankful for this news, because from the very beginning of the epidemic, they combatted AIDSphobia within the medical profession through practice. They did not have a needlestick prevention protocol in place, nor did they use gloves when interacting with their patients. As 5B nurse Diane Jones put it, "We were basically role modeling one way of relating to the patients, which was to go in without any kind of precautions."[29] The nurses were fully aware that the virus was blood-borne, but they were also emboldened by a combination of denial, political zeal, and good fortune. That good fortune came to an end in 1987, when a nurse at San Francisco General Hospital—to this day known only as Jane Doe—contracted the virus. Diane Jones and the rest of the 5B staff finally had to confront the potentially-deadly extent to which their politics had clouded their judgement. "We were very adamant that we were going to prove to people that it was safe taking care of people with AIDS," she told an interviewer, adding, "I had eight, nine, ten needlesticks. Any one of those could have resulted in a seroconversion, but the climate or the environment was such that they were downplayed. Any needlestick that people had was more a confirmation that this was not transmitted casually, and it wasn't a risk to health care workers."[30]

Alasdair Geddes, 711-712; "Needlestick Transmission of HTLV3 from a Patient Infected in Africa," Lancet, no. 2 (1984): 1376-1377; Communicable Disease Surveillance Centre, The Communicable Disease Report, (Dec 27, 1985).

[29] Diane Jones, R.N., "First Wave of the Nursing Staff on the AIDS Ward, San Francisco General Hospital," oral history conducted by Sally Smith Hughes, in *The AIDS Epidemic in San Francisco: The Response of the Nursing Profession, 1981-1984*, *Volume III*, 19.

[30] Jones oral history, 20.

As the Jane Doe (and other) seroconversion cases emerged, 5B's nursing staff shifted their approach to infection control. They adopted hepatitis-B precautions, which meant gloving whenever they could potentially encounter bodily fluids (i.e. drawing blood inserting IVs, and toileting).[31] The modification did not, however, mean the end of intimate caregiving by nurses, counselors, and volunteers on 5B—those practices, like the rest of the San Francisco model, withstood scrutiny from outside researchers.

By the late 1980s and early 1990s researchers all over the country were writing up studies on the importance of AIDS nursing as a specialty.[32] C.L. Bennett, a health services researcher and AIDS clinician, authored multiple studies demonstrating that a hospital's

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[31] Hepatitis-B had been endemic in the gay community since the 1970s—approximately seventy-five percent of gay men in San Francisco had the virus. Approximately 200 healthcare workers died from the disease every year, which was significantly more infectious than HIV, with between five-and-ten percent of all exposures resulting in transmission. Because there was a vaccine for the disease, hep-B never provoked the kind of fear within the medical community that HIV/AIDS did. Still, the nurses would have known even before 5B opened that a disproportionate number of their patients would carry hepatitis-B, and, theoretically, should have instituted precautions at that time. Gary Stephen Carr, "Nurse Practitioner at the AIDS Clinic, San Francisco General Hospital," oral history conducted by Sally Smith Hughes, in *The AIDS Epidemic in San Francisco: The Response of the Nursing Profession, 1981-1984*, *Volume II*, 61; Donald I. Abrams, M.D., "The KS Clinic, Lymphadenopathy and AIDS-Related Complex, and the County Community Consortium," oral history conducted by Sally Smith Hughes in *The AIDS Epidemic in San Francisco: The Medical Response 1981-1984*, *Volume II*, 119; Andrew R. Moss, Ph.D., "AIDS Epidemiology: Investigating and Getting the Word Out," oral history conducted by Sally Smith Hughes in *The AIDS Epidemic in San Francisco: The Medical Response 1981-1984*, *Volume II*, 215; Pogash, *As Real as it Gets*, 46.

[32] For a larger sample of studies released during this period, see D. Rothman and E. Tynan, "Advantages and Disadvantages of Special Hospitals for Patients with HIV Infection," *New England Journal of Medicine* 323, no. 1 (1990): 764-768; B Christianson and Clifford Morrison, "AIDS-Designated Units or Scatter Beds: Which Is Better?" *Journal of the Association of Nurses in AIDS Care* 4, no. 1 (Jan-Mar 1993): 64-6; M.C. Fahs et al, "The Inpatient AIDS Unit: A Preliminary Empirical Investigation of Access, Economic, and Outcome Issues," *American Journal of Public Health* 82, no. 4 (1991): 29-39.

"AIDS experience" was the *single most important factor* determining whether a PWA survived their first hospitalization for *pneumocystis*. Indeed, one was more than three-and-a-half times more likely to die in a low-familiarity hospital than in a hospital like SFGH.[33] In the mid-1990s Linda H. Aiken et al published a study in *Medical Care* that found AIDS patients housed on dedicated units were significantly more satisfied with their nursing care; further, her study found "no evidence that patients feel isolated or stigmatized on dedicated AIDS units compared with patients on general units, and many patients have a clear preference for dedicated units."[34] Indeed, Aiken found precisely the opposite, that patients on scattered-bed units were "*more* likely to perceive stress associated with impersonal or discriminatory treatment and were *more* likely to have feelings of abandonment, just the opposite of what had been predicted by many."[35] In another study, Aiken demonstrated that nurses working on special care units like 5B were less likely to experience burnout than nurses working with PWAs on scattered-bed units.[36] These studies found that AIDS wards were more egalitarian, had better amenities (thanks to community support), and did more to involve patients and advocates in medical decision-making. Aiken hypothesized that the striking similarity in patient satisfaction with

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[33] Sheila Hutman, "Choosing the Best Hospital for AIDS Care: Experience Seems to Be Important," *AIDS Patient Care* 5, no. 1 (Feb 1991): 6.

[34] Linda H. Aiken et al, "Satisfaction with Inpatient Acquired Immunodeficiency Syndrome Care: A National Comparison of Dedicated and Scattered-Bed Units," *Medical Care* 35, no. 9 (Sept 1997): 948.

[35] Aiken et al, "Satisfaction with Inpatient Acquired Immunodeficiency Syndrome Care," 950.

[36] Linda H. Aiken and Douglas M. Sloane, "Effects of Organizations Innovations in AIDS Care on Burnout Among Urban Hospital Nurses," *Work and Occupations* 24, no. 4 (Nov. 1997): 453-477.

dedicated units around the country was "probably because of the strong influence of the model unit at San Francisco General Hospital in the design of subsequently developed units around the country."[37]

Quality of care was not the only area where dedicated units were distinguishing themselves; researchers also found that they elevated the status of nurses. Historically, nurses rarely had the opportunity to specialize—that was the province of doctors. In a hospital environment, researchers wrote, "the specialization of physicians and The Generalized responsibilities of nurses reinforce the professional dominance of the former over the latter."[38] Specializing in HIV/AIDS offered nurses the opportunity to demonstrate their competence and exercise greater autonomy in patient care. After all, AIDS was a caring disease; PWAs had a unique constellation of needs that "nurses are characteristically and in many respects, singularly educated to provide."[39] As a faculty member at New York University's AIDS Mental Health Program put it: "While anybody can wipe a dirty bottom, a nurse sees the relationship between the disease process and the fact that a patient is putting out copious diarrhea."[40] She elaborated on this point, saying that "If the patient is being fed by a tube, maybe he isn't tolerating the formulation. The diarrhea might signify a

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[37] Aiken et al, "Satisfaction with Inpatient Acquired Immunodeficiency Syndrome Care," 950.

[38] Linda H. Aiken and Douglas M. Sloane, "Effects of Specialization and Differentiation on the Status of Nurses: The Case of AIDS," *Journal of Health and Social Behavior* 38, no. 3 (Sept. 1997): 207.

[39] *Ibid*.

[40] Kristin White, "AIDS and the Nursing Profession: Speaking Out on Shortage and Care Issues," *AIDS Patient Care* 3, no. 4 (August 1989): 16.

new infection. Maybe the skin on the patient's backside is beginning to deteriorate. The nurse would remind him not to spend all his time lying on his back."[41] She also called attention to the nurses' psychosocial training, another element of their training that distinguished them from non- and para-professionals: "If someone is visiting, the nurse would sense the dynamic between them, and if there seemed to be a problem, the nurse might consider contacting the social worker."[42] Dedicated AIDS units were not just good policy. They also made nurses' value manifest in a moment when the profession was under political and economic strain.

Important as research and professional accolades were for establishing them as the foremost authorities on AIDS care, 5B's nurses did not wait for external validation to start promoting the San Francisco model, and the re-envisioning of the nursing profession that it required.

Promulgating the SF Model

In May 1984, *Oncology Nursing Forum* (*ONF*) published the first-ever journal article on Ward 5B, for which Clifford Morrison served as third author. The other two authors, Carol S. Viele and Marilyn J. Dodd, worked at the University of California, San Francisco—Viele in oncology and Dodd in psychological nursing. 5B had been operational for less than ten months at the time of publication. It is no coincidence that Clifford and his coauthors published "Caring for Acquired Immune Deficiency Syndrome Patients" in the journal of the

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[41] *Ibid*.

[42] *Ibid*.

Oncology Nursing Society. Oncology nurses specialized in palliative care, embraced the hospice model, and were comfortable talking to patients about death—the journals readers, by and large, would have had the kind of care background Morrison recruited for on 5B. It is also worth noting that *Kaposi Sarcoma*—one of the most common opportunistic infections contracted by PWAs—is a viral cancer that manifests plaques on the skins as the disease progresses. That meant oncology nurses were often the first caregivers to see AIDS patients as the virus spread around the country. Instead of going to the *American Journal of Nursing*, the authors of the study submitted their first article to a publication that was more likely to be supportive, both of the ward and of the principles upon which it was built.

The six-page article was essentially a how-to guide for nurses who might want to replicate Ward 5B in other hospitals; this required foregrounding the same politically-charged issues that the *AJN* article obscured. Morrison et al described that "Fears about Contagion of AIDS" and "The Confounding Effect of Homophobia" made a dedicated unit necessary.[43] The authors provided vivid examples of the kinds of prejudice PWA patients experienced at the hands of SFGH staffers, and the logistical problems that came with having a single clinical nurse specialist (Morrison, in his pre-5B capacity) attending to all their needs. They wrote that 5B would have been even more successful in its first months had the nurses better educated their peers in other departments about the virus in advance of opening the ward. They also wrote about encountering stigma-by-association—discrimination against 5B nurses borne of their contact with PWAs.[44] This stigma

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[43] Carol Viele et al, "Caring for Acquired Immune Deficiency Syndrome Patients," *Oncology Nursing Forum* 11, no. 3 (May/June): 58.

[44] The use of "they" here is somewhat misleading. While written by three authors, the article is essentially a summary Morrison's experience as Clinical Coordinator of 5B.

manifested in several ways, from refusing to touch or be in the same room with AIDS nurses to questioning the orientation of heterosexual individuals working on the unit.[45]

Within three years of the *ONF* article, AIDS nursing had its own journal. *AIDS Patient Care* released its first volume in 1987; the *Journal of the Association of Nurses in AIDS Care* (*JANAC*) followed in 1989. That was also when the first textbooks on AIDS and AIDS nursing began to appear, and when the University of California, San Francisco became the first American institution of higher education to offer graduate nursing courses on AIDS.[46] Ward 5B's nurses made sure to contribute to all the different emerging academic fora for discussing PWA care, maintaining their authority status as AIDS nursing transitioned from a specialty into a discipline.

In 1987, Jerry D. Durham, R.N., Ph.D., and Felissa Lashley Cohen, R.N., Ph.D., published an edited volume called *The Person with AIDS: Nursing Perspectives*. It was the first textbook on AIDS nursing. There were twelve contributors, three of whom were members of the Ward 5B nursing staff: Clifford Morrison, the founder and nurse coordinator of the ward; Allison Moed, who started as a 5B staff nurse and later became the head nurse; and William J. Nelson, a founding member of the 5B team, and staff nurse educator. They contributed three chapters (forty-two pages total) to *The Person with AIDS*. Their contributions were explicitly political, and called—sometimes implicitly, and sometimes explicitly—for radical change in the nursing profession and healthcare writ large. Though they are all interesting in their own rights, for our purposes, William (Bill)

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[45] Viele et al, 59.

[46] Peter J. Ungvarsky, "The Past 20 Years of AIDS Through the Eyes of One Nurse," *American Journal of Nursing* 101, no. 6 (June 2001): 28.

Nelson's chapter—which addresses multiple different taboo topics—is the most instructive.

Nelson's "Nursing Care of Acutely Ill Persons with AIDS" provided a general overview of the challenges one could expect to face when caring for PWAs. The enumerated issues ranged from infection control procedures and pain management, to common respiratory and gastrointestinal complications, to skin care for bedbound patients. In theory, all nurses would (through their nursing school training) have been equipped to handle these issues in isolation—they would not, however, have seen all these issues coincident in a single patient, much less in a patient population. Nelson also shared hard-won insights born of years spent troubleshooting complications idiosyncratic to PWAs on 5B.

Nelson foregrounded psychosocial issues PWAs faced—focusing specifically on the impact prejudice had on the nurse-patient relationship. He wrote that, "The nurse should provide an atmosphere of individual acceptance for the patient. This means putting aside one's personal feelings or prejudices about the patient's life-style or background." He added that "Because of the nurse's intimate contact with the patient, the person with AIDS quickly discovers if the nurse is bringing his or her own agenda to the bedside. Since the nurse will often become the confidante of the patient, it is important not to betray that trust relationship."[47] To be clear, Nelson stopped just short of calling prejudice an abnegation of one's nursing duty. If nurses' personal "agendas" were legible to the patient, after all, it risked the trust relationship that is at the heart of patient-centered care. Putting

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[47] William Nelson, "Nursing Care of Acutely Ill Persons with AIDS," *The Person with AIDS: Nursing Perspectives*, ed. Jerry Durham and Felissa Cohen (New York, NY: Springer Publishing Company, 1987), 97.

one's feelings to the side, it seems, only does so much, especially considering the other skills Bill Nelson directed nurses to build. Nelson also addressed many of the taboo subjects like resuscitation, safe sexual practice counseling, and legal issues.

Regarding code blue status, Nelson stated outright that nurses should expect to take a more significant role in conversations around death than they might usually be expected to in a hospital setting. In addition to initiating the conversation about resuscitation and checking to ensure the patient fully understands his or her options, Nelson also suggested that one have a nurse from the hospitals' intensive care unit speak with the patient about what it would be like to live (and die) in the Intensive Care Unit (ICU). He advocated that nurses coordinate with members of the patient's psychosocial and religious support system, so that their life and death decisions could be made with input, and, hopefully, a degree of confidence. Nelson argued that nurses were the individuals with the best insight into when or if a conversation about code blue status may need to be re-evaluated, and, accordingly, should be responsible for communicating that information to all other members of the care team.[48] Far from avoiding discussions of death, then, Nelson positioned nurses as the hub through which all discussions of death should flow.

