



Digital Commons@

Loyola Marymount University
LMU Loyola Law School

Women's and Gender Studies Theses

Women's and Gender Studies

Fall 2024

Comparing the Social Responses of AIDS and COVID-19 through Oral History

Elise Lee

Follow this and additional works at: https://digitalcommons.lmu.edu/wgst_thesis



Part of the [Lesbian, Gay, Bisexual, and Transgender Studies Commons](#), and the [Women's Studies Commons](#)

This Thesis is brought to you for free and open access by the Women's and Gender Studies at Digital Commons @ Loyola Marymount University and Loyola Law School. It has been accepted for inclusion in Women's and Gender Studies Theses by an authorized administrator of Digital Commons@Loyola Marymount University and Loyola Law School. For more information, please contact digitalcommons@lmu.edu.

Comparing the Social Responses of AIDS and COVID-19 through Oral History

by

Elise Lee

A thesis presented to the

Faculty of the Department of
Women's and Gender Studies
Loyola Marymount University

In partial fulfillment of the
Requirements for the Degree
Bachelor of Arts in Women's and Gender Studies

May 2, 2024

This thesis has been examined and approved in partial fulfillment of the requirements for the Bachelors Degree in Women's and Gender Studies by:



Thesis Advisor

Amanda Apgar, Ph.D.



Mairéad Sullivan, Ph.D.

Abstract

In the past 40 years, the United States has faced 2 major public health crises: the AIDS epidemic, and the global COVID-19 pandemic. In this project I consider the various aspects of these public health emergencies such as sharing the burden of survival, the role of fear, the bastardization of identity politics, and queerness as a political project. I do this by analyzing oral histories and I argue that we can look at the AIDS epidemic and the COVID-19 pandemic in parallel. During both AIDS and COVID, despite severely lackluster governmental responses, we saw overwhelming amounts of community organizing and collective action on the part of the public. Why do public health crises, such as the HIV/AIDS epidemic and the COVID-19 pandemic push people towards collective social action? I will be drawing on ideas from feminist care ethics, especially ideas of interdependence. ACT UP was given life through the community they created for themselves but a hallmark of COVID-19 was isolation. I will explore how interdependence and community plays out in the context of COVID-19 since we were all alone for so long. Additionally, drawing on ideas about the social contract and Foucault's ideas about governmentality, what is it about COVID and AIDS in particular, that made people feel so powerless and made our bodies available for governing in ways that they previously had not been? Lastly, I will explore queerness as a political position. Queerness is not about sexuality but rather, relationships to power and the state. Especially regarding COVID, some people just wanted things to go back to "normal" as quick as possible while others saw it as an opportunity to change the social order, and how do these perspectives affect the way people respond to major crises?

Table of Contents

Introduction.....	1
Chapter 1: On Sharing the Burden of Survival.....	13
Chapter 2: On the Role of Fear	24
Chapter 3: On Intersectionality, the Dangers of Identity Politics, and Queerness as a Political Commitment	35
Conclusion: Silence = Death Revisited	47
Works Cited	48

Introduction

In 1987 the AIDS Coalition To Unleash Power (ACT UP) adopted the slogan “Silence = Death.”. This slogan called for mobilization within the gay community—as neither silence nor self-reliance had stopped the deaths caused by AIDS—as well as outside the gay community, letting the public know that their silence made them complicit with the mass deaths associated with AIDS. Silence = Death was a call to action and inspired many to turn their fear into action.

In his article “Waiting = Death: COVID-19, the Struggle for Racial Justice, and the AIDS Pandemic,” David Caron outlines how the waiting that is often asked of us during nationwide crises, becomes unbearable for people and pushes them to action. Caron writes,

[t]o wait often entails obeying a set of rules and submitting to limitations on our dominion over ourselves. How we deal with these limitations, then, inevitably implicates our sense of self in relation to modalities of power. This holds true for African Americans urged to wait quietly for their civil rights; for queer people and other minorities told to calm down and wait for the cure that will surely come; and today [pandemic times] to, say, women made to hunker down at home with an abusive spouse. (97)

However, in times of crisis, particularly the AIDS epidemic and the COVID-19 pandemic, we see masses of people refusing to “wait it out”, rather we see mobilization and community care on a massive scale. This project seeks to investigate the following: what is the relationship between early AIDS activism and responses to the COVID-19 pandemic? What comparisons can we make between the social responses to both public health crises and what lessons can they teach us about care?

Background

Throughout the early 1980s AIDS was proving to be a rapidly spreading and deadly disease. By 1982 the media had created a striking narrative about a “gay plague” (Johnson 24). It wasn’t until 1985, five years after America saw its first HIV infections and 5000 deaths later, that President Reagan addressed AIDS as a public health problem. As Brier explains, “he did not

sign a document dealing with AIDS until the end of 1985, did not mention the term 'AIDS' in public until 1986, and spent very little money on researching the epidemic even though the first reported cases of AIDS coincided precisely with Reagan's first months in office" (Brier 79-80). The 2015 short film *When AIDS was Funny*, illustrates the Reagan administration's disturbing response to the crisis. Using audio clips from press conferences in 1982, 1983, and 1984, the film exposes how when reporter Lester Kinsolving brought up questions about the ongoing epidemic, he was scoffed at, laughed at, and met with snarky remarks and homophobic jokes. Jennifer Brier writes, "Reagan failed to act on AIDS because of his commitment to the New Right, which required a moralistic stance against gays and lesbians and drug users, the people most associated with AIDS" (80). While the federal government was largely ignoring the issue of AIDS, queer activists were mobilizing. Invoking the feminist phrase "the personal is the political" feminist and AIDS activist Cindy Patton insisted that "lesbians and gay men needed to see their collective health as a political problem, even if only some of them were actually sick or personally affected by the illness" (Johnson 12). Coalitions such as ACT UP, advocated and ultimately radically altered both medical research and public perceptions of AIDS.

Around 40 years after the emergence of HIV, another colossal public health emergency emerged: the COVID-19 pandemic. Despite the myriad lessons that should have been learned from the HIV epidemic, the Trump administration responded to COVID in an eerily similar and equally underwhelming fashion. Both Reagan and Trump took the path of downplaying the severity of the crisis and when that failed, blaming a minority group. For Reagan the scapegoat was gay men, for Trump it was Asians and Asian Americans. Despite the first cases of COVID-19 in the US appearing in January 2020, "President Trump, rather than heeding the advice of public health experts (utilize containment strategies,) continued to deploy 'othering' techniques,

referring to COVID-19 as the ‘China virus,’ the ‘Wuhan virus,’ or ‘Kung Flu’” (Johnson 28). COVID-19 continued to run rampant and over the course of 2020 and 2021 we saw a plethora of masking mandates, shelter-in-place orders, business shut-downs, and severe unemployment. While all of this was happening, there was another pressing issue facing Americans (not for the first time): the issue of police brutality. Triggered by the deaths of a number of innocent Black civilians including Ahmaud Arbery, Breonna Taylor, and most notably George Floyd, a nationwide resurgence of the Black Lives Matter movement came to fruition.

Archive

Formed in New York in 1987, The AIDS Coalition To Unleash Power (ACT UP) is a political, grassroots organization aimed at ending the AIDS epidemic. Over the course of 15 years, (2002-2017), AIDS activists Jim Hubbard and Sarah Schulman coordinated the ACT UP Oral History Project, which is a series of 187 video interviews with (surviving) members of ACT UP New York in which they discuss the history of the organization, the types of civic engagements they were involved in, and the kinds of social changes they were able to put into effect. Schulman and Hubbard knew the importance of solidifying the achievements of ACT UP in the public record. Schulman writes, “I know that people with AIDS, are not just gay. But homophobia was the prototype of the oppression that people with AIDS experienced. Active neglect. Cruel exclusion. Dehumanizing abandonment. From friends, family, class, job, race, neighborhood, religion, and country. Now, add history” (ACT UP Oral History Project). The aim of this project is not only to document the rich history of the organization, but also to “reveal what motivated [ACT UP activists] to act and how they have organized these complex endeavors...[in hopes] that this information will de-mystify the process of making social change,

remind us that change can be made, and help us understand how to do it” (ACT UP Oral History Project).

The COVID-19 Oral History Project from the IUPUI (Indiana University-Purdue University Indianapolis) Arts and Humanities Institute, is an open access and open-source oral history dedicated to archiving individuals’ lived experiences of the COVID-19 pandemic. Some of the oral histories are collected by scholars trained in oral history methodology, and some of the oral histories are recorded and uploaded by members of the public who have been provided with a set of questions to answer. The COVID-19 Oral History Project is an ongoing project, with oral histories continually being submitted. As of November 26, 2023, there are 604 published oral histories with the earliest one dated March 24, 2020, and the most recent dated June 1, 2023 (dates refer to the day they were recorded, not published). Most of the oral histories are from participants in the United States, but there are also participants from Canada, Spain, London, France, Ukraine, Romania, Australia, New Zealand, South Africa, South Korea, Honduras, and Mexico. The goals of this archive are not only to compile the experiences of living through a global pandemic, but also to be “a resource to help researchers, policy makers, activists, artists, and communities interpret and respond to current and future pandemics” (IUPUI Arts & Humanities Institute). The COVID-19 Oral History Project is an example of “Rapid Response Collecting,” which is a method in which historic circumstances are recorded as they play out, rather than looking for historical relics years down the road. Because of obvious restrictions on in-person interviews, the interviews were/are conducted via phone call or some other form of telecommunication, “[b]ecause of this, the recordings are not just documents; they embody the primary material form in which social interaction takes place during a modern pandemic” (IUPUI Arts & Humanities Institute).

Theoretical Framework

In her 1999 book, *Love's Labor*, Eva Feder Kittay contends that John Rawls' theory of justice is incomplete because it relies on assumptions of people as self-sufficient and independent. Kittay asserts that these presumptions disregard the important role of the caregiver, particularly in the context of caring for individuals with severe disabilities. She suggests that caregiving is an essential human activity that is undervalued within traditional justice frameworks. Kittay notes that while some women have been able to move away from traditional caregiving roles, this transition has been made possible by other women taking on those responsibilities. She challenges the essentialist association between women and care by introducing the idea of "dependency workers" and emphasizes the need for institutional and conceptual reforms to achieve equality for both dependency workers and dependents. Centered on the concept of interdependence, Kittay proposes a third principal for Rawls' theory of justice "To each according to his or her need, from each to his or her capacity for care, from each according to his or her capacity for care, and such support from social institutions as to make available resources and opportunities to those providing care, so that all will be adequately attended in relations that are sustaining" (Kittay *Love's Labor* 121). Feminist care ethics posits care as a political commitment. Care is not simply a virtue, rather, a "praxis that reorients people toward new ways of living, relating, and governing" (Woodly et al. 891). Feminist care ethics will inform how I read the archives because I will be analyzing ways in which community organizers work towards shifting social relations in the face of public health crises. In what ways does interdependence become a mechanism of survival and a foundation for political organization?

