# Archives, Criticism, and Care: Tending to Archival Work in the Rhetoric of Health & Medicine

## Julie Homchick Crowe and Ryan Mitchell

Abstract: This essay centers care as a generative methodological orientation for feminist rhetorical historians working in medical archives. Moving beyond archival research that prioritizes recovery, the authors outline how caring for the materials housed in medical archives shifts focus to the ideological and institutional infrastructures that shape how rhetorical histories of health and medicine are preserved and produced. Through theoretically informed mediations on their respective work in polio and AIDS archives, the authors illustrate how seemingly mundane archival practices can significantly impact how researchers engage with historical materials and the stories they tell. This essay encourages RHM scholars to develop a more nuanced understanding of how archives shape and constrain historical narratives by foregrounding care as an intellectual, embodied, and sensuous mode of engagement. Ultimately, the authors argue that caring for medical archives requires a commitment to understanding and addressing the transhistorical forces that continue to marginalize and silence marginalized communities.

Keywords: care, archives, infectious disease, health, rhetorical histories

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## Introduction

Rhetoricians of health and medicine study diverse texts to understand the rhetorical practices that constitute and resist the normative scripts that define what it means to occupy un/healthy bodies. This task can be particularly harrowing for those of us who work in medical archives. The objects we work with often tell stories of sickness, loss, trauma, and institutionalized violence that quite literally pile up on top of one another, providing material evidence of the physical, emotional, and textual weight of illness. In writing rhetorical histories of health and medicine, it can be tempting to alleviate some of that weight by recovering hidden, potentially liberatory strategies housed in medical archives. Through such acts of recovery, we might attempt to reanimate the stories of victims of biomedical neglect and abuse in ways that (re)invest them with familiar forms of rhetorical authority. However, as critical feminist, queer, and queer of color scholars from a range of disciplines have repeatedly demonstrated, focusing too narrowly on acts of recovery ery risks inadvertently reinforcing the exclusionary and patriarchal discourse norms endemic to liberal

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models of the public sphere.

Feminist researchers working in medical archives can avoid such affirmations by following Glenn's (2018) lead and developing tools "exploring other sides of rhetorical production and histories" (114). Moving beyond concerns for merely incorporating excluded voices into already-established rhetorical frameworks, the tools that Glenn calls for prompt active, self-critical reflection on how we—as historically and politically situated knowledge-producers—orient ourselves conceptually, methodologically, and affectively to the documents we study. Instead of engaging with archival materials from a detached zero-point perspective, Glenn urges feminist rhetorical historians to "attempt respectful, dialogical connection rