INTRODUCTION

"Women Don't Get AIDS, They Just Die from It"

In 1987, Patricia Nalls sat at the kitchen table in her new apartment planning her funeral and waiting for the phone to ring.[1] This was not the life, or death, she expected. For years she had been happily married and living in the suburbs. She had two beautiful children – each a blend of her Indo-Guyanese and her husband's African American heritage. They were thriving and happy. And she was pregnant with a third. While her husband had injected drugs in the past – it was in the past. His frequent illnesses were dismissed by doctors as a cough, the flu, and allergies. It wasn't until one protracted hospital visit, when his body seemed to be withering away, that he was finally tested for HIV. His shocking diagnosis didn't allow time for the family to process.

Patricia's positive test result came shortly after her husband's diagnosis. Her youngest child, born a few months later, was immediately diagnosed with AIDS. Patricia's daughter and husband died within months of each other. As Patricia planned her own funeral, she mourned the loss of her child and her husband. She grappled with the reality that her own fate would mirror theirs.

Patricia also worried. Her children, who did not have HIV, would long survive her. She worried about their future and who would take care of them when she died. She was struggling financially and afraid to disclose to her family why she was unable to work. She was alone.

Patricia did not know any other women living with HIV. Like most people in the United States at the time, she didn't think women could even get the virus. To her, and nearly everyone else, AIDS was a disease associated with gay men and people who injected drugs. On one visit to the doctor, tired of feeling so isolated, Patricia asked her physician if she was the only woman in America living with AIDS. She was surprised when her doctor reassured her there were others. Desperate to make contact with these women, she installed a landline in her home, a financial stressor for her but worth it for the possibility of connecting with other women living with HIV. Patricia pasted signs at her physician's office asking women living with HIV to call her. Then, she waited.

To her amazement, her phone began to ring. And ring and ring again. She spoke to women who were living in secrecy and fear. They shared their stories of living with HIV, their desire to protect their children, and their inability to get support. Before long, the women began to regularly meet. Together, they supported each other in doing the unthinkable: Putting on a brave face to drive their children to school in the morning, only to return home to make arrangements for dealing with sickness and death.

Patricia began to encourage the women who called her to pool resources. They took turns driving each other's kids to school, babysat during doctor's appointments, and shared food stamps so that the children could eat. When a woman fell ill, the others took her children in; without that, the kids could be lost to child protective services and sent to live with strangers.

To them, the AIDS response itself excluded women and ignored their particular needs. In the late 1980s, no one was talking about women and AIDS. The few services that existed felt alienating: Children were not allowed to board the buses that picked up AIDS patients to take them to doctor's appointments. Because of this, women with few childcare options often missed their checkups. Support groups designed for men had little to offer women who were caring for sick children while they themselves were unwell. Food programs only provided food for people living with AIDS, not for their children. Women starved so their children could eat.

Heartbroken, Patricia watched her friends as they became weak and succumbed to death due to AIDS-related complications. She watched as children were lost to the foster system, the lucky ones taken in by family or friends. And she battled her own health challenges – but she did not die. She is still alive today. Her survival is the remarkable outcome of a feminist struggle that altered the regulatory and scientific landscape on AIDS.

* * *

Fifteen years after Patricia asked her doctor if she was the only woman in America living with AIDS, the United Nations Joint Program on HIV and AIDS (UNAIDS) declared that women were the fastest growing group of people living with HIV. The epidemic had been "feminized."

AIDS was not supposed to impact women in large numbers. In the 1980s, when confusion and death reigned, scientists and epidemiologists chased hypotheses about the disease: Was it a gastrointestinal virus? A pneumonia? A cancer associated with gay men? A gay plague?[2] The now infamous nonresponse by the United States government to the epidemic included the disregard by the Reagan administration of the spread and impact of the virus, a lack of investment in access to treatment, and the stigmatization of people living with HIV. The sexual politics of AIDS complicated the possibilities for research and public health interventions and contributed to a lack of clarity about the virus.

Experts disagreed about the likelihood that heterosexual sex was a key mode of HIV transmission. The idea that women were resistant to contracting HIV gained traction in the popular press. Take the 1985 *Discover Magazine* cover story "AIDS: The Latest Scientific Facts," which reported that women have "rugged vaginas."[3] According to text accompanying a cross-sectional image of a vagina, the organ's tough and resistant cells made women unlikely to contract HIV. This idea was repeated time and again. In a book published in 1990, reviewed by the *New York Times* and *New England Journal of Medicine*, *The Myth of the Heterosexual AIDS Epidemic: How a Tragedy Has Been Distorted by the Media and Politics*, journalist Michael Fumento reproduced the idea that differences in the tissue construction of the male urethra and rectum and the female vagina – the latter being constructed of tough cells that "resist rupture".[4]

In the broader struggle to understand who was at risk for HIV, the idea that women were biologically resistant to AIDS was repeated time and again by science journalists, in popular women's magazines including *Cosmopolitan*, on nightly news programs, and in national newspapers including the *New York Times*.