What is the difference between care that comes from the community and more formalized structure of care, such as those that comes from the government? We live in a society that tells us that government is meant to care for its citizens, but feminists know that true care can only happen between people. In *The Care Manifesto*, The Care Collective (what the authors call themselves), argue that “over the past few decades, ideas of social welfare and community had been pushed aside for individualized notions of resilience, wellness and self-improvement” (2). The neoliberal idea that individuals should be wholly self-sufficient has done nothing except undermine all forms of care that do not serve to extract profit.

“Self-care” is often touted as an essential part of a healthy lifestyle, but it is putting a band-aid on problems that are created by neoliberal capitalism. You can take a nice bath and light a candle and put on a face mask and do a meditation, but if you still have to work 40+ hours a week at a job that barely pays you enough to make rent and put food on the table, then come home and take care of your children, an hour of “self-care” (if one even has time for that) is a short term solution to a long term problem that is only becoming increasingly worse. We are encouraged to take part in forms of care that take the onus off the society to just make life more bearable. Moreover, we are encouraged to take part in forms of self-care that make us more productive workers. Is it self-care? Or self-optimization?

The Care Collective define “care” as “our individual and common ability to provide the political, social, material, and emotional conditions that allow the vast majority of people and living creatures on this planet to thrive - along with the planet itself” (6). Care is more than looking out for a friend or family member, it is acknowledging and accepting interdependence (The Care Collective 7). Care is a verb, it is political, it is actionable. Truly meaningful and

revolutionary care necessitates political mobilization in order to transform the world (The Care Collective 21).

French philosopher Michel Foucault describes power not only as hierarchical structures, but also as forms of social control and selective dissemination of knowledge. He writes, “Power would no longer be dealing simply with legal subjects over whom the ultimate dominion was death, but with living beings, and the mastery it would be able to exercise over them would have to be applied at the level of life itself: it was the taking charge of life, more than the threat of death, that gave power its access even to the body” (qtd. in D. Taylor 43). In simpler terms, there was a time in which those in power maintained control through fear of death, but the nature of power has changed. Power and control are no longer just about ending lives but extends to influencing how people live their lives. Power is the ability to control people’s lives, not just cause their death. Throughout both the AIDS epidemic and the COVID-19 pandemic, we saw how people felt like control over their own lives were slipping out of their hands. In terms of AIDS, we saw a lack of governmental concern regarding the crises, resulting in death on a mass scale. In terms of COVID-19, with the introduction of mask mandates, vaccine mandates, conflicting safety procedures, and a lack of clarity about how the world would move forward, there were widespread feelings of powerlessness and fear. What kinds of power are exerted over people when they experience a complete lack of control? How do our bodies become objects on which power is exerted? How do power dynamics shift in the face of public health emergencies?

Methods

On the Importance of Oral History

How do we understand the past? Historians, scholars, academics, journalists, writers, and artists have always had their ways of documenting and recording both past histories, and contemporary moments, but if you ask someone what they were doing when a major historical event happened, 9//11 for example, everyone has some sort of personal story and unique understanding of the past. For many, history is not what is not found in books but in their memories and the memories of people who came before them. In recent years, there has been a concerted effort to include marginalized voices in the historical record. Revisionist history has gained increasing popularity (and rightfully so) as many have started to question whose perspectives write our history (Banner n.pag). Oral histories are a valuable tool for understanding the past (and the present) as they can provide a more robust story. Eyewitnesses can fill in the gaps in the written record and challenge the status quo and “personal retrospection can produce vital information about collective perceptions of community and work” (Milner 327). Additionally, oral history can give us insight into how the forces of history are experienced on a smaller scale.

Oral history archives or collections, such as the ACT UP Oral History Project and the COVID-19 Oral History Project, can be even more valuable than individual interviews because they reveal that memory is socially produced, knowledge is an unstable entity, and there is no such thing as a singular, objective truth. Oral history “collections often speak as a group, revealing insights that individual interviews cannot...[and] [t]hey represent snapshots of how people reconstructed the past and the way they chose to translate their experience in light of all kinds of influences, including community pressures, changing political and social values, and the presence of a particular interviewer and his or her questions” (Mercier 43).

A feminist practice of oral history reminds us that memory is subjective, and it too is shaped by forces such as gender, race, and class; any study of oral history must include these as categories of analysis. Gender, race, and class not only influence our experiences of the past, they are also involved in the construction of memory. Joan Sangster writes, “Cultural values shape our very ordering and prioritizing of events, indeed our notions of what is myth, history, fact or fiction” (Sangster 7). The influence of gender, race, class, and how they influenced people’s experiences with both AIDS and COVID-19 may reveal themselves explicitly, through the content of the interviews, or implicitly, through narrative form.

Methodology

This is a critical discourse analysis. My objects of analysis are the ACT UP Oral History Project and the COVID-19 Oral History Project. I analyzed a total of 24 oral histories, 10 from the ACT UP Oral History Project and 14 for the COVID-19 Oral History Project. I will be looking for common themes within each and between both oral histories. I will be looking at how interviewees narrate institutional abandonment and care. I’m interested in how people remember the movement as they move further away from it. There are interviews that were conducted as recently as 2017, and I’m wondering if there are differences in the language people use to describe the movements, or if perspectives are different based on different social and political landscapes. What did different narrators choose to stress even if similar questions were asked. Additionally, the ACT UP interviews were all conducted in person and the interviewer and interviewee were peers and had a personal relationship. On the other hand, the COVID-19 interviews were conducted over the phone and there was no relationship between the interviewer and interviewee. And some of the COVID-19 oral histories are not interviews at all, rather, individuals recording themselves and creating their own oral histories. These oral histories are

particularly interesting to me due to isolation being a hallmark of the COVID-19 pandemic and something that differentiates it from previous public health crises. How did people create an ethic of care that is based on community and interdependence in the context of COVID-19 since we were all alone? I'm also interested to see the differences between each style of oral history and wonder if different modalities elicit different styles of oral history and different kinds of information.

In terms of sampling strategy, I will use a different strategy for the two oral histories. For the ACT UP oral histories, I will be randomly sampling 30 oral histories. I will assign each of the 187 oral histories a number and use a random number generator to pick 30 oral histories at random. Although I will only be analyzing 25, I have extras in case there are a few abnormally short or long interviews. In terms of the COVID-19 oral histories, each transcript has a list of key words and topics discussed, so I will be looking for interviews tagged with key words such as "Black Lives Matter"/ "BLM", "community", "care", "communication", "online", and "zoom." I will be paying particular attention to the role of community in a time of such isolation.

In all cases in which a video interview is possible, I will analyze that rather than an audio recording or a transcript. Being able to see and hear voice inflection, emotion, and body language provides a potential for analysis that is unique to oral history and video interviews. What can we learn from video that is not apparent in written form? I will also be paying attention to what interviewees deem important and compare that to the current literature. What themes seem most poignant to interviewees and are those the same themes highlighted in the literature surrounding AIDS and COVID-19? What important information can we learn from the oral histories that is missing from other accounts?

Chapter Outlines

The first chapter is about care, community, and sharing the burden of survival. I pull from feminist care ethics and I discuss the role of interdependence during crisis. This chapter focuses somewhat more on the COVID-19 pandemic, because, although community and interdependence played an important role in AIDS activism, community during the COVID-19 pandemic was more complex as it was a time hallmarked by isolation. This chapter begs the question, how do we find creative ways to lean on each other? Many describe doing this by drawing strength from their family histories, and creating their own meanings of resiliency that transcends time and space.

My second chapter explores the role of fear in social responses to AIDS and COVID-19, specifically: fear of the unknown, fear of loss of personal autonomy, and fear of state abandonment. I also discuss how many viewed these health crises as potential opportunities for major social change, while simultaneously reverting to the status quo as quickly as possible. Pulling from Sara Ahmed, I suggest that fear of the unknown is still a fear one feels in the present moment (page or range). It transcends time and space and propels us into the future such that we feel a looming threat, even in the absence of actual danger. What results is an urgent reflex to return to “normal.”

Using ACT UP as a case study, my final chapter is an exploration of the how identity politics—which has its roots in Black feminism and was meant to be a way of understanding how one’s identity can be an avenue of to political radicalization—has been watered down and come to colloquially mean representation and subsequently, assimilation. Many former ACT UP activists describe a split in the group between those who wanted to extend the organization’s radical politics into other realms of social justice, and those who wanted to assimilate and focus on being accepted into the normative society. ACT UP began to lose momentum when some

members began to view the group as a single-issue organization rather than one aimed at radical upheaval of unjust structures. The chapter closes discussing how intersectionality and queer politics can act as interventions against the co-opting of identity politics.

Chapter 1: On Sharing the Burden of Survival

“Revolution is sharing the weight and burden of discomfort with others rather than swallowing it down until it forms a cancerous tumor of shame and alienation in your gut.”

-- Dayna Lynn Nuckolls

2020 was a great awakening for many people. A global pandemic disrupted life as we knew it and the lynching of George Floyd forced Americans to deal with the stark realities of system racism. 2020 forced people to reckon with the responsibilities we have towards each other and ourselves. This is not the first time, however, that we have been forced to negotiate our social responsibilities in the midst of a public health crisis. The AIDS epidemic of the 1980s united masses of people together, notably through the efforts of organizations like ACT UP, in the battle to raise awareness about a public health crisis that the Reagan administration largely neglected. The throughline in both these historical moments is the way people came together en masse to fight for a more dignified life. ACT UP was given life through the community they created for themselves, but a hallmark of COVID-19 was isolation. Using a framework of feminist care ethics, I will explore how interdependence and community plays out in the context of public health emergencies, but especially in the context of COVID-19, since we were all so alone for so long.