"Nursing Care of the Acutely Ill Person with AIDS" also included a brief discussion of the legal concerns many patients had upon admittance to the hospital—another area in which nurses likely had limited training or responsibility, but which, he argued, became vital on a ward populated by the dying. His primary directive to his peers was to secure all the necessary legal resources to ensure patients could craft wills and designate a Durable

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48. Nelson, 105.

Power of Attorney upon hospital admittance. Proper PWA nursing, he suggested, required one understand, anticipate, and, wherever possible, circumvent the political and social injustices that their patients would likely experience.

Holistic patient advocacy also meant advocating for patients' rights to sexual pleasure. "Sexuality is a vital part of the human experience," Nelson wrote, adding that "Just as there is sexual functioning for a man or woman after a myocardial infarction, there is sex after an AIDS diagnosis."[49] As would be the case for anybody else recovering from a serious accident or illness, he suggested that, "Of necessity, the sex must be different, but it can be erotic. The patient can still enjoy a sexually fulfilling life through alternative practices." [50] Nelson wrote that patients should be encouraged to verbalize their fears about sexuality to their nurses, be they physical, emotional, or moral. "The nurse should become comfortable with discussions about sex," he wrote, "since it is often as vital to the patient's future as anything done at the bedside."[51] Not only did Nelson advocate sex positivity regardless of lifestyle, he also offered concrete, medically-based justifications for modifying risky sexual behavior, writing that "The nurse should explain that some bodily excretions and areas need to be avoided. The reasons for this avoidance stem from the potential for disease for the person with AIDS and cross-contamination for their significant other." [52] He also,

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[49] *Ibid.*, 106.

[50] *Ibid.*, 107.

[51] *Ibid.*, 107.

[52] *Ibid.*, 107.

crucially, wrote that "*In any case, if the patient is in a primary relationship it's important that this relationship be affirmed in whatever ways possible*."[53] [emphasis added]

To a contemporary reader, the above instructions might not seem particularly radical, but in the late 1980s, explicit conversations about patients' erotic lives—both their modification and preservation—fell far outside the norm. It is worth remembering that, during this time, homosexual sex was not only taboo; in many places, it was illegal. There was also no sign that sodomy laws would change. The year before the publication of *The Person with AIDS: Nursing Perspectives*, *Bowers v. Hardwick* saw the Supreme Court uphold the constitutionality of a Georgia state law that criminalized oral and anal intercourse. The law applied equally to homosexual and heterosexual sex, but the concurring opinion written by Chief Justice Warren E. Burger, which stated that "To hold that the act of homosexual sodomy is somehow protected as a fundamental right would be to cast aside millennia of moral teaching,"[54] demonstrated that the ruling had more to do with the sensibilities of the justices than with legal precedent. Sex-positive nursing—especially *gay* sex-positive nursing—was still the province of the profession's progressive fringes; Nelson's contribution to *The Person with AIDS* was, thus, a direct challenge to the conservative status quo.

5B's nurses were successful in promulgating the San Francisco model, but how successful were the over-forty hospitals that implemented the model between 1984 and 1988?

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[53] *Ibid.*, 107.

[54] "Bowers v. Hardwick," Legal Information Institute, accessed June 28, 2017, https://www.law.cornell.edu/supremecourt/text/478/186.

The San Francisco Model: Mileage May Vary

In the years following 5B's creation, forty similar units formed in other cities. Johns Hopkins Hospital in Baltimore, MD, and Mount Sinai Medical Center in New York City were two of them. These two facilities' experiences, as reported in *AIDS Patient Care*, demonstrate that the care paradigm 5B's nurses advocated relied on the political support of healthcare providers, local government, and the public.

Johns Hopkins nine-bed special care unit for PWAs was the third such unit to open in the United States. The hospital housed an average of fifteen-to-twenty AIDS patients a day, the vast majority of whom were enrolled in clinical trials; at the time of the *AIDS Patient Care* article, JHU planned to add thirteen more beds to the unit, which (given the number of patients on study protocols) was located in the Clinical Research Center. Using a space that already held most of the hospitals' PWAs obviated the need for extensive staff recruitment—the only start-up expense was hiring a few more nurses for the interdisciplinary team. Like Ward 5B, the JHU unit was comprised of rotating attending physicians and a permanent nursing and psychological staff. John Hopkins' AIDS unit reported cost and length-of-stay statistics comparable to 5B within sixteen months of opening. Their patients were more satisfied, too. Per unit director John Bartlett, M.D., "Before I had the unit I'd get a call about an incident [of differential treatment] once a day."[55]

What did San Francisco General have that Johns Hopkins Hospital lacked? Long-term placement options. At the time, there were no inpatient hospice facilities in the state

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[55] McCaffrey, 6-7.

of Maryland, which meant the primary next step for JHU patients post-discharge was a nursing home. According to the ward's social worker, Gloria Fairhead, she was only able to place nine of the forty patients that needed long-term care; lacking other options, between ten and twelve patients died at the hospital. There was not nearly the same political support for AIDS work in Baltimore. Even if there had been comparable support, Hopkins' status as a private hospital meant it likely would not receive the same kind of government support SFGH did. (Of course, as a large research center, Hopkins had significant resources at its disposal; by 1987 the facility boasted $40 million for basic and clinical AIDS research.)[56] The epidemic also presented differently in Baltimore than it did in San Francisco. There, approximately 60 percent of the PWA population was gay; another 20 percent were IV drug users. The epidemic was also much smaller in Baltimore, which meant the city could rely more heavily on hospitals to provide AIDS Care; in 1987, only about 250 PWAs had been hospitalized at Hopkins, and the outpatient clinic was following 700 people. In San Francisco, where 18,000 people were living with AIDS, a much more robust public infrastructure was necessary.[57]

While Baltimore counted its AIDS patients in the hundreds, New York City had the largest PWA population in the world, to which both the local government and the public responded with antagonism. Efforts to develop nursing homes, drug-treatment facilities, housing, and ambulatory-care programs for PWAs in New York City neighborhoods were met with violence. Political researchers reported that the atmosphere toward PWAs was so

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[56] *Ibid.*, 8.

[57] *Ibid.*, 7-8.

unwelcoming, that direct action organizations responding to AIDS accused the health department of dropping its estimated number of HIV-infected New Yorkers from 400,000 to 200,000 citizens, "just to decrease the allocation of resources for combating AIDS."[58]

The San Francisco model of AIDS care placed primary responsibility for PWAs in the community, something New York City lacked the infrastructure and political will to pursue. As was the case at Johns Hopkins' Hospital, many New York City PWAs remained hospitalized for lack of discharge placement; in NYC, though, the scale of this problem was far greater. In a 1989 article in *Daedalus*, Aran Ron and David E. Rogers reported that the city needed approximately 1,000 nursing-home beds to care for all the PWAs that needed them; unfortunately, none of the cities' voluntary nursing homes accepted PWAs. The result: there were forty-four beds available to PWAs in the whole of New York City. The city's more-diverse patient demography also meant that infrastructure needs existed that the San Francisco model of AIDS care did not address. The New York metropolitan area had more children and babies with AIDS than any other part of the country: 141 (compared to 209 in the rest of the country combined), many of whom were either orphaned or abandoned.[59] These children often spent months—sometimes years—in the hospital, for want of a foster home or residential facility.[60]

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58. Aran Ron and David E. Rogers, "AIDS in the United States: Patient Care and Politics," *Daedalus* 118, no. 2 (Spring 1989): 51.

59. Margaret C. Heagarty, "AIDS: A View From the Trenches," *Issues in Science and Technology* 3, no. 2 (Winter 1987): 113.