How did the world ultimately come to see women as "at risk" for HIV? How did a disease of men come to kill women? Against a linear narrative of scientific discovery and progress, as accounts of disease mitigation are often told, *Risk and Resistance* shows that it was the work of women's rights lawyers and activists, not only scientific experts, that fundamentally altered the legal and scientific response to the AIDS epidemic by changing core conceptions of who was at risk of contracting HIV. With this powerful example of the feminist struggle in AIDS, I argue that public health advocates not only fight to change legal rules, they may also destabilize scientific settlements and expert consensus for the sake of redistribution. In the context of AIDS, feminists not only changed the legal governance of AIDS, they altered the scientific trajectory of the epidemic. In doing so, feminists channeled money and services toward women in the AIDS response. Many of these feminists were women of color who centered race in their advocacy; they both raised critiques of the mainstream AIDS movement and joined forces with broad advocacy to demand services for people of color. Feminists advocated for women to be seen as a risk group for HIV in multiple locations: in US administrative agencies, courthouses across the country, as well as in global governance institutions.[5] This book excavates the impact feminism – with all of its ideological diversity – has had on scientific ideas and legal reform agendas in the AIDS response.

Risk and Resistance makes several contributions to existing scholarly literatures on law, feminist theory, science and technology studies, and public health.

Health law scholars and epidemiologists broadly define the social determinants of health as the conditions in which people live their lives that impact their health outcomes. Health law scholars understand law to be a social determinant of health in that the legal environment shapes health outcomes. While much attention has been paid to understanding legal frameworks, less attention has been dedicated to understanding how legal transformations occur with the specific goal altering epidemiology and medicine to bring about legal reforms.

Risk and Resistance bears down on the question of how social movements mobilize to transform laws and unsettle scientific consensus in order to alter the distribution of public health resources toward particular groups.[6] Most often, science in this book refers to epidemiology, the science of disease and its spread. At some points, however, as noted in the text, I discuss shifts in basic science.

The focus on social movements allows for a greater examination of how politics shapes public health law. The book argues against the idea that it is necessary to excise politics from health governance; instead I argue that a deep understanding of how law, science, and politics interact is necessary to understand and remedy deep inequalities that persist in healthcare.

Examining the role of social movements allows for a sustained examination of how legal and political activism can redistribute resources and legitimate its claims in the register of scientific neutrality. In the literature on law and social movements, legal advocacy plays an unsettled role in social change: Some social movement scholars argue that lawyers and litigation have the potential to deradicalize social movements and derail social change. In response, other scholars argue that while outcomes are indeterminate, advocates utilizing litigation strategies and seeking legal transformation are frequently propelled forward through the fight for reforms.[7] Rather than derail social change, the law offers a set of possible goals, a new vernacular for channeling movement desires, and the legitimation of advocacy claims.

Yet, while law and social movements scholars are interested in social change, and many have long recognized that legal mobilization has impact far beyond simply changing legal rules and their formal application, law and social movements scholarship might ignore the role of law, lawyers, and litigation for the sake of explicitly altering scientific consensus in order to redistribute material resources toward a particular group. In turn, this creates gaps in the legal scholarship about how social change related to a host of areas depending on science and technology occurs, including, as relevant here, in the realm of public health law.

The idea that law and science are made in isolation of one another is tied to the notion that law lags behind science. In other words, the legal regulation of science is doomed to perpetually lag behind scientific progress or, even worse, constrain scientific discovery.[8] Science and technology studies (STS) scholars call this the "law lag" thesis. More specifically, public health scholars similarly argue that the legal regulation of health should be based on medical and scientific evidence. In other words, science and expertise should lead the way. Each of these arguments suggests that while law and science interact, they are fundamentally distinct from one another.

Scholars, activists, and legal practitioners tend to reify the notion that science and law are distinct. This is done through the insistence that scientific and medical evidence should lead the way in crafting the regulatory environments on gender and health and through the flip of this, which is an insistence that good scientific and medical research and advancement not be tainted by an overly burdensome regulatory environment.[9] The feminist activist claim that women's decision-making on abortion be left to "a woman and her doctor" – a slogan found on buttons and bumper stickers – operationalizes (and exemplifies) the law/science distinction in its insistence that we preserve expert and evidence-driven medical practice without the taint of law. This analytic and activist move elides the way that evidence itself is the product of legal and social contestation.

Attempting to remedy this gap, STS scholars, largely drawing on the work of STS scholar Sheila Jasanoff, challenge the view that legal regulation and science can be kept distinct. Instead, these scholars use the idea of coproduction to examine the relationship between governance and the production of scientific and technical knowledge.[10] In the legal literature on social movements, very little attention is paid to the specific contours and pathways that legal rules, legal institutions, and court decisions – as well as litigation in court – alter the field of knowledge and can shape the distribution of material resources – including healthcare – between populations.[11]

As evidenced in the case of the feminist AIDS movement, this mode of inquiry – one in which the coproductive aspects of law and science are interrogated with an eye toward the distributive consequences – helps to identify the legal–scientific settlements that justify legal regulation.[12]