In what ways do we see people building systems of interdependence in times of crisis and isolation? In regard to COVID, many people, particularly women of color, describe drawing strength from experiences of their ancestors and family, and knowing the hardships they went through. Jeida K. Storey recounts how throughout her COVID pregnancy, she thought a lot about her great grandmother who was born during the Spanish flu pandemic. She found comfort in

knowing that we are not the first people to experience something like this and protecting herself meant following in the footsteps of people before her who have survived hardship: “protecting ourselves was more than just about the virus. It was about continuing on the legacy of all those who have survived insurmountable pain and hard days, if they could survive then I will too” (Storey 12:26-12:42). Drawing strength from the resilience of others who have overcome great difficulties reminds us that we are part of a broader human experience, connected by our ability to persevere in the face of diversity. By continuing their legacy, we affirm our own ability to endure. COVID-19 and the ways people responded to it showed just how much people rely on one another in times of crisis. Many people talk about looking to their friends, family, and neighbors to see how they were handling things because there was so much conflicting information in the media. For many, decisions regarding safety during the pandemic were based on the comfort levels of those around them. COVID interviewee, Tony states, “everyone has different understanding and comfort zones...I think that’s more about communication rather than overprotection” (58:26-59:13). Laura Larson describes safety as a negotiation between how those around her feel, what experts recommend, and trusting her gut instinct (30:13-30:48). Even during times of isolation and separateness, the virus exposed our interdependence. In other words, “...COVID-19 showed us just how much the idea of a society made up of separate entities is fundamentally misguided” (Dowling 170). People have an understanding that they exist in communities greater than themselves. COVID interviewee, Fiona Tang, explains that she views herself as a part of a whole, not separate from the rest of society (26:09-26:15). Another COVID interviewee, Christopher Sequeria, echoes this sentiment stating, “wellness [is]...personal and planetary...the health of an ecosystem is multifaceted (2:12-2:28).

Media has also been a site of community care. Former ACT UP member, Chip Ducket, describes how ACT UP used media to push back against popular narratives of what it meant to have AIDS. Sandra Elgear expands on this idea when talking about her involvement in the ACT UP media campaign, explaining that activist video is different from documentary films in that she was not just commenting or observing ACT UP, she was an active member, describing her storytelling as “truthful but not objective” (47:09-7:11). What is present in both these accounts is the ability of media to shape narrative. Regarding the COVID-19 pandemic, Jeida K. Storey reveals that despite twitter being a social media platform, she felt like this was actually the place she got factual information from because she was able to read about people’s personal accounts and had the ability to talk to people she wouldn’t otherwise have access to. Storey also discusses children’s media; she talks about how seeing Sesame Street and Blue’s Clues do pandemic episodes made her realize that she was supported as a parent. She compares this to post-9/11 media—another major historical moment when things shifted—and describes 9/11 media as scary while COVID media was more kid-appropriate and normalized masking and concern for the safety of others. It is particularly interesting how she describes children’s media at the beginning of the pandemic as focused on safety, and not political (Storey 27:44-31:08). Although I would argue that safety is political, we once again see how the messages we get from media play a defining role in shaping our perceptions of current events, and have the power to make people feel seen, resulting in a feeling that these burdens are shared. Media can also, however, be extremely polarizing.

Although it may have seemed like during the pandemic people were more divided than ever, when you actually listen to what people have to say about care throughout the pandemic, most describe having an immense amount of patience and understanding, bringing us back to this

idea of sharing the burden of survival. COVID interviewee Fiona Tang reports maintaining a serious concern for others since the beginning of the pandemic. Even though she herself would likely be fine if she contracted the disease, she felt a moral responsibility to keep others safe (1:53-2:14). And even though she herself was very pro masking and vaccines, she tried to understand where anti-vaxxers and anti-maskers were coming from, recognizing that other people have not been treated well by the health care system (pre, during, and post-pandemic) and that their concerns are valid (4:38-5:14). These discrepancies in the health care system were only exacerbated by the pandemic, which hospitalized thousands, and pushed the limits of what our health care system can handle. Dowling, quoting Anand Giridharadas, writes, “Your health is as safe as that of the worst-insured, worst-cared for person in your society. It will be decided by the height of the floor, not the ceiling” (170). This quote perfectly sums up how the United States health care system handled the pandemic. According to the John’s Hopkins University Coronavirus Resource Centre, Despite being the world’s richest country, and among the most industrialized, the US had some of the highest COVID-19 mortality rates. COVID-19 “did not discriminate between us in terms of its attempts at contagion, yet the social structures it spread through certainly did” (Dowling 170).

What are the parallels between AIDS and COVID-19 with respect to inequitable distributions of health burdens? In the same way that the wealthy were able to maintain a level of normalcy during the pandemic, white gay men have been able to move away from bearing the majority of the burden of HIV/AIDS and shifted that onto Black gay men and intravenous drug users. That 1 in 2 Black gay men will contract HIV—a deadly disease—is indicative of more than just neglect (Johnson 36). Madison Johnson writes, “both the unequal access to PrEP for black gay men compared to white gay men as well as the toilet paper hoarding that was profound

at the early stages of the COVID-19 pandemic...are just two examples of the massive effects of the inequitable distribution of health burdens [and] they represent the larger imbalance of resources in society,” quoting Dr. Sheldon Applewhite, “you could only hoard toilet paper if you had access to the internet and you had to a car to go pick it up” (Johnson 37). Both Reagan and Trump, the presidents during AIDS and COVID-19, respectively, were ineffective at mitigating the health outcomes of their respective pandemics but also ineffective at addressing the structural issues through which those health outcomes are experienced (Johnson 39).

So, although there seem to be many instances when public health crises result in a deep sense of care and responsibility for one another, the burden of survival is not always distributed equally. Vanessa Green asserts that COVID should not be considered a collective trauma because describing it in that way minimizes the suffering of marginalized groups and asserts that essential workers that would have received more support if COVID had truly been recognized as a collective trauma (Green 1:43:27-144-15). Essential workers and health care workers were celebrated as “heroes,” “but we failed to care for them in advance of the catastrophe through adequate pandemic preparedness and early response. We identify populations as “vulnerable” or “at risk” concerning Covid-19, but we failed to care for them in advance” (Mercer and Berlinger 56). In many ways, the COVID and AIDS crises only further entrenched social inequality that was already pervasive. How can we change the way we understand “essential” and/or “care” work and turn it into a social responsibility rather than pushing it onto certain “heroic” individuals? There must be a policy emphasis on how the workforce responsible for care work lives. Of course, this means livable wages and decent working conditions, but it also means affordable and accessible housing, access to food, health care, transportation, childcare;

everything a person would need to live a comfortable life. As Eva Feder Kittay points out, all moral theories aim to prevent harm (Kittay *Learning from my Daughter* 178).

An ethics of care does not only concern the well-being of the person who is being cared for, it also ensures the carer is not exploited. As we begin to move away from the pandemic, “we may grow impatient with the ‘vulnerable’ and the ‘at risk,’ with those of us who are older, sicker, poorer, more disabled, more dependent, [and] less ‘resilient’”, but we must come to terms with how our tolerance for social inequity has affected both carers and those who are cared for (Mercer and Berlinger 57). Whether it be “those institutionalized in long-term care facilities, prisons, and detention centers; those members of poor and working-class communities, especially communities of color, at disproportionate risk of chronic conditions; and those who are aging or immunocompromised” (Mercer and Berlinger 57). This is an opportunity to improve all our lives rather than return to the status quo. In the words of social epidemiologist Nancy Kreiger, “This is a housing crisis. This is an economic crisis. This is racial injustice. This is gender inequity. Right now, people through their bodies are showing what the problems are in our society, but also what the potential is for people coming to work together to make a better world — one where people can thrive, with dignity, with their rights, in a sustainable way” (Ellis and Lin n.pag). We have a collective responsibility to address these issues, a shared burden of survival.

Who does the burden of care fall on, especially in times of crisis? According to the New York Times, women make up 52% of all essential workers and 77% of healthcare workers (Robertson and Gebeloff n.pag), making them especially susceptible to COVID-19. In addition to this physical toll, working in healthcare has a serious emotional burden as well. Having to watch people dying everyday takes a serious toll on the human psyche, so much so that “[e]arly

reports indicate that women working in healthcare occupations are exhibiting especially high rates of symptoms associated with acute and post-traumatic stress disorders as a result” (Leap et al. 5). Moreover, “non-white women are more likely to be doing essential jobs than anyone else” (Robertson and Gebeloff). This puts people—women, especially women of color—who find themselves in care taking roles particularly vulnerable to exploitation. Care work is different from other kinds of work because it requires relationship building. This makes it difficult to just quit a job, even when experiencing poor or unfair working conditions. There is an idea that care work is a “labor of love,” and that money should not be the motivating factor in why somebody chooses to engage in this work. ICU nurse Angela Lindley recounts, “I didn’t sign up for a pandemic...but I am not going to walk away when people need me” (Robertson and Gebeloff). There is a certain guilt that is pushed onto people but especially women who are not able or willing to continue care work because it is seen as a moral failure rather than an inability to sustain a life so full of sacrifice.

In addition to making up the majority of essential workers during COVID-19, women, especially those who are mothers, also had to take on more responsibility within the home as their children were no longer able to go to school. The massive increase in the numbers of both men and women working from home could have been an opportunity to balance out the gendered division of reproductive labor, however, the data shows that “[e]ven in heterosexual households where men and women both began working from home, women...[increased] their time [spent] on unpaid domestic labor” (Leap et al. 4). The naturalization of woman as caregiver and is deeply linked to the idea of the public and private spheres. Even though for many families, both men and women were at home and the public and private sphere became one, the coding of reproductive labor as feminine has resulted in continued and even exacerbated imbalances of

labor within the home. We see this playing out in the AIDS epidemic as well: “Separates spheres ideology permeates almost all aspects of the AIDS pandemic. It has coded AIDS as a male disease and as a “public,” global crisis, while AIDS in women, as well as women’s caregiving in response to AIDS, is still seen as a marginal, “domestic” problem (Hogan 18). Caretaking is a fundamental part of the human existence; at some point, we will all be on both the giving and receiving ends of care work, however, “it is worrisome that those members of American society who sacrifice the most are often those with the least amount of power” (Hogan 4).

Care workers were not the only population whose labor put them at risk during the pandemic. In her work, *Delegating Death* Zoe Mack describes how many penitentiaries shifted their prison labor programs to accommodate for the pandemic. Inmates across the United States produced face shields and other PPE (personal protective equipment), as well as bottled hand sanitizer (10). In one Texas prison, female inmates produced face masks yet were not allowed to wear any themselves, nor were proper social distancing guidelines enforced (Mack 10). This exploitative labor put the inmates at an even higher risk of contracting COVID-19. Using Foucault’s notions of biopower, we can understand these “essential workers” marginal status as a way for them to be excluded from the protected population; by relegating them to the most dangerous professions, “the state implicitly designates this group as ‘less desirable,’ establishing a hierarchy of human life...” (Mack 9-10). During the pandemic, essential workers were praised for putting themselves on the front lines, and ultimately risking their lives, even though they were not awarded material protections. Wearing masks and constant cleaning/sanitizing were presented as necessary to ensure safety and preserve human life, yet already marginalized and at risks groups are not seen as valuable enough for their lives to be protected.