60. Aran Ron and David E. Rogers, 53.

It was in this grim setting that, in 1987, Mount Sinai Medical Center opened its "AIDS Cluster": an eight-bed AIDS unit staffed by two senior clinical nurses, five nurses' aids, and "a variety of consulting specialists."[61] Unlike 5B, where every patient had a private room, four patients were confined to a single room. At the time Mia Oberlink wrote about the unit for *AIDS Patient Care* in 1988, the staff planned to add five more beds, but was struggling to hire more nurses. Mount Sinai was experiencing a nursing shortage—as were many hospitals around the country—and the AIDS unit was not a desirable work environment. As one nurse put it, "[I]t is more difficult to recruit nurses in New York City than in San Francisco to work with AIDS patients because there is a larger IVDA [IV Drug-Addicted] population here and they stay in the hospital longer."[62] She continued, "San Francisco nurses get more satisfaction out of their patient loads. But here, where we have more patients than they do and keep them longer, there tends to be less satisfaction."[63]

For all the problems Mount Sinai faced, the ward was still an improvement for AIDS Care at the hospital. Patient confidentiality improved, care was more individualized thanks to more extensive discharge planning and patient education efforts, and an AIDS clinical specialist (a la Clifford Morrison) ensured that any PWAs the ward could not accommodate received high-quality care. Not only did ward staffers undergo a three-month educational intensive on HIV/AIDS, an interdisciplinary team called the AIDS Education Task Force provided inservices on the virus for the entire hospital. Mount Sinai's Narcotics

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[61] Mia Oberlink, "The AIDS Cluster: New York's Mount Sinai Establishes Inpatient Unit," *AIDS Patient Care* 2, no. 2 (April 1988): 26.

[62] *Ibid*., 26-27.

[63] *Ibid*., 26-27.

Rehabilitation Center and Regional Comprehensive Hemophilia Diagnostic and Treatment Center also provided crucial services to PWAs. Length-of-stay and cost-of-care were high, and the units' nurses frustrated and overextended, but the AIDS Cluster was still a better option for PWAs than what was on offer in most NYC metropolitan hospitals.[64]

While several elements of the 5B's patient-care paradigm proved non-transferable outside the city's political context, care disparity issues seemed to follow the model around the country. In 1999, a national review of dedicated AIDS units around the country revealed that—if patient satisfaction was substantially higher in segregated units than it was on scatter-bed units—both AIDS care and patient satisfaction had a lot to do with identity. Statistics showed that, across the country, minorities, women, and geriatric patients were less likely to end up on an AIDS ward. There are several benign explanations for this trend. The U.S. gay community was more educated about (and involved in community efforts addressing) the epidemic.[65] Moreover, as Aiken et al hypothesized in "Organization and Outcomes of Inpatient AIDS Care," heterosexual and older patients (of all sexual identities) "could be more concerned about the potentially stigmatizing nature of being cared for on a unit labelled as an AIDS unit."[66] In other words, many of the same problems with AIDS care existed across the United States.

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[64] For more information see Kristin White, "AIDS and the Nursing Profession: Speaking Out on Shortage and Care Issues."

[65] Aiken et al, "Organization and Outcomes of Inpatient AIDS Care," 770.

[66] *Ibid*.

In 1998, long after Clifford Morrison left 5B, he contributed an editorial to the *Journal of the Association of Nurses in AIDS Care* called “HIV/AIDS Units: Is there still a need?” The article came out in the aftermath of combination anti-retroviral therapy, which had, within a couple of years, “moved us towards the goal of dealing with HIV as a manageable chronic condition.”[67] Inpatient censuses were down around the country, leading healthcare providers to wonder if dedicated units had outlived their usefulness. As Morrison noted in the article “[I]t has always been the goal to close these units.”[68] Had the time finally arrived, after nearly two decades, to reintegrate PWAs onto general wards? Morrison did not think so. He made strong practical arguments against “mainstreaming” people with HIV and AIDS, but his discussion of culture was more compelling. “We still hear reports of jealousy and perceived favoritism toward AIDS specialty units by providers in other areas,” he wrote, adding “There continues to be resentment toward the patients, the kinds of specialized services that have developed and the perception of this new subspecialty and the patients, as well as the staff, as being in some way elites...”[69] The irony not being lost on him, Morrison noted that “[T]his is a very interesting contradiction when you review the issues and reasons for establishing the units to begin with.”[70]

The perceived favoritism toward HIV-positive patients that Morrison described was still more irrational because the demographics of HIV/AIDS had changed considerably

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[67] *Ibid*.

[68] Clifford Morrison, “HIV/AIDS Units: Is There Still A Need?” *Journal of the Association of Nurses in AIDS Care* 9, no. 6 (December 1998): 17.

[69] *Ibid*.

[70] *Ibid*.

since 1981.[71] The changing face of the virus was the result of a disproportionate public-health focus on gay white men of (generally) higher socioeconomic status in the early years of the crisis. The same year Morrison wrote his *JANAC* article, UNAIDS reported that the virus was most prevalent in underprivileged communities, especially communities of color. African Americans were eight times more likely than whites to have HIV, despite constituting only thirteen percent of the population; AIDS was the number-one killer of black men aged twenty-five to forty-four, and the number-two killer of women.[72] HIV and AIDS nurses may have been perceived as elite by the rest of the medical establishment, but the poz and PWA patients they served were far from it.

While some elements of AIDS work were changing, Morrison made clear that both AIDSphobia and homophobia still created care disparities for PWAs in many American medical facilities. Morrison wrote that nearly twenty years into the epidemic, he still heard "alarming stories of patients encountering prejudice, judgements on lifestyles, and a basic lack of knowledge and understanding, by professional providers, related to the care and treatment of HIV disease in areas [without] specialty services."[73] For better and worse, AIDS wards remained the hub for everything from education and case management to community support programs (in the hospitals that had them). Effective though they were,

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[71] 71. Cathy J. Cohen, *The Boundaries of Blackness: AIDS and the Breakdown of Black Politics*, (Chicago: University Of Chicago Press), 1999; Jennifer Brier, *Infectious Ideas: U.S. Political Responses to the AIDS Crisis* (Chapel Hill: The University of North Carolina Press, 2011).

[72] 72. "AIDS Epidemic Update: December 1998," The Joint United Nations Programme on HIV/AIDS and the World Health Organization, December 1998, http://data.unaids.org/Publications/IRC-pub06/epiupdate98_en.pdf.

[73] 73. Morrison, "HIV/AIDS Units: Is There Still A Need?" 18.

the need for those hubs was no victory. As Morrison pointed out, "[T]hese are some of the very issues that we have been dealing with since the beginning of the epidemic."[74]

The ambivalence of Morrison's editorial reflected a larger tension. As the new millennium approached—despite the discovery of the antiretroviral cocktail, and its Lazarus-like effect on the PWA community—cultural perceptions of HIV/AIDS and homosexuality had largely stagnated. This became especially clear a month before Morrison's editorial came out, when pernicious homophobia overshadowed the gay community's recently-renewed hope. That was the month that two men lured twenty-one-year old University of Wyoming student Matthew Shepard into a car by "playing gay." They beat and tortured Shepard, tied his body to a fence, and left him to die. He was discovered 18 hours later, comatose, and rushed to Poudre Valley Hospital, where he died of his injuries six days later.[75] During his hospitalization, his family learned that Shepard had been HIV positive.[76] Shepard did not live long enough to see the benefit of the cocktail; he did not even live long enough to die in a specialty unit like 5B. Virulent homophobia struck him down before the virus could. Shepard's murder, one of the most famous anti-gay hate crimes of all time, was evidence of the extent to which homophobia—one of the cultural forces 5B's nursing staff worked so hard to counter, in speeches, in writing, and in their

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[74] *Ibid*.

[75] "Murder Charges Planned in Beating Death of Gay Student," CNN, Oct 12, 1998, https://web.archive.org/web/20060822005855/http://www.cnn.com/US/9810/12/wyoming.attack.03/index.html.

[76] "Magnificent New Book About Matthew Shepherd Astonishes," *Lavender Magazine*, Nov 19, 2009, http://www.lavendermagazine.com/uncategorized/magnificent-new-book-about-matthew-shepherd-astonishes-an-interview-with-judy-shepard/.

day-to-day lives—continued to structure American culture and society in the late 1990s.[77] The San Francisco model of AIDS care, and nurses behind it, played a defining role in creating the HIV/AIDS nursing as a discipline. As activists, 5B's nursing staff succeeded in many different ways; the continuing need for their services, however, represented a failure of American political culture.

The intellectual labor 5B's nurses undertook yielded both successes and failures. The staff succeeded in demonstrating the efficacy of the dedicated-unit system generally, and the SF model specifically. While their policies regarding infection control ultimately proved imprudent, their larger argument—that the risk of seroconversion was minimal for healthcare workers—was borne out by the numerous, multi-year studies, for which they repeatedly opened their veins. The nurses built a model of care that, if actualized in diverse ways around the country, always led to the same basic outcomes: happier, healthier patients; lower costs; shorter length-of-stay statistics; and greater autonomy for the nursing staff. Despite these myriad victories, however, there were distinct limits to the cultural change they could create. Qualitative and quantitative evidence to the contrary notwithstanding, many members of the American public and the medical profession continued to believe that people living with AIDS were dangerous well into the 1990s. If tremendously effective in the San Francisco context, 5B's patient-care paradigm also did not map cleanly onto other urban hospitals, whose patient populations looked different, and faced a different constellation of structural inequalities and barriers to care. While they were not able to completely remake the healthcare system, AIDS care around the country

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[77] The Matthew Shepard Act—which extended federal hate crime legislation to include homosexual individuals, women, and people with disabilities—did not pass until October 2009, eleven years after Shepard's murder.

nevertheless improved for the 5B nurses' efforts. They defined the contours of a new discipline, and established the San Francisco model of AIDS care as the standard against which all other care-paradigms would be measured. That the city is now on the verge of ending its AIDS epidemic is in large part a result of the intellectual groundwork laid on ward 5B in the 1980s and 1990s.

CONCLUSION

The nurses who founded and staffed Ward 5B of the San Francisco General Hospital have earned a prominent place in the history of radical HIV/AIDS activism. The San Francisco model of AIDS Care was a fundamentally political project, built around a vision of queer, feminist reform of healthcare and the nursing profession. The men and women who volunteered to staff the ward—many of whom were involved in social movement politics long before becoming involved with the virus—brought their clinical experiences and activist perspectives to the construction of the ward. Their day to day labor was a physical refutation of homophobia and AIDSphobia. It was also a provocation, a call to action directed at both fellow healthcare professionals and the public.

5B's nursing staff recognized that the best patient care modality would allow PWAs (a stigmatized minority group if ever there was one) to determine not just the course of their treatment, but also the policies and ethos of the ward. They understood that AIDS was as much a social disease as it was a scourge, that prejudice and irrational fears of contagion directly impacted their patients' psychosocial states, and, in turn, their broader health outcomes. Since getting PWAs out of the hospital and back into their community for as long as possible was the best outcome 5B's nurses could hope for, caring for their patients also meant preparing the city of San Francisco to accommodate the needs of this new population. By encouraging community presence on and support for the special care unit, 5B's nursing staff educated and engaged the public, and built a support system for their patients outside of the hospital walls that has only become more effective over time.

5B's nurses also did important work to transform their profession. They authored textbooks and journal articles with explicitly political bents. They gave talks and conducted training programs around the country. They represented themselves as nurses in the city's gay pride parade. Many became nurse educators. They (and other healthcare providers at SFGH) submitted their bodies to research, hoping to prove their patients were not dangerous. They publicly challenged AIDSphobic healthcare providers in the hallways, in administrative offices, and in the media. The dividends of these efforts were undeniable: by 1989, there were forty urban hospitals with dedicated AIDS units, all of whom measured their success against 5B.[1] While the circumstances and metrics for success in the fight against AIDS are different today, the San Francisco model retains—and continues to augment—its reputation for excellence.

Some of the most potent political action of the early AIDS-rights movement took place in a state-funded medical institution. Before the AIDS Coalition to Unleash Power, there was San Francisco General Hospital Ward 5B. Before Larry Kramer, there was Clifford Morrison. The nursing staff of the special care unit became famous for their compassion long before ACT UP became famous for its anger. Decentering direct action and highlighting the role caring played in the AIDS Rights Movement does not just make the movement

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[1] Linda Aiken, Douglas Sloane, and Eileen Lake, "Satisfaction with Inpatient Acquired Immunodeficiency Syndrome Care: A National Comparison of Dedicated and Scattered-Bed Units," *Medical Care* 35, no. 9 (September, 1997): 951.

longer; it makes it richer, more diverse. Centering care expands the role women played in, and underscores the importance of "women's work" to, what has traditionally been understood as a social movement dominated by middle and upper-class white gay men. Elevating the significance of a radical politics of care does not—indeed it *cannot*—cheapen the transformative power of direct action advocacy groups like the AIDS Coalition to Unleash Power. To the contrary, adding a new dimension to the AIDS Rights Movement enriches all its constituent parts.

The story of Ward 5B matters. The nurses who staffed it were nothing less than healthcare pioneers. In opening the first dedicated AIDS unit, the nurses of Ward 5B took a big risk that yielded a still bigger reward. They also absorbed almost incomprehensible losses: this small cadre of volunteer nurses cared for over twenty-thousand patients over two decades, at least half of whom died on the ward. The nurses also made bold efforts to ensure their patients would never be forgotten. They submitted to oral histories and television interviews, and saved everything from news clippings, to patients' drawings, to the records of a disarmingly-robust debate over the best color for the ward's pride-parade t-shirts.

Still, they made mistakes along the way. And, in some instances, their efforts increased marginalization for entire groups of AIDS sufferers. PWA identity was artificially restricted throughout the eighties and early nineties—a result of a whole swathe of cultural prejudices and structural inequalities in healthcare. Accordingly, many doctors and public health officials in San Francisco thought of (or at least responded to) AIDS as a disease of gay white men. That meant the voices of women, people of color, and IVDUs, among others, often went unheard and unrecorded in the archive. Institutional and community support for PWAs would be dangerously contingent upon the demography of the sick, and even the nurses' most admirable actions had negative political consequences. Making 5B a hub of queer culture and community marginalized already underprivileged patients who did not fit the "AIDS patient" stereotype. Fighting for an all-R.N. ward while simultaneously elevating the role of untrained community members devalued the labor of L.V.N.s and other nurses' aides. The adversarial relationship between 5B nurses and those hospital staffers that questioned or refused to comply with AIDS policy sometimes bred racist discourse, a la the "Filipino death squad." And of course, that 5B mobilized the gay community to provide resources and services in lieu of federal assistance lent tacit legitimacy to the Reagan administration's vision of healthcare reform: to a certain extent, altruism worked. Sitting at a bedside can be as radical an act as marching in the streets, but that does not change the reality that people cannot be in two places at once, and that hours devoted to caregiving were hours taken away from other forms of political activism. Such tensions are both productive and instructive. The United States will experience an epidemic of this scope and scale again, and will encounter similar silences, similar political paradoxes. Historical research need not have utility to have value, but this project offers both.

That does not mean this case study is without its problems. Historians of HIV/AIDS often (and rightly) warn about the dangers of New York and San Francisco exceptionalism; one could argue that focusing on The San Francisco model of AIDS care reinforces that exceptionalism—and to a certain extent, it does.[2] Uncomfortable as it is to use the word

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[2] Elizabeth Clement, "AIDS and the Silent Majority," (keynote lecture, McMaster University Medical Humanities Program, Hamilton, Ontario, Canada, November 18, 2016); Stephen J. Inrig, *North Carolina and the Problem of AIDS: Advocacy, Politics, and Race in the South* (Chapel Hill: University of North Carolina Press, 2011).

"privilege" in reference to a city that lost tens of thousands of residents, the fact remains that caregivers in San Francisco enjoyed far greater state and public support for its response to AIDS than caregivers in any other city in the United States did. Ward 5B's nursing staff was never unique in their desire to give aid and comfort to the sick, and this dissertation should not be understood as suggesting otherwise. Future research will likely undermine—or at least contextualize—the monochromaticity of this history, which is especially apparent when juxtaposed with recent scholarship centering AIDS activists of color and the politics of the welfare state.[3]

There is also an unavoidable problem with the sources, namely, that the nature of the virus circumscribed patient narratives. Very few people who passed through 5B were well enough to tell their story, and still fewer of those individuals remain alive today. This projects' ability to access the patient experience is similarly constricted by the Health Insurance Portability and Accountability Act of 1996 (HIPAA), which restricts access to medical records. Expanding the research focus of the project to include more people and institutions involved with AIDS nursing will not address all of these lacunae. However, raising the historiographical profile of Ward 5B will only encourage the emergence of new sources and diverse perspectives.

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[3] Dan Royles, "'Don't We Die Too?'": The Political Culture of African American AIDS Activism" (PhD diss, Temple University, 2014); Emily K. Hobson, *Lavender and Red: Liberation and Solidarity in the Gay and Lesbian Left* (Berkeley: University of California Press, 2016). Also look forward to forthcoming dissertations by George Aumoithe (Columbia University) and Kevin McKenna (University of Washington).

In December of 1984, John Selby penned a letter to then-San Francisco Mayor Dianne Feinstein, relaying his experiences as a patient on San Francisco General Hospital Ward 5B, which was, at that time, about a year-and-a-half old. When he first arrived at the hospital—and received his *pneumocystis pneumonia* diagnosis—he was housed on a scattered-bed unit, Ward 4C. "Although I had several fine nurses there," he wrote, "I was overjoyed to become a part of this spirited community. This is a haven, and will need to be expanded most certainly."[4] Selby's letter went on to praise 5B's nurses and The Shanti Project counselors working on the ward.

The tone of Selby's letter was disarmingly positive given the circumstances that necessitated it. Despite having received a death sentence a week previous, he wrote that he was lucky. "I have started out in a good condition," he said, "with a powerful base of friends and family. I'm relieved not to have to worry about getting AIDS, since I have it. I'm on a spiritual high, and determined to keep my optimism and humor til the end. With these marvelous healers all about me, it should be easy."[5] Selby died two years later, in Pomona—the nurses memorialized the date and location of his passing in the 5B necrology.[6] He was hundreds of miles away at the time of his passing, but, when the time came to add his name to the book, 5B's nurses took care to include his old room number in the entry.

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[4] SFGH Scrapbook, Volume One, San Francisco General Hospital AIDS Ward 5B/5A Archives, 1983-2003 (SFH 12), San Francisco History Center, San Francisco Public Library.

[5] *Ibid*.

[6] *Ibid*.

The nurses of Ward 5B responded to the AIDS crisis by building a principled, "spirited community," a "haven" to welcome people like Selby at the end of their lives. The nurses not only provided a safe and supportive place for these individuals to die, they also offered the assurance that somebody would remember their *lives*, however short and painful they were. Through these and other intimate gestures, 5B's nursing staff made suffering from one of the most stigmatized diseases in human history more bearable. Their political work impacted tens of thousands of lives directly, and indirectly improved the experiences of still-more hospitalized PWAs around the world. Their efforts prove that caregivers were not ancillary to the AIDS Rights Movement; they were its heart.

EPILOGUE
"LOOK FOR THE HELPERS"

The physical space and character of San Francisco General Hospital has changed considerably in the thirty-four years since Ward 5B first opened its doors. By the late 1980s, SFGH was overcrowded, and its facilities were aging poorly. Constructed in the 1970s, with a few of the buildings dating back to 1915, The General did not meet the seismic standards required by California law.[1] Funding and redesigning the hospital took nearly thirty years. The past decade has been especially busy.

In 2008, San Francisco voters approved Proposition A, an $887 million bond to provide funding for the construction of a new building at San Francisco General.[2] Seven years later, Facebook CEO Mark Zuckerberg and his wife—pediatrician and former SFGH resident Dr. Priscilla Chan—announced that they would donate $75 million to complete the hospital. The hospital changed its name in acknowledgement of the gift, believed to be the largest-ever private gift by individuals to a US public hospital. The General is now known as the Zuckerberg San Francisco General Hospital and Trauma Center, Zuckerberg SFGH, or,

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1. The Loma Prieta earthquake of 1989 offered a tragic reminder of the importance of regularly maintaining or retrofitting all public safety facilities for maximum seismic integrity. SFGH was (and remains) the only level-one trauma center in San Francisco and Northern San Mateo County, and, accordingly, needed to not only withstand an earthquake, but to handle the serious injuries that would result from such a disaster. Victoria Colliver, "Zuckerberg, Wife Give $75 Million to S.F. Hospital," *SFGate*, February 6, 2015, http://www.sfgate.com/bayarea/article/Zuckerberg-wife-give-75-million-to-S-F-hospital-6065958.php.

In 1994, California Senate Bill 1953 (SB 1953) included amendments to the Hospital Seismic Safety Act (Alquist Act) of 1973. Ryan (Chris) Dunne, "San Francisco General Hospital Rebuild Planning: Utilization of Prior Space," Master's project, University of San Francisco, 2015, 3.

2. Colliver, "Zuckerberg, Wife Give $75 Million to S.F. Hospital."

sometimes, ZSFG.[3] A new, nine-story building on campus houses all acute care facilities, bringing the hospital in compliance with The Hospital Seismic Safety Act of 1973. The other buildings that comprise the hospital remain standing, and currently house outpatient services, administrative offices, and research facilities.[4] Those facilities will change soon, too. In 2017, the city approved construction of another new building at ZSFG, a $200 million academic and research facility that will be bankrolled by the University of California, San Francisco.[5] Upon completion, remaining hospital staff will vacate the structurally-unsound building that once housed Ward 5B, a facility remembered in oral histories for the graffiti in its elevators and desiccated vomit in its tunnels.[6]

San Francisco General Hospital looks very different today, and so does its famous AIDS program. Ward 5B no longer exists. The PWA patient population declined shortly after hitting its peak in 1994. The advent of combination anti-retroviral therapy emptied still more beds. The nurses filled those empty beds with cancer patients, whose needs closely mirrored those of PWAs. By the early 2000s only one-third of 5B patients were PWAs. Indeed, on the 2003 day that the ward celebrated its twentieth anniversary, it only

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[3] *Ibid.*

[4] Dunne, "San Francisco General Hospital Planning," 2; "Rebuilding Zuckerberg San Francisco General," San Francisco General Hospital Foundation, accessed April 4, 2017, https://sfghf.org/about/capital-campaign/rebuilding-zuckerberg-san-francisco-general/.