The story of women's activism in the AIDS response provides a powerful example of coproduction, as feminist lawyers go deep into the tangle of science and the distribution of welfare benefits to recraft who can be diagnosed with AIDS.[13] It is a clear example of how law does not always lag behind science. Instead, the law can play an important role in mediating, constraining, and creating possibilities at the intersection of science and rights.[14] And, in turn, how the ideologies of social movements, in this case the feminist critique of science, shape legal claims. By tracing one site of the constitutive relationship between law and science, the book draws out several lessons for law and social movements scholars thinking about how legal actors mobilize the law to alter science and vice versa: First, that social movement actors utilize litigation to unsettle scientific and medical consensus with the explicit goal of altering the distribution of rights and resources, and, second, that social movement frames – like the feminist critique of science – shape the form and substance of rights claims made by advocates.

The book proceeds as follows. Chapter 1, "'We Are Not Immune': A New Branch of the Feminist Women's Health Movement," begins by describing the emergence of a new coalition of feminists who turned their attention to the HIV epidemic in an attempt to understand how the virus would impact women. Together, they realize that an epidemic is brewing among women. The failure to recognize and respond to it is due, in part, to the Centers for Disease Control and Prevention (CDC) definition of AIDS that did not include gynecological infections. This definition resulted in the exclusion of women from AIDS data and in the Social Security Administration's determinations of who should receive benefits. Allying with lawyers and fellow activists, feminists set out to challenge the law and science of the epidemic.

Chapter 2, "Litigating Risk: The Law and Politics of Disease in the Administrative State," turns to the litigation and activism that resulted in the shift in the AIDS definition and turned attention to women's risk from HIV. The chapter tracks how litigation and advocacy changed settled ideas of who was at risk for contracting HIV. Feminists prevail – their success would result in many more women being diagnosed with HIV, resulting in a greater ability to access benefits. This life-changing shift would mark a major victory for the feminist women's health advocates focused on AIDS. Their story challenges the narrative of scientific progress and produces a new legal–scientific settlement on the question of women and AIDS.

Once women were diagnosed with AIDS in large numbers, and AIDS treatments were developed, more people with HIV began to survive longer. New AIDS drugs turned out to be toxic or intolerable for some people leading researchers to conduct new trials. A new problem emerged: Women were being excluded from clinical trials due to a 1977 Food and Drug Administration (FDA) guideline concerned about the impact on women's reproduction and the fetus. In practical terms, however, this meant that women could not access new drug trials and that what physicians knew about how to treat women was severely limited. Chapter 3, "Experiments in Risk: Clinical Trials and Women," follows feminist advocates as they set out to change the regulatory environment around clinical trials to mandate the inclusion of women. They did so by asserting – in keeping with the broader feminist women's movement at the time – that women have full autonomy over their bodies and may choose to take part in risky trials. Partly due to the shifting sensibility around ideas of women's choice and autonomy, the FDA produced new guidance in 1993 that took steps toward addressing the discrepancy between men and women in clinical trials.

The growing numbers of women living with HIV begged a question: Why and how were women at risk for HIV? Chapter 4, "Sex Bargains," tracks the emergence of a new logic that centers heterosexual sex as the site of women's vulnerability. Attributing vulnerability to HIV to heterosexual sex had a powerful effect: It minimized the emphasis on structural responses to the epidemic, from housing to harm reduction, and instead focused public health interventions on individual behavior. Feminist activists and scholars, as well as law and economics scholars, motivated by a desire to shape lawmaking on the epidemic in light of their own theories of sex debated one another on how to best respond. Partly due to the political and economic backdrop of the time, the two movements focused in on the sex bargain, the negotiation between two people before engaging in sex. Despite their different perspectives and goals, the convergence between these two scholarly and activist movements helped drive a response to HIV that would shift attention away from structural interventions and focus on individual behavior. This chapter tracks this debate and the impact it had on the legal response to HIV.

As heterosexual sex became a driving explanation, feminist debates about sex and power took center stage in the AIDS response. At the heart of this feminist struggle is the question of sex work. Some feminists, carceral antitrafficking feminists, saw sex work as the objectification and exploitation of women. Others saw it as a potential site of agency and power. Chapter 5, "The Sex Wars Come to AIDS: Risk and Consent," follows these debates as they moved into public health and the AIDS response. Sex workers were (and continue to be) among the hardest hit with HIV. They were also some of the most powerful advocates of a safe-sex approach. Empowering sex worker communities would turn out to be one of the most reliable ways to slow the spread of HIV. But for feminists who saw sex work as exploitation, these public health interventions were aiding in harming women. Buoyed by political conservatives and a larger movement to end human trafficking, carceral antitrafficking feminists successfully lobbied for restrictions on funding sex worker projects. The consequences were deadly.

In reflecting on the social movement activism documented in the book, and in thinking about contemporary public health crises, the Conclusion offers a new framework to describe the momentary stabilization of scientific facts in and through lawmaking: legal–scientific settlements. These legal–scientific settlements produce a range of distributional consequences that have material effects on people's lives and shape the ability of individuals to survive and thrive despite public health crises.