The pandemic forced us to reckon with two major realities: (1) human interdependence and (2) the American society's tolerance for inequality. Care as a political ethic is necessary to recover from the 2 major public health crises we have endured in the last 40 years, and ensure we are well prepared for the next health emergency. In *Moral Boundaries*, political theorist Joan Tronto describes care as "everything that we do to maintain, continue, and repair our 'world' so that we can live it as well as possible" (103). Crucial to this definition of care is its actionability; not simply "caring for" or "about." Tronto argues that democracy thrives when care becomes a shared responsibility among citizens, and this idea is also expressed by ACT UP activist, Scott Robbe, "democracy doesn't work unless you participate, you can't foster change unless you participate" (Robbe 20:34-41). Defining care as a political commitment also allows us to make peace with the limits of our activism. When asked what he thought the biggest failure of ACT UP, activist Chip Duckett states, "I think we all could have taken better care of each other emotionally" (58:00). During the AIDS epidemic, everyone was fighting so much pain and so many individually difficult things that people couldn't always be there for each other. And yet, we are able to retrospectively point towards ACT UP as a major hub of care and care work. Duckett, the same person who says ACT UP members could have taken better emotional care of each other, in the same breath recognizes that ACT UP was important because the organization was willing to do more radical and startling actions (56:10-58:26). This sentiment is echoed by Sandra Elgear and Jean Carlomusto, who say ACT UP reminded people that civil disobedience works and they have the power to change things. Dudley Saunders adds that ACT UP permanently altered the relationship of the patient community to the medical community and made people realize they have the right to expect better treatment (1:09:42-1:09:49). Despite the

difficulty of being emotionally present during times of crisis such as COVID-19 and AIDS, people practice an ethic of care by sharing the weight of existence.

Despite many instances of community care during both the COVID-19 pandemics and the AIDS epidemic, they were also times marked by times of intensified awareness about social injustice. During the summer of 2020, the United States saw a major resurgence of the Black Lives Matter movement, triggered by the murders of countless innocent Black individuals including Ahmed Arbery, Breonna Taylor, and maybe most notably George Floyd. Trisha Vaughn describes her experience of the pandemic as an excuse not to talk about issues of police brutality and the Black Lives Matter movement. She recounts how many in her workplace had the attitude that the pandemic “topped” BLM issues and how she was not given the space to acknowledge how the social issues of the time were affecting her. Vaughn states that for her and people like her (Black community), the social injustices have been just as much a part of the pandemic as the sickness (31:26-31:53). Concerning ACT UP, John Weir, Moisés Agosto, and Dan Keith (all members of ACT UP) report that ACT UP never worked out its issues with racism and sexism. Moisés Agosto contends that when community-based leaders in organizations of color started to realize that ACT UP had racial and class biases, it may have kept them from getting treatment information and participating in treatment discussions (1:09:35-1:09:55). Agosto also reveals that women in ACT UP, especially in the Latino caucus felt left out and that their issues as Latina women and mothers were being ignored (27:04-27:44). Dan Keith Williams adds that many Black women wanted to be involved but didn’t feel it was worth it to put up with so much racism for an issue they didn’t feel the direct consequences of (referencing the low infection rate for lesbians). Williams states, “how many fights can you fight at once?” (43:41-43:44). He adds that there was a lot of sentiment from white members of ACT

UP that they knew better for him, a Black man, than he knew for himself (58:41-59:04).

Williams goes on to say that racism was underlying in ACT UP, so he was not fully supported in that organization, but also got backlash from his Black community because of his sexuality and perceptions of AIDS as a disease for white gay men (43:02-44:05). So, although we can point to numerous instances of community care and shared distribution of burden during both the AIDS epidemic and the COVID-19 pandemic, these were still times of tremendous turmoil, brutality, and inequality.

Although community and interdependence played important roles in both the AIDS epidemic and the COVID-19 pandemic, COVID was hallmarked by isolation, resulting in an expanded definition of interdependence and creative ways to find support. In the midst of a pandemic, the meaning of safety becomes more abstract. Vanessa Greene describes safety as a community where people support you (1:23:34-1:25:04) and Laura Larson describes safety as being able to live an honest life, with fearing yourself or your surroundings (29:29-30:05). The idea of fear will be further discussed in the following chapter, as we examine how fear can stand in dialectical opposition to a shared burden of survival and can disrupt the opportunity for social change that accompanies these majorly disruptive health crises (AIDS and COVID-19).

Chapter 2: On the Role of Fear

When you think back on the COVID-19 pandemic, or the AIDS epidemic, what emotions do you remember feeling, especially during the early stages? Many will answer: fear. A new disease on the horizon, spreading quickly and killing many is no doubt cause for fear, but what are effects of a society living in fear? What does it do to the collective psyche? How does it change our demands and responses? In this chapter, I will explore the role of fear in social responses to public health crises. I will first address what exactly it is people are afraid of, namely, fear of the unknown, fear of loss of personal autonomy, and fear of state abandonment. Drawing on Foucault's theory of power, I will argue that fear may be misplaced due to narrow and normative understandings of power. Next, I will explore if fear as a paralyzing force. Finally, I will discuss how fear can prompt collective action.

Fear of the unknown future is something that looms among many in their day to day lives. What will my life look like after college? What kind of career will I have? What kind of world will my children grow up in? These existential questions can be anxiety-inducing, but they can also be calmed by the ability to think ahead, to make contingency plans. When a pandemic comes into the picture, this really throws a wrench in our plans. We stop thinking about the future because we do not know if we will even be alive tomorrow. We are forced to shift our priorities while we wait to see what will happen to our world. In his essay, "Waiting = Death: COVID-19, the Struggle for Racial Justice, and the AIDS pandemic" David Caron writes,

Waiting uncomfortably dilates the present moment and makes us aware of our situation between past and future events, whence perhaps the urge to reflect on it in vast existential terms we would prefer to avoid. As Harold Schweizer remarks in his essay "On Waiting," "The waiter—the impatient waiter—is an unwilling student of philosophy. When we

wait, we who have no time to philosophize are made philosophers against our will (25).”
(95)

Despite not consciously intending to engage in philosophical thought, the act of waiting forces individuals into a contemplative state, whether they desire it or not. During this time, people may find themselves reflecting on deeper questions about existence, time, and the human condition. Philosophy, typically seen as a discipline pursued by scholars and intellectuals, becomes something thrust onto ordinary people in mundane situations.

During both AIDS, and COVID-19 we see this phenomenon of “lifting the veil”; people realizing the severity of the situation and understanding that they have to take care of themselves and each other because if they don’t, nobody will. Moisés Agosto of ACT UP describes discovering ACT UP as an almost religious experience (15:25-15:29) in terms of finally finding people who understood the devastation of the disease. In regard to COVID-19, with the introduction of stimulus checks and COVID leave (which have since been, for the most part, discontinued) a lot of people finally started to realize that the government is actually capable of much more than it claims in regards to social welfare. Furthermore, many working class people began to realize how much their employers were exploiting them, and we began to see people quitting their jobs en masse, and the phenomenon of “quiet quitting” (doing nothing more than the minimum requirements of one’s job and not putting in any more effort or enthusiasm than necessary). And lest we not forget the Black Lives Matter movement of 2020, when people came out in droves to demand an end to police brutality and a dismantling of the police system, as a whole. Trisha Vaughn describes the movement as bringing a whole new meaning to the phrase “no justice no peace” (34:41-35:08), once again reiterating the perspective that comes with helplessness in times of crisis. What we see as a result of both AIDS and COVID-19 is a radical

shift in worldview for a lot of people. Often, this leads to a newfound clarity and determination to incite change, but sometimes the novelty and quick-paced transformation can be paralyzing.

In times of fog and disorientation, we struggle with making decisions. COVID interviewee, Brad Peterson, describes the mental health toll of the unknown and the inability to plan ahead, stating: “I think the biggest thing for, you know us as a society moving forward in continuing to pandemic is to not let the fear of everything drive us. But at the same time, also try to, you know, do what we can for the sake of our neighbor” (40:42-41:09). Christopher Sequeria says he wasn’t personally worried about COVID in the beginning but went along with the guidelines of his city to be a good citizen (5:08-5:31), however, when it came to the vaccine, he was and is staunchly opposed to it for himself. On one hand we have people who want to be good citizens but are afraid that regulations will be taken too far (or fears that they already have been taken too far), on the other hand, there were also people who felt the regulations did not go far enough and wanted much stricter mandates.

Laura Larson asserts that one of the reasons people had so much fear and ambiguity surrounding proper precautions and behaviors in relation to COVID, was because we had to take in a lot of information about the virus, but ultimately decide for ourselves what actions we would take. This brings up the question of who and what we believe in times of crisis? Vanessa Green describes being confused about science denial stating that she had never really encountered antivaxxers until COVID, but “the science deniers didn’t exist for me until the pandemic. I know they did, but they came out of the woodwork during the pandemic” (15:58-16:11). This mistrust of science was a hallmark of COVID, but Dudley Saunders of ACT UP says he experienced this during the AIDS epidemic as well stating (14:24-15:29).

For COVID interviewee Christopher Sequeria, the answer to the question of who to trust is: yourself. He believes there are other ways of knowing what's best for yourself than just facts and figures (5:56-6:11). Sequeria does not feel safe when he is forced to do something; for him, safety is about freedom above all else, and there is no such thing as "one size fits all" when it comes to personal health. Christie Peetoom feels similarly, emphasizing that our freedoms cannot be forgotten and each person has a right to live their life in the way that feels best for them (59:48-60:08). With these sentiments we begin to see another hallmark of pandemics: our bodies becoming available for governing in ways that they had not previously been. In his work on governmentality, Foucault argues that governmental power comes in the forms of social control, disciplinary institutions, and forms of/access to knowledge. Throughout the oral histories, a common thread was that people felt there was a lot of conflicting information and they really had to discern for themselves what decisions they were going to make about their bodies. With so much that was unclear about vaccines, safety procedures, how long we would be in a pandemic, and the lack of continuity between government municipalities, a lot was left up to individuals to decide, even though it seemed like COVID was a time characterized by severe restriction. While we saw an oversaturation of information and recommendations during COVID, the AIDS epidemic had the opposite problem. After years of ignoring HIV, when Reagan did finally acknowledge it as a public health problem, there was so little known about the virus that early treatments were essentially just experimental drug cocktails. In both situations, we see how when our bodies are made available for governing we lose a certain level of autonomy. Whether we are overly restricted or vehemently ignored (by governing bodies), we lose the ability to make the choices we want about our bodies.