[5] Pete Farley, "UCSF Research Building at Zuckerberg San Francisco General Hospital Gets City Approval," University of California San Francisco, accessed June 22, 2017, https://www.ucsf.edu/news/2017/02/405696/ucsf-research-building-zuckerberg-san-francisco-general-hospital-gets-city.

[6] Paul A. Volberding, M.D., "Oncologist and Developer of the AIDS Clinic, San Francisco General," oral history conducted by Sally Smith Hughes in *The AIDS Epidemic in San Francisco: The Medical Response 1981-1984, Volume III,* 147.

held four AIDS patients. No longer a dedicated unit, the ward slowly faded away. Today, people with AIDS are treated in the new acute care and trauma facility, and are integrated with the rest of the patient population. By and large, poz and PWA individuals are able receive care on an outpatient basis, a powerful testament to the changing landscape of the epidemic in San Francisco, and growing acceptance of people living with the virus.

The outpatient clinic that preceded 5B, Ward 86, is still operational, and remains a cornerstone of the San Francisco model of AIDS care.[7] When it first opened, anybody displaying symptoms of AIDS could become a patient—today, all the ward's patients are uninsured or on public assistance. The clinic that once handed out death sentences by appointment now boasts a viral-load suppression rate of 84 percent, a shocking statistic considering only thirty-percent of HIV-positive Americans have achieved viral suppression nationwide.[8] While the stigma of AIDS persists to this day (albeit to a lesser extent), the lived reality of the virus in San Francisco, even for the economically-disadvantaged individuals who require Ward 86's services, is that of a manageable chronic condition.

5B nurse Diane Jones is the only member of the original 5B staff still working at SFGH. She moved to Ward 86 when 5B dissolved, and has retained local-celebrity status in the Bay Area. In total, she has spent nearly thirty years working with San Francisco General Hospital's poz and PWA patients; in that time, almost everything about her job, and about

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[7] Hospital maps now refer to the facility as the Positive Health Program.

[8] Donald G. McNeil, Jr., "San Francisco Is Changing Face of AIDS Treatment," *New York Times,* October 5, 2015, accessed June 22, 2017, https://www.nytimes.com/2015/10/06/health/ san-francisco-hiv-aids-treatment.html.

AIDS nursing, has changed.[9] As one newspaper reported, Ward 86 now serves as a drop-in clinic "where men and women as old as eighty two get help leading increasingly long lives. Doctors now pepper their patient exams with suggestions to open a retirement account, to keep their cholesterol levels in check, to plan for the future."[10] While many miss the *espirit de corps* and the queer, feminist environment that manifested on Ward 5B, its absence is, by all measures, a positive development for the city.

Challenges on the Horizon

For all of San Francisco General Hospital's successes, stigma (if less toxic than it was in the early years of the crisis) remains a problem. Many still discuss AIDS as if were a product of moral turpitude, thirty-six years later. According to Diane Jones, when she gives contemporary patients an HIV positive diagnosis, "[Their] first thought is that they're going to die, the second is that they can't tell anyone and the third, if they're a woman, is that they can't have children."[11] None of those assumptions are correct, but they are also understandable in a sociopolitical climate that continues to demonize the sick and the

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[9] Heather Knight, "AIDS/HIV Ward at S.F. General Has Come Long Way in 30 Years," *SFGate*, June 4, 2011, accessed June 22, 2017, http://www.sfgate.com/news/article/AIDS-HIV-ward-at-S-F-General-has-come-long-way-2369259.php.

This article contains a factual error that—while not hurting its legibility—is important to note. The author conflated inpatient and outpatient care, and, accordingly, wrote that Diane Jones worked on Ward 86 for three decades. In fact, she was part of the inaugural staff of Ward 5B, and later transitioned to Ward 86, which is now the only AIDS-focused wing of San Francisco General Hospital.

[10] *Ibid*.

[11] *Ibid.*

poor—in which patriarchy, racism, and homophobia remain central organizing principles of American society.

I am writing the conclusion to this dissertation at a pivotal moment in the AIDS Rights Movement. The 2016 election of Donald Trump—and, in turn, the ascension of anti-LGBTQ governor Michael Pence to the role of Vice President—has placed the poz community in jeopardy, both here and abroad. The Trump Administration intends to slash funding that is crucial to both HIV/AIDS research and maintaining the health and wellbeing of the United States' PWA community. The budget proposal for fiscal year 2018 includes decreasing the budget of the National Institutes of Health by $5.8 billion, a substantial decrease of approximately twenty percent.[12] The Administration has likewise proposed that the Centers for Disease Control institute a $500 million block grant program. This would give state governments—including states that discriminate against LGBTQIA persons, like Indiana—the ability to decide which emerging infectious diseases are worth fighting, and which are not.[13]

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[12] 12. Melissa Healy, "20% Cut to NIH Budget Would Leave Americans More Vulnerable to Cancer and Other Diseases, Experts Warn," *Los Angeles Times*, March 16, 2017, http://www.latimes.com/science/sciencenow/la-sci-sn-trump-budget-nih-20170316-story.html.

[13] 13. The block grant program is also misguided because it treats infectious disease as a local or state problem, which, of course, it is not. The illogic of a block grant program becomes still clearer when one examines the epidemiological track of the AIDS virus. In the early 1980s, the disease emerged and flourished in urban centers, specifically New York City, San Francisco, and Los Angeles. Today, HIV is a Southern disease. Despite having only twenty-eight percent of the total U.S. population, nine states in the Deep South account for nearly forty percent of national HIV diagnoses. Not only do these states have the highest diagnosis rates and the largest poz populations, they also have the lowest five-year survival rate. The combination of poverty, poor health care infrastructure and stigmatization is proving deadly for Southerners. Put simply, it does not make sense to ask impoverished states with poor healthcare infrastructure and an unsupportive population to take over control of research and treatment processes that have, until now, been the province of the

Equally unsupportable policy changes are being proposed at the international level. As the world leader in the fight against HIV/AIDS, the United States' trend toward isolationism and xenophobia may have consequences far beyond its borders. In addition to restructuring the CDC, the Trump administration recently proposed taking $300 million away from The U.S. President's Emergency Plan for AIDS Relief, commonly known by its acronym, PEPFAR. The initiative, created by George W. Bush in 2003, provides crucial support to HIV/AIDS prevention and treatment efforts around the globe, and particularly in Sub-Saharan Africa. Thanks to a leaked memo sent to the State Department by the Trump transition team, we know that the administration looks on PEPFAR as a "massive, international entitlement program" for African countries, which have been deemed security concerns.[14] The Trump Administration plans to treat PEPFAR like a business—not the humanitarian and global development program it is—as evidenced by their budget proposal's suggestion that "money could be saved by putting fewer new patients on HIV meds and by cutting funding to 'low-performing countries.'"[15]

The Trump administration's assault on HIV/AIDS funding is part and parcel of a larger conservative plan to repeal and replace the 2010 Affordable Care Act, commonly referred to as Obamacare. Many poz folks and PWAs rely on the ACA for their survival. The

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federal government. Ed Yong, "How a Pandemic Might Play Out Under Trump," *The Atlantic*, December 20, 2016, https://www.theatlantic.com/science/ archive/2016/12/outbreaks-trump-disease-epidemic-ebola/511127/; Susan Reif and Carolyn McAllaster, "Stigma and Poverty Make HIV/AIDS Deadlier in the Deep South," *New Republic*, April 22, 2015, https://newrepublic.com/article/121619/why-does-hivaids-kill-more-people-deep-south.