The fear of a loss of personal autonomy, or, put differently, a fear of being controlled or coerced is a legitimate fear. Drawing on Foucault's theory of power, we can understand the state response to COVID-19 as a form of biopower. Traditionally, power structures are understood to be function from the top down; to have power is to be at the top of the pyramid. Foucault suggests that modern power—the ability to influence thoughts and actions—is “capillary,” it is diffused throughout society and operates at the ground level of society; it operates at the “base” of the pyramid (Fraser 18). In this way, power can arise in any relationship. Foucault's term “biopower” refers to the control at a population level. Biopower functions not through law, but through norms “because it is internalized by subjects rather than exercised from above through acts or threats of violence” (D. Taylor 43). Discourse is a form of normalizing power, a mechanism guide people's thinking and to push people to *want* to do what must be done.

The language surrounding COVID-19 turned it into an object with a life of its own. Specific scientific vocabulary such as “R naught”, “flattening the curve”, and “herd immunity”, became vernacular for lay people. According to Foucault's understanding of power, these words do not innately hold power but are legitimized because of the people they come from. Scientists, doctors, politicians, and new media repeated these words until their instructions were deemed common sense, and to question mandates and procedures was to put oneself, and more importantly, the society, at risk. Those who were opposed to vaccine or suggested that the contact tracing and vaccine card requirements were dismissed as fringe or “conspiracy theorists,” but their underlying fears that these were forms or social control or as Foucault would call it, “biopower,” are not wrong. That is not to say that mask mandates, vaccine requirements, or lockdowns were necessarily a bad thing, but they do work to monitor and guide people's actions. The fear of loss of personal autonomy is a fear that has been somewhat misdirected towards the

government because power is typically understood to be both repressive and working from the top down. When we adopt more expansive, Foucauldian notions of power, the fear is mitigated because we can understand power as diffused throughout all strata of society, and therefore can be challenged in creative ways.

In contrast to the fear of overregulation of our bodies in times of mass crisis, there is also the fear of state abandonment. I want to preface by defining what I mean by “state” abandonment or “government” abandonment. Government is a very broad term that can mean anything from the smallest local municipalities to the largest and most far-reaching federal branches. When I talk about people mistrusting the government, it’s not important to me that they specify what specific aspects of government they mean, rather, I am more focused on why they feel powerless at the hands of institutions.

Additionally, before the discussion about what state abandonment looks like commences, we must first outline what responsibility the state has to its citizens. The social contract has long been the basis of understanding the role of government and society. It can be boiled down to the idea that a society is formed by individuals who give up personal freedoms in exchange for security, protection, and/or a set of rights that they would not otherwise have access to. It is an agreement between citizens, as well as an agreement between the sovereign body and the governing body. It is generally accepted that the state has certain responsibilities towards those they govern, but by looking at the cases studies of the COVID-19 pandemic and the AIDS epidemic, we can begin to see what it looks like when those duties are abandoned.

Michel Foucault asserts that “modern Western subjects learn how to self-discipline, exonerating governments from their duties toward the people as a result” (cited in Caron 103). Assigning people to dichotomous categories of responsible vs irresponsible, as has been

repeatedly observed throughout the pandemic, allows governments at all levels, local and federal, to deflect responsibility. Rather than positioning themselves as responsible and accountable leaders managing the crisis, they wash their hands of any responsibility for bad outcomes (Caron 103). Recall images of crowded beaches in Miami, for example, filled with college students determined not to let COVID get in the way of their spring break trips. In the foreground, local officials insist that these deviants who are endangering themselves and the community are “outsiders,” “not from here,” not “us.” This othering was present from the beginning of the pandemic, which was often characterized, in America, as caused by some distant, non-white country with a barbaric lack of separation between man and beast (Caron 103). This total shifting of blame went as far as government officials, namely President Trump, calling COVID the “kung flu” and the “Chinese virus.” Even the reactions to the protests that erupted in response to the murder of George Floyd—the so-called “looting and rioting”—were dismissed by many as politically illegitimate acts of violence caused by people going against the grain and disrupting an otherwise peaceful social order. This phenomenon is not exclusive to COVID. In the early years of AIDS, especially, gay men “...were similarly designated as geographical, social, or sexual others who, having disrespected national, cultural, or behavioral boundaries, were now putting the rest of us at risk” (Caron 103). The narrative always centers the misdeeds of “other” individuals, rouses determined not to be stopped, absolving governments from their obligations, as a result. Shifting the burden of responsibility is one of the ways in which the state abandons its citizens.

Fear is an interesting lens through which to examine AIDS and COVID, in particular, because there was not just fear about contracting the disease, there was also fear of the groups associated with the disease. For AIDS, that fear manifested as homophobia, and for COVID, it

manifested as anti-Asian racism. In *The Cultural Politics of Emotion*, Sara Ahmed writes, “objects of fear become substituted for each other over time” (67). For AIDS, fear of contracting the HIV virus becomes substituted for fear of gays and for COVID-19, fear of contracting the SARS-CoV-2 virus becomes substituted for fear of Asian people, particularly Chinese people. Over time, we stop fearing the virus itself, and begin to fear the body the virus inhabits. When we think about what it would mean to become infected, we don’t view ourselves and others as potential victims of a widespread and indiscriminate pandemic, we view ourselves as potential victims of the people who infect us. In this way, “fear does not simply come from within and then move outwards towards objects and others...rather, fear works to secure the relationship between those bodies; it brings them together and moves them apart through the shudders that are felt on the skin, on the surface that surfaces through the encounter” (Ahmed 62-63). Fear is not a static emotion confined to an individual, rather, it is a dynamic force that operates within social relationships. Moreover, fear is a collective response. It is not an abstract concept but something that is experienced viscerally by those who fear and those who are feared.

A common theme amongst many of the interviews, particularly the COVID interviews, was disappointment in how the pandemic could have and should have been an opportunity for major change. When asked about the future, Laura Larson, who was interviewed in February of 2021 stated, “the short term and the long term are just big question marks right now. And I don’t think the world should go back to the way it was before the pandemic. I don’t think anything was working before then either. And I think the pandemic has really showed us how, how those systems have been so screwed up for so long. And now we can’t ignore it anymore” (36:12-36:48). Vanessa Green, who was interviewed a year and a half later in August 2022 echoed those sentiments, saying, “the pandemic was showing us that we could be a better country, and it

didn't last" (12:38-12:56). Green reemphasizes this point later in the interview stating she does not feel good about the near future because people have just reverted to their pre-pandemic ways (1:45:16-1:45:33). COVID interviewee and spiritual healer, Alesha Van Buren, declares, "it's such a lonely [feeling] to exist in a world of millions but not have a voice" (13:30). She goes on to infer that we are so tired and beaten down which is why we don't demand more change and we just take morsels of change that will appease the masses temporarily, but ultimately change nothing. Even when we look at the AIDS pandemic, many ACT UP activists express disappointment in how the ACT UP coalition has been diffused, it no longer exists with the fervor or energy it once did. Scott Robbe of ACT UP even goes as far as to say he believes that the reason we still don't have a cure to HIV/AIDS is because ACT UP has been co-opted. Robbe states "A lot of people who were part of ACT UP went to work for pharmaceutical companies, and became lobbyists, and accepted pharmaceutical money. And they were co-opted. And many of the leading HIV docs that I knew back in the '80s went to work for pharmaceutical corporations. They were co-opted" (1:16:15-1:16:46). What can be gathered from both these accounts is that radicalism and hope for the possibility of change seem to have a time limit.

Why do these moments in time that seem to be serendipitous opportunities to disrupt oppressive social orders seem to fizzle away and result in a regression to the status quo? The anger is certainly there—Laura Larson proclaims, "this moment in time is indeed as difficult as I think it will look, in retrospect...people are very resilient...but the systems in place right now are as barbaric to us as they will probably feel in the future" (41:14-41:56)—and yet the momentum is eventually lost. One possible explanation could be that the terror of the present crisis and the fear of the unknown future makes us want to return to what we know; better the devil you know, as they say. Something bad but known feels safer than something unknown. Sara Ahmed writes,

“fear involves an anticipation of hurt or injury. Fear projects us from the present into a future...the object that we fear is not simply before us, or in front of us, but impresses upon us in the present, as an anticipated pain in the future” (65). A fear of the unknown future is still a fear one feels in the present moment. It transcends time and space and propels us into the future such that we feel a looming threat, even in the absence of actual danger. What results is an urgent reflex to return to “normal.”

Fear isn't always a bad thing and does not necessarily translate to how communities care for each other. COVID interviewee, Jeida K Storey, describes almost missing when people were a little afraid because she saw the way people cared for one another during the pandemic (ex: store hours that were exclusively for the elderly, care for the disabled, everyone being masked in medical buildings). She even misses the inconveniences because that was evidence of community care (18:06-19:15). What Storey is describing here is how fear does not need to be a paralyzing force but rather a motivating one. This phenomenon is present throughout the AIDS pandemic as well. ACT UP was comprised by mainly gays and lesbians, many of whom had HIV/AIDS, or at the very least had lost a loved one to the disease, and most probably had a very legitimate fear of contracting it themselves. Yet, ACT UP accomplished so much. Materially, ACT UP made strides with early approval for medications, sped up drug trials, and changed the patient advocacy model (actupny.com). In a more metaphysical sense, “ACT UP's greatest achievement was in providing a whole generation of people that activism works, a sense that they could make a change by advocacy and resisting normalcy” (Carlomusto 1:37:23-1:37:50). When asked about what they thought was ACT UP's biggest accomplishment was, Sam Avrett stated it was “teach[ing] audacity” (1:21:55), Sandra Elgear said it was that ACT UP “reminded people that civil disobedience works” (1:10:22-1:1-:26), and Dudley Saunders said it was that

ACT UP showed people they had the right to expect better treatment and to have power (1:09:45-1:09:58). What each of these ACT UP activists is pointing to is how despite immense fear surrounding the HIV/AIDS—whether it was fear on the unknown, fear of a loss of autonomy, or fear of state abandonment—people were still able to come together and make change. Fear, and emotions more generally, are legitimate points of reference to comprehend the world, and should not automatically be written off in exchange for logic/rationality; our senses point to very real truths.

Fear can function as a tool of power, but it can also be used as a tool to empower people to take decisive action. Those in positions of authority may use fear to maintain dominance, instilling a sense of intimidation or threat to enforce compliance or obedience. Fear can also be a tool of power in the Foucauldian sense, passed around from one person to the next and internalized in a way to compel a population in a certain direction. Conversely, fear can also serve as a powerful motivator to prompt mobilization. In the following chapter, I will further explore what that mobilization looks like. Using an understanding of queerness as relationships to power and positionality within dominant power structures, I will examine what radical activism that seeks to dismantle oppressive institutions looks like in comparison to politics that seeks to assimilate marginalized groups into hegemonic power structures.

Chapter 3: On Intersectionality, the Dangers of Identity Politics, and Queerness as a Political Commitment

In chapter one, I argued that care is not simply generosity and a kind disposition, but rather, it is actionable and a political commitment. In a similar fashion, in this chapter I will argue that queerness is not so much about sexuality as much as it is about positionality. To be queer is to stand in opposition to the state. Using the ACT UP organization as a case study, this chapter will explore the origins of identity politics and its limitations when co-opted, as well as the potential for a more radical, intersectional, and queer politics.

Originally coined by the Combahee River Collective, identity politics comes from the idea that oppression on the basis of identity can be a foundation for political radicalization. However, identity politics “was not just about who you were; it was also about what you could do to confront the oppression you were facing. Or, as Black women had argued within the broader feminist movement: ‘the personal is political’” (K. Taylor 11). Identity politics was about the way in which people could mobilize and confront their own oppressions. Identity politics was meant to validate the experiences of Black women, while also giving them an avenue through which to become politically active.

Since the creation of the term “identity politics,” we have seen it be used and abused. It has been co-opted such that identity politics are conflated with representation within normative structures. Fixed identities have become essentialized and representation of diverse identities has been bolstered as the pinnacle of social justice, while a focus on improving the material conditions of those living on the margins of society has largely been ignored. This phenomenon can be further studied using queer politics and the AIDS activist group, ACT UP, as a case study. Following the diffusion of ACT UP’s radical nature allows us to understand how identity politics

becomes co-opted, and what we can do to resist the tendency to assimilate. Moreover, we will investigate how queer politics and intersectionality can help ensure identity politics do not become watered down.

In Cathy J. Cohen's "Punks, Bulldaggers, and Welfare Queens: The Radical Potential of Queer Politics" she writes:

...queer theory stands in direct contrast to the normalizing tendencies of hegemonic sexuality rooted in ideas of static, stable sexual identities and behaviors. In queer theorizing, the sexual subject is understood to be constructed and contained by multiple practices of categorization and regulation that systematically marginalize and oppress those subjects thereby defined as deviant and "other." And, at its best, queer theory focuses on and makes central not only the social constructed nature of sexuality and sexual categories, but also the varying degrees and multiple sites of power distributed within all categories of sexuality, including the normative category of heterosexuality. (201-202)

Queer theory, although rooted in rejections of heteronormativity, concerns itself with pushing back against all normative power relations. If we define queer as standing in opposition to the state, individuals who are not cis-gender or heterosexual necessarily fall under this category because of their rejection of a heteronormative, nuclear family structure, but so do heterosexuals who do not conform to these hegemonic family structures, as well as anyone whose existence threatens the normative social order. What makes someone queer is not their sexuality, rather, it is about how people relate to dominant social structures. Following this same line of thinking, we see how there can be people who are not heterosexual, but also not queer, because despite their sexuality, they adopt heteronormative ideals. This can be described as "homonormativity," in other words, following hegemonic structures despite a queer sexuality. Homonormativity is an extension of normative power relations and an appropriation of queerness.

How we wish to fit into the existing social order greatly shapes our political aims. Those who are focused on assimilation will have drastically different goals than those concerned with

dismantling oppressive structures. During the AIDS epidemic in America, there were some AIDS activists who were very concerned with assimilation and the medicalization of AIDS activism and discourse, while others engaged in more radical politics, which would later be labeled as queer politics (Cohen 202). What set these activists apart was “their willingness to confront normalizing power by emphasizing and exaggerating their own anti-normative characteristics and non-stable behavior” (Cohen 202). Rather than attempt to police their behavior or act in a “respectable” manner, early AIDS activist chose to amplify aspects of themselves that deviated from social norms. In stark contrast to the more contemporary and liberal, “identity politics,” queer activism aims for “the destabilization of collective identity is itself a goal and accomplishment of collective action” (Gamson 403). Queer theory rejects the idea that stable and mutual identities are necessary for mobilization. Cohen writes, “I envision a politics where one’s relation to power, and not some homogenized identity, is privileged in determining one’s political comrades” (201). At ACT UP’s peak, it seems that the organization embodied the idea of solidarity based on shared goals rather than shared identity. When discussing what the common thread that linked ACT UP activists was, ACT UP member and primary interviewer for the ACT UP Oral History Archive, Sarah Schulman, stated,

people do not say the same things...They don’t repeat each other; they don’t use the same phrases. With very few exceptions, it’s overwhelmingly individual thinkers...the way I understand what all these people have in common is that it’s characterological. It’s a certain kind of person, regardless of what their experience was, or class background, anything; they could not sit still in the middle of a historic cataclysm, and do nothing... And that’s what links them. But nothing else links them. (1:18:41-1:19:18)

Schulman reveals how it was shared values and objectives that connected ACT UP activists rather than the mirage of shared identity. There were even straight members of ACT UP and ACT UP member Sam Avrett states that the lack of bureaucracy allowed anyone to join (42:28-43:43). If the organization had been centered around the idea of a common identity rather than

being centered around political action, it likely would not have made as much of an impact as did because there would have been concerns around who belonged in the group rather than what sorts of actions would improve the material conditions of those suffering from or at risk of contracting HIV/AIDS.

To further understand the dangers of identity politics and coalition-building on the basis of one-dimensional identity, we can look to Kimberlé Crenshaw's theory of intersectionality. As a legal scholar, Crenshaw first coined the term intersectionality in response to a discrimination lawsuit against General Motors. The purpose of *DeGraffenreid v General Motors* was to bring a lawsuit specifically on the behalf of Black women, alleging discrimination on the basis of both race *and* sex. The court, however, found

The legislative history surrounding Title VII does not indicate that the goal of the statute was to create a new classification of 'black women' who would have greater standing than, for example, a black male. The prospect of the creation of new classes of protected minorities, governed only by the mathematical principles of permutation and combination, clearly raises the prospect of opening the hackneyed Pandora's box. (Cited in Crenshaw page)

This leaves a gap in the legal system for Black women specifically whose identities as Black and as woman intersect, creating a unique lived experience which differs from that of Black men or White women. These intersecting identity categories cannot be separated from each other or analyzed in isolation. Intersectionality is what allows us to remain steadfast in the original definition of identity politics. Part of the reason why identity politics or aligning yourself with others based on a single axis of identity is problematic is because it leaves out people whose experiences are shaped by intersecting axes of oppression. Moreover, identity and experience are not always synonymous. Mobilizing based on shared goal, while understanding how one's personal identity fits into that goal will be more effective politically than simply aligning ourselves with people who claim a certain identity.

The Combahee River Collective (a Black feminist group) writes about the need to carve out a space of their own because they were excluded from the black nationalist movement as well as the (overwhelmingly White) feminist movement. They write, “The most general statement of our politics at the present time would be that we are actively committed to struggling against racial, sexual, heterosexual, and class oppression, and see as our particular task the development of integrated analysis and practice based upon the fact that the major systems of oppression are interlocking. The synthesis of these oppressions creates the conditions of our lives” (Combahee River Collective 292). For many, to mobilize around a single identity category is to deny to compounding effects of intersecting identity categories. Moreover, oppressive structures are interconnected and it is impossible to tackle a single form of oppression without understanding how these structures are interconnected and reinforce each other. If activist groups formed on the basis of liberation from all normative and hegemonic structures, our goals would be more aligned. Writing about the Combahee River Collective, Keeanga-Yamahtta Taylor states,

Black women’s social positions made them disproportionately susceptible to the ravages of capitalism, including poverty, illness, violence, sexual assault, and inadequate healthcare and housing, to name only the most obvious. These vulnerabilities also made Black women more skeptical of the political status quo and, in many cases, of capitalism itself. In other words, Black women’s oppression made them more open to the possibilities of radical politics and activism. (11)

Fixed categories can both empower, and constrain, but when it comes to queer politics, attempts to construct precise and homogeneous political identities obstruct the potential for radical politics.

Not only can organizing around an assumed shared identity be exclusionary, but it may also assume that said identity category is stable and the primary axis of oppression experienced

by members of that group. In “Must Identity Movements Self Destruct? A Queer Dilemma,” Joshua Gamson writes,

Gay and lesbian social movements have built a quasi- ethnicity, complete with its own political and cultural institutions, festivals, neighborhoods, even its own flag. Underlying that ethnicity is typically the notion that what gays and lesbians share—the anchor of minority status and minority rights claims—is the same fixed, natural essence, a self with same. (291)

The idea that sexuality has become a quasi-ethnicity assumes fixed characteristics and continuity of experience. Queerness differs from other identity categories in the sense that it is inherently fluid, something that a category such as race, ethnicity, disability, or class is not. Additionally, the term “queer” is very expansive, and even ignoring all other identity categories, can encompass a diverse set of experiences. For many, oppression on the basis of sexual identity may not be a primary concern.

In fact, for sexuality to be a primary concern requires a certain level of privilege, particularly in regard to race and class. Ruben Zeneca discusses this phenomenon in “Shameless Interruptions: Finding Survival at the Edges of Trans and Queer Migrations.” Zeneca describes how Trans Queer Pueblo, a queer of color, migrant, activist group located in Arizona, interrupted a 2017 Pride parade, toting banners stating, “Police out of Pride” and “Sin Justicia, No Hay Orgullo” which translates to “no justice, no pride.” The demands of the organization were to make pride safe for people of color, specifically migrants of color, by abolishing police presence at pride and cutting financial ties with organizations that support of mass incarceration of migrants of color (Zeneca 186). In response, “Pride attendees are seen harassing Pueblo members, shouting racial slurs, and shaming them for interrupting their festivities” (Zeneca 187). One white gay man tackled organizers carrying the “Sin Justicia” banner, while another yelled “SHAME, SHAME” and others yelled “This is our day, move it to the park . . . you are ruining

our parade” (Zeneca 187). These Pride attendees are attacking Pueblo for criticizing dominant power structures. While these white gay men are focused on acceptance and assimilation, for many queer, racialized migrants, assimilation is not even an option.