[14] "Will the Trump Administration Cut AIDS Funding to Africa?" *POZ*, January 17, 2017, https://www.poz.com/article/will-trump-administration-cut-aids-funding-africa.

[15] *Ibid.*

Republican debate around repealing and replacing Obamacare raises the equally devastating prospect of insurance companies again being able to deny coverage to people with pre-existing medical conditions, like HIV/AIDS. Entitlement programs like Medicaid—upon which many poz and PWA Americans rely—may also experience cuts.

Conservatives are not the only ones energized by the prospect of effecting a second dramatic shift in healthcare within the space of a decade. The same populist wave Donald Trump rode into the White House in 2016 made Vermont Senator (and Medicaid-for-all advocate) Bernie Sanders a superstar in American politics. The left-wing fight for universal healthcare has accordingly gained tremendous grassroots support. Sensing the changing political climate, high-ranking members of the Democratic Party are increasingly voicing support for single-payer health insurance. As was the case in the early 1980s, California nurses have distinguished themselves as leaders in the fight to remake the American healthcare system.

In March of 2017, the California Nurses Association (CNA)—with the cooperation of National Nurses United (NNU), the nation's largest union and professional association of registered nurses—became the lead sponsor of SB 562, the Healthy California Act. If signed into law, the bill would essentially provide single-payer healthcare to all Californians. The press releases around SB 562 echoed those from the early years of the AIDS crisis, with Executive director of both the CNA and the NNU, Roseann DeMoro, writing that "At a time of critical disarray of our national healthcare system, California can once again lead the nation."[16] At present, passing the Healthy California Act seems a task of Sisyphean

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16. "Amidst National Debate on Future of Healthcare California Alternative Bill," press release, National Nurses United, March 30, 2017,

proportions, but California's nurses appear undeterred. Speaking to the *Los Angeles Times* on behalf of the NNU, DeMoro said that "There has been a seismic shift in our political system through grassroots activism; we have an inspired, motivated base that will make its voice heard." Suffice it to say, the nursing profession has changed a lot in the past three and a half decades.

"A Caring Disease" is disturbingly relevant to our current political moment, but it is also—deliberately—incomplete. This dissertation uses a case study to assert that scholars of the AIDS crisis have overlooked a radical politics of care that was central to the larger movement. More broadly, the project asks that we consider who is accorded the "activist" label when we write history. What are the distinguishing characteristics of an activist? What kind of labor counts as *political* labor? How transformative must an idea be to be radical? And, perhaps most importantly: who are the gatekeepers?

The longstanding devaluation and degradation of caregivers (chronicled in books like *Caring for America* and *Ordered to Care*) has allowed some of the most complex efforts for PWA and poz rights to go unnoticed.[17] For all the research conducted to make this case, and all the sources invoked to advance the dissertation's argument, the single greatest validation of the project has come from AIDS activists, both nurses and non-nurses alike. Their support for this dissertation speaks volumes. "A Caring Disease" tells story of Ward

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http://www.nationalnursesunited.org/press/ entry/amidst-national-debate-on-future-of-healthcare-california-alternative-bill/.

17. Susan M. Reverby, *Ordered to Care: The Dilemma of American Nursing, 1850-1945* (Cambridge: Cambridge University Press, 1987); Eileen Boris and Jennifer Klein, *Caring for America: Home Health Workers in the Shadow of the Welfare State* (Oxford: Oxford University Press, 2015).

5B, and in so doing, invites both scholars and participants in the AIDS Rights Movement to historicize the various kinds of contributions caregivers made—and to do so quickly, while those they and their long-time-survivor patients are still able to share their stories.

There are other reasons it is important to historicize the work done by AIDS nurses in the 1980s and 1990s. Before being phased out entirely—Ward 5B began to take on a lot of oncology patients, which made sense, as many of the philosophies and practices on 5B were adapted from oncology nursing. While they may not have anticipated caring for non-PWA patients on their unit, the nurses of Ward 5B always understood their work as having broader significance. The care they provided PWAs was the kind of care they hoped to see *all* patients receive one day. That day may be coming. The United States lacks the infrastructure needed to accommodate the rapidly approaching "Elder Boom." If we want the Baby Boom generation to grow old and pass away with dignity, healthcare and social services will need to undergo yet another tectonic shift.[18] Equally important, as the first generation of poz Americans enters old age—more than half of all people living with HIV are currently over the age of fifty—we are discovering that the virus (or perhaps its treatment) accelerates the aging process by approximately ten years.[19] Radical gerontologists and activists fighting to provide patient-centered, ethical care to the elderly poz population will thus benefit from this study.

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[18] Ai-jen Poo, *The Age of Dignity: Preparing for the Elder Boom in a Changing America* (New York: The New Press, 2015); Atul Gawande, *Being Mortal: Medicine and What Matters in the End* (New York: Picador, 2015).

[19] "HIV and Aging," *POZ*, accessed June 22,2017, https://www.poz.com/basics/hiv-basics/hiv-aging.

For my part, I will continue to study the contours of Ward 5B and the San Francisco model of AIDS care, as many of its components and complexities fall beyond the scope of this dissertation. Throughout "A Caring Disease," I have tried to demonstrate that 5B's nursing staff was the progenitor of the SF model, but that many different institutions, disciplines, and culture brokers had to come together to make the model work. In expanding my focus to include organizations like the California Visiting Nurses Association, the San Francisco Gay Men's Choir, and Coming Home Hospice—and people like Bobbi Campbell—my future work will once again demonstrate that radicalism can take many forms.

I will also further expand the comparative project that I gesture at in this dissertation, by bringing in the voices of AIDS nurses and caregivers from around the country. In addition to conducting research in new archives, I will be undertaking an oral history project which will not only capture the voices of nurses, but also of patients' families and friends and—wherever possible—long-term survivors. A broader examination will facilitate stronger analysis of the San Francisco model; it will also illuminate the extent to which the AIDS virus *and* the nursing profession's response influenced opinion and uptake of hospice, primary care, and alternative therapies in the United States.

The late Fred Rogers, host of the eponymous PBS children's show *Mister Roger's Neighborhood* often recalled that, as a child, when he saw scary things on the news:

> My mother would say to me, "Look for the helpers. You will always find people who are helping." To this day, especially in times of 'disaster,' I

> remember my mother's words, and I am always comforted by realizing that there are still so many helpers—so many caring people in this world.[20]

There is much in the news today about which Americans who care about HIV/AIDS should be scared and angry. For poz and PWA individuals, people with disabilities, and queer communities (especially queer communities of color) the form and function of the American healthcare system is a matter of life and death. The fear and anger of these and many other communities is justified, and—just as fear and anger motivated thousands of Americans to join the AIDS Coalition to Unleash Power in the late 1980s—healthcare inequality is motivating a grassroots resistance to the Trump administration.

Productive as fear and anger are, though, they are not what helps one sleep at night. As LGBTQIA and HIV/AIDS activists take to the streets, once again fighting to survive, it is crucial to cultivate empathy and compassion alongside our rage. They are rarely the most visible activists, and their political contributions are often overlooked, but the helpers—the caregivers—are the beating heart of social justice movements. If this dissertation has accomplished nothing else, I hope it has reminded you to look for the helpers.

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20. "Helping Children with Scary News," *PBS Kids, Parents & Teachers*, 2005, accessed June 22, 2017, http://www.pbs.org/parents/rogers/special/scarynews-thoughts.html.

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