Queer identity also differs from other identity categories because what it means to be “queer” in many ways has been produced as the queer liberation movement has developed, but it was not a stable identity category prior to mobilization around sexual oppression. Gamson writes, “Identities... are typically conceived as existing before movements, which then make them visible through organizing and deploy them politically; feminism wields, but does not create, the collective identity of ‘women’” (392). The boundaries of what it means to be queer are negotiated in ways that other identity categories are not, and we see this in the example of ACT UP, as identity categories and even goals have changed over time.

Although it seems there was a time when ACT UP was a goal-oriented organization that was not overly concerned with identity politics, it seems that over time, the organization became less radical. Some former members say ACT UP started to fizzle out because of infighting and some people wanting a more radical politics while others were more focused on assimilating into the dominant power structures. Sandra Elgear says that ACT UP’s biggest failure was that ‘its activism didn’t move to other realms of social justice (1:12:12-1:12:14). Gary Kleinman alleges that splits in the organization had to do with people bringing in issues unrelated to AIDS such as marijuana and homelessness (1:25:43-1:26:1:26:38). It seems that ACT UP began to lose momentum when some members began to view ACT UP as a single-issue organization rather than an organization aimed at radical upheaval of unjust structures. It is especially interesting that former ACT UP member, John Weir, says that the biggest failure of the organization was the valorization of the person living with HIV and the sentiment that these were the only people able

to set the agenda (1:14:18-1:24:30). The valorization of the individual living with AIDS, as suggested by John Weir, sets up yet another hierarchical system in which only the people who hold certain identities are given a voice. Centering marginalized voices is important, but an awareness of intersectional identities of individuals living with HIV is necessary because a focus on only white gay men with HIV, is still hierarchal. Additionally, it excludes the plight of families, caregivers, and healthcare workers that are all deeply impacted by proxy. Privileging HIV-positive individuals over the unifying mission is an example of one-dimensional identity hampering intersectional coalition building and more expansive goals of radical social change that brought ACT UP's diverse members together initially. In contrast to earlier years, where ACT UP's strength came from its willingness to embrace anyone committed to the cause, the valorization of HIV-positive status as a prerequisite for leadership contradicts that ethos.

As mentioned in chapter one, many activists of color who were a part of ACT UP reveal that the organization never reconciled its issues with racism and sexism. Black, lesbian feminist, Barbara Smith, writes,

Unlike the early lesbian and gay movement, which had both ideological and practical links to the left, black activism and feminism, today's "queer" politicians seem to operate in a historical and ideological vacuum. "Queer" activists focus on "queer" issues, and racism, sexual oppression and economic exploitation do not qualify, despite the fact that the majority of "queers" are people of color, female or working class...Building unified, ongoing coalitions that challenge the system and ultimately prepare a way for revolutionary change simply isn't what "queer" activists have in mind. When lesbians and gay men of color urge the gay leadership to make connections between heterosexism and issues like police brutality, racial violence, homelessness, reproductive freedom and violence against women and children, the standard dismissive response is, "Those are not our issues." At a time when the gay movement is under unprecedented public scrutiny, lesbians and gay men of color and others committed to antiracist organizing are asking: Does the gay and lesbian movement want to create a just society for everyone? Or does it only want to eradicate the last little glitch that makes life difficult for privileged (white male) queers?" (n.pag)

Although written in 1993, this excerpt is just as poignant today. Queer politics must resist the urge to integrate into dominant social structures because they are exclusionary in nature and contradictory to what it means to be politically queer. Differing relationships to power exist among those who label themselves as queer, as well as those who engage with heteronormativity (although not mutually exclusive). Attempting to build coalition on the basis of a single identity category will always be exclusionary because it assumes a sameness that does not and has never existed.

The danger of singular focuses goes beyond identity; Sam Avrett reveals how focusing on only one aspect of a social problem, similar to how focusing on only one aspect of identity, does not do enough to address the root of the problem and eradicate it long term:

I think that there is something interesting, where there are organizations to tackle LGBT homeless. And there is a constituency, there's a large constituency to help the homeless teen; but not to help the homeless teen deal with the fact that they're schizophrenic, or that they're using heroin, or that they're HIV-positive. So there's a constituency for rights that doesn't necessarily want to embrace pathology, dysfunction, or services. (1:09:07-1:09:54)

Avrett also touches on the distinction between advocating for rights and providing practical services. While there may be widespread support for rights-related initiatives (such as LGBTQ+ rights or homeless rights), there is less enthusiasm for providing the necessary services to address the complex needs of individuals experiencing homelessness, particularly when those needs involve mental health or substance abuse issues. Focusing solely on the identity aspect of marginalized groups (in this case queer identity) can overshadow the broader and sometimes more complex issues they face and fail to address the underlying systemic factors contributing to marginalization results in inadequate solutions. Moreover, it can flatten the additional challenges posed by interlocking factors such as gender, race, and class. As stated by the Combahee River

Collective, “We are not convinced . . . that a socialist revolution that is not also a feminist and antiracist revolution will guarantee our liberation” (295).

Although it is important to advocate for tolerance and acceptance of all identities, Sarah Schulman argues that identity politics becomes problematic when the focus shifts from being accepted by the mainstream, to wanting to work within the system that once oppressed you, rather than dismantling it. Sarah Schulman discusses how in Canada, the integration of gays into the normative social structure has allowed for the development of a system of behavioral regulation. Schulman states,

But one of the issues there is that [Canada is] more advanced in gay rights than we are in the U.S...They have gay marriage, gay adoption; they have anti-discrimination, they have everything. And so in a weird way, straight people do look at gay marriage as an approximation of straight marriage, and they project onto it a certain kind of control of gay male sexual culture. And so it becomes antithetical to AIDS in their minds. In a way, gay marriage has been sold as a kind of antidote to AIDS. Because you never see the poster boys for gay marriage saying, I’m HIV-positive...So in a way, it helps allow a nation like Canada to get behind HIV criminalization. Because now they have the good queers and the bad ones. (1:07:56-1:08:44)

In Canada, same-sex marriage and other gay rights have worked to regulate sexual behavior; it casts queer individuals who adopt heteronormative family structures as “good” and those who refuse to assimilate as “bad.” When we fight for civil rights “by demonstrating similarity (to heterosexual people, to other minority groups) in a nonthreatening manner” (Gamson 396), in other words, on the basis that we will be able to assimilate without disrupting hegemonic social structures, we inherently allow ourselves to be policed by hegemonic standards. Representation requires assimilation, which is why identity politics focused on representation (as opposed to an identity politics that views identity as a locus for radicalization) fails.

If what’s most important to us is to be recognized and accepted by the mainstream, we lose sight of more actionable goals. The allure of mainstream validation can divert attention

away from addressing more deep-rooted issues. Scott Robbe, a former member of ACT UP, aptly points out that the failure to achieve a cure for AIDS may be attributed, at least in part, to the co-option of the movement. Robbe claims that some previous ACT UP activists went on to become lobbyists for pharmaceutical companies, or at minimum went to work for these companies or took their money in some way (1:16:15-1:16:46). As ACT UP's activism gained visibility and traction, some of its members transitioned into roles that aligned with the very institutions they once protested against. The trajectory of these activists reflects a compromise of principle for pragmatic gains. This example underscores a broader challenge faced by identity-based grassroots movements: the risk of being absorbed into the status quo they seek to challenge. The allure of assimilation or integration into dominant power structures dilutes the possibility of radical change, perpetuating the cycle of incremental, surface level change, at the expense of genuine progress.

Queerness represents a political position of resistance to normative power structures and hegemonic social orders; it is so much more than just an identity category based on sexuality. ACT UP demonstrated both the radical potential for a coalitional politics, as well as the pitfalls of identity politics that are devoid of intersectionality. Identity politics has radical potential when it is not watered down to representation of singular, essentialized identity categories, but rather, used to understand the importance of our positions in relation to dominant social structures. Liberatory queer politics must learn from Black feminism to reject assimilationist tendencies and the privileges of partial inclusion. Cohen writes, "At the intersection of oppression and resistance lies the radical potential of queerness to challenge and bring together all those deemed marginal and all those committed to liberatory politics" (203). Queer politics has an immense

transformative potential to upend the status quo and create new liberative models of being, community, and politics, beyond the constraints of singular identity categories.

Conclusion: Silence = Death Revisited

The conclusion to my thesis was presented as an oral history to Dr. Amanda Apgar on April 1, 2024, at 1:30pm. It will live in the collective memory.

Works Cited

- Abela, Arianne. IUPUI Arts & Humanities Institute. “The COVID-19 Oral History Project.” *A Journal of the Plague Year*, <https://covid-19archive.org/s/oralhistory/page/welcome>.
- ACT UP Accomplishments and Partial Chronology* | *ACT UP NY*. <https://actupny.com/actions/>.
- Agosto, Moises. “ACT UP Oral History Project.” *ACT UP Oral History Project*, <https://actuporalhistory.org>.
- Ahmed, Sara. “”*The Cultural Politics of Emotion*, NED-New edition, 2, Edinburgh University Press, 2014. *JSTOR*, <https://www.jstor.org/stable/10.3366/j.ctt1g09x4q.8>.
- Avrett, Sam. “ACT UP Oral History Project.” *ACT UP Oral History Project*, <https://actuporalhistory.org>.
- Banner Jr, James M. “All History Is Revisionist History.” *The National Endowment for the Humanities*, <https://www.neh.gov/article/all-history-revisionist-history>.
- Carlomusto, Jean. “ACT UP Oral History Project.” *ACT UP Oral History Project*, <https://actuporalhistory.org>.
- Caron, David. “Waiting = Death: COVID-19, the Struggle for Racial Justice, and the AIDS Pandemic.” *Being Human during COVID*, edited by Kristin Ann Hass, University of Michigan Press, 2021, pp. 93–116. *JSTOR*, <https://www.jstor.org/stable/10.3998/mpub.12136619.9>.
- Chatzidakis, Andreas, et al. *The Care Manifesto: The Politics of Interdependence*. Verso Books, 2020.

Cohen, Cathy J. “Punks, Bulldaggers, and Welfare Queens: The Radical Potential of Queer Politics?”

Sexual Identities, Queer Politics, edited by Mark Blasius, Princeton University Press, 2001, pp.

200–28. *JSTOR*, <https://doi.org/10.2307/j.ctv19fvxz3.12>.

Combahee River Collective. “‘The Combahee River Collective Statement’ (1977).” *Available Means*,

edited by Joy Ritchie and Kate Ronald, University of Pittsburgh Press, 2001, pp. 292–300.

JSTOR, <https://doi.org/10.2307/j.ctt5hjcnj.50>.

Crenshaw, Kimberlé. *Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of*

Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics. Source?

Dowling, Emma. *The Care Crisis: What Caused It and How Can We End It?* Verso Books, 2021.

ProQuest eBook Central,

<http://ebookcentral.proquest.com/lib/lmu/detail.action?docID=6450597>.

Ducket, Chip. “ACT UP Oral History Project.” *ACT UP Oral History Project*,

<https://actuporalhistory.org>.

Elgear, Sandra. “ACT UP Oral History Project.” *ACT UP Oral History Project*,

<https://actuporalhistory.org>.

Ellis, Maliya V., and Kevin Lin. *A Harvard Epidemiologist’s Reminder of Our Common Humanity* |

Magazine | *The Harvard Crimson*. 17 Apr. 2020,

<https://www.thecrimson.com/article/2020/4/17/nancy-krieger-coronavirus/>.

Fraser, Nancy. *Unruly Practices: Power, Discourse, and Gender in Contemporary Social Theory*.

University of Minnesota Press, 1989. *ProQuest eBook Central*,

<http://ebookcentral.proquest.com/lib/lmu/detail.action?docID=310198>.

Gamson, Joshua. "Must Identity Movements Self-Destruct? A Queer Dilemma." *Social Problems*, vol. 42, no. 3, 1995, pp. 390–407. *JSTOR*, <https://doi.org/10.2307/3096854>.

Greene, Vanessa. IUPUI Arts & Humanities Institute. "The COVID-19 Oral History Project." *A Journal of the Plague Year*, <https://covid-19archive.org/s/oralhistory/page/welcome>.

Heintzman, Kit. IUPUI Arts & Humanities Institute. "The COVID-19 Oral History Project." *A Journal of the Plague Year*, <https://covid-19archive.org/s/oralhistory/page/welcome>.

Held, Virginia. *The Ethics of Care: Personal, Political, and Global*. Oxford University Press, 2005. *academic.oup.com*, <https://doi.org/10.1093/0195180992.001.0001>.

Hobbes, Thomas. *Leviathan*. Lerner Publishing Group, 2018. *ProQuest eBook Central*, <http://ebookcentral.proquest.com/lib/lmu/detail.action?docID=5443203>.

Hogan, Katie. "Women and Aids: Paradox of Visibility." *Women Take Care*, Cornell University Press, 2001, pp. 1–32. *JSTOR*, <https://www.jstor.org/stable/10.7591/j.ctv3s8s70.5>.

Ilas, Maria Ignacio. IUPUI Arts & Humanities Institute. "The COVID-19 Oral History Project." *A Journal of the Plague Year*, <https://covid-19archive.org/s/oralhistory/page/welcome>.

John's Hopkins University. "Mortality in the Most Affected Countries." *Coronavirus Resource Centre*, 11 Oct. 2021, coronavirus.jhu.edu.

Johnson, Austin H., et al. "'We Already Knew What Time It Was:' HIV, COVID19, and Black Transgender Women in the South." *Journal of Health Care for the Poor and Underserved*, vol. 34, no. 3, 2023, pp. 99–118.

Johnson, Madison. “The HIV Epidemic and the COVID-19 Pandemic: Conversations with LGBTQ+ Elders of Color on Two Public Health Crises.” *Journal of Black Sexuality and Relationships*, vol. 8, no. 3, 2022, pp. 23–46.

Kittay, Eva Feder. *Learning from My Daughter: The Value and Care of Disabled Minds*. Oxford University Press, 2019. *academic.oup.com*,
<https://doi.org/10.1093/oso/9780190844608.001.0001>.

---. *Love’s Labor: Essays on Women, Equality and Dependency*. 2nd ed., Routledge, 2019,
<https://www.taylorfrancis.com/pdfviewer/>.

Kleinman, Gary. “ACT UP Oral History Project.” *ACT UP Oral History Project*,
<https://actuporalhistory.org>.

Larson, Laura. IUPUI Arts & Humanities Institute. “The COVID-19 Oral History Project.” *A Journal of the Plague Year*, <https://covid-19archive.org/s/oralhistory/page/welcome>.

Leap, Braden, et al. “Reorganizations of Gendered Labor During the COVID-19 Pandemic: A Review and Suggestions for Further Research.” *Sociological Inquiry*, Apr. 2022, p. page range needed
10.1111/soin.12488. *PubMed Central*, <https://doi.org/10.1111/soin.12488>.

Lerner, David. IUPUI Arts & Humanities Institute. “The COVID-19 Oral History Project.” *A Journal of the Plague Year*, <https://covid-19archive.org/s/oralhistory/page/welcome>.

Locke, John. *Second Treatise of Government: An Essay Concerning the True Original, Extent and End of Civil Government*. John Wiley & Sons, Incorporated, 1982. *ProQuest eBook Central*,
<http://ebookcentral.proquest.com/lib/lmu/detail.action?docID=7104098>.

Lorde, Audre. "Age, Race, Class, and Sex: Women Redefining Difference." *Campus Wars*, by John Arthur, edited by John Arthur and Amy Shapiro, 1st ed., Routledge, 2021, pp. 191–98. *DOI.org (Crossref)*, <https://doi.org/10.4324/9780429038556-22>.

Peetoom, Christie. IUPUI Arts & Humanities Institute. "The COVID-19 Oral History Project." *A Journal of the Plague Year*, <https://covid-19archive.org/s/oralhistory/page/welcome>.

Peterson, Brad. IUPUI Arts & Humanities Institute. "The COVID-19 Oral History Project." *A Journal of the Plague Year*, <https://covid-19archive.org/s/oralhistory/page/welcome>.

Locke, John. *Second Treatise of Government: An Essay Concerning the True Original, Extent and End of Civil Government*. John Wiley & Sons, Incorporated, 1982. *ProQuest eBook Central*, <http://ebookcentral.proquest.com/lib/lmu/detail.action?docID=7104098>.

Lorde, Audre. "Age, Race, Class, and Sex: Women Redefining Difference." *Campus Wars*, by John Arthur, edited by John Arthur and Amy Shapiro, 1st ed., Routledge, 2021, pp. 191–98. *DOI.org (Crossref)*, <https://doi.org/10.4324/9780429038556-22>.

Mack, Zoe. "Delegating Death: Foucault, Biopower, and Race in the Covid-19 Pandemic." *Living Histories: A Past Studies Journal*, vol. 1, June 2022, pp. 8–13. *ojs.library.queensu.ca*, <https://doi.org/10.24908/lhps.v1i1.15386>.

Mercer, Gary, and Nancy Berlinger. "Interdependent Citizens: The Ethics of Care in Pandemic Recovery." *The Hastings Center Report*, vol. 50, no. 3, 2020, pp. 56–58. *PubMed Central*, <https://doi.org/10.1002/hast.1134>.

Mercier, Laurie. "Probing Memory and Experience: The Untapped Potential of Oral History (Re)Collections." *Oral History, Community, and Work in the American West*, edited by Jessie L.

Embry, University of Arizona Press, 2013, pp. 42–58. *JSTOR*,
<https://www.jstor.org/stable/j.ctt183pbgk.7>.

Milner, Clyde A. “Afterword: When History Talks Back.” *Oral History, Community, and Work in the American West*, edited by Jessie L. Embry, University of Arizona Press, 2013, pp. 327–38. *JSTOR*, <https://www.jstor.org/stable/j.ctt183pbgk.20>.

Robbe, Scott. “ACT UP Oral History Project.” *ACT UP Oral History Project*,
<https://actuporalhistory.org>.

Robertson, Campbell, and Robert Gebeloff. “How Millions of Women Became the Most Essential Workers in America.” *The New York Times*, 18 Apr. 2020. *NYTimes.com*,
<https://www.nytimes.com/2020/04/18/us/coronavirus-women-essential-workers.html>.

Rousseau, Jean-Jacques, et al. *On the Social Contract*. Hackett Publishing Company, Incorporated, 2019. *ProQuest eBook Central*,
<http://ebookcentral.proquest.com/lib/lmu/detail.action?docID=5717471>.

Saunders, Dudley. “ACT UP Oral History Project.” *ACT UP Oral History Project*,
<https://actuporalhistory.org>.

Sequeria, Christopher. IUPUI Arts & Humanities Institute. “The COVID-19 Oral History Project.” *A Journal of the Plague Year*, <https://covid-19archive.org/s/oralhistory/page/welcome>.

Smith, Barbara. *Where’s the Revolution?* 2 Jan. 1998. *www.thenation.com*,
<https://www.thenation.com/article/activism/wheres-revolution/>.

Storey, Jeida K. IUPUI Arts & Humanities Institute. “The COVID-19 Oral History Project.” *A Journal of the Plague Year*, <https://covid-19archive.org/s/oralhistory/page/welcome>.

Tang, Fiona. IUPUI Arts & Humanities Institute. "The COVID-19 Oral History Project." *A Journal of the Plague Year*, <https://covid-19archive.org/s/oralhistory/page/welcome>.

Taylor, Dianna, editor. *Michel Foucault: Key Concepts*. Acumen, 2011.

Taylor, Keeanga-Yamahtta. "How We Get Free: Black Women and the Combahee River Collective," Haymarket Books. Year

Tronto, Joan. *Moral Boundaries: A Political Argument for an Ethic of Care*. Routledge, 2020, <https://doi.org/10.4324/9781003070672>.

Van Buren, Alesha. IUPUI Arts & Humanities Institute. "The COVID-19 Oral History Project." *A Journal of the Plague Year*, <https://covid-19archive.org/s/oralhistory/page/welcome>.

Vaughn, Trisha. IUPUI Arts & Humanities Institute. "The COVID-19 Oral History Project." *A Journal of the Plague Year*, <https://covid-19archive.org/s/oralhistory/page/welcome>.

Weir, John. "ACT UP Oral History Project." *ACT UP Oral History Project*, <https://actuporalhistory.org>.

When AIDS Was Funny. Directed by Scott Calonic, Vanity Fair, 2015.

Williams, Dan Keith. "ACT UP Oral History Project." *ACT UP Oral History Project*, <https://actuporalhistory.org>.

Woodly, Deva, et al. "The Politics of Care." *Contemporary Political Theory*, vol. 20, no. 4, Dec. 2021, pp. 890–925. *Springer Link*, <https://doi.org/10.1057/s41296-021-00515-8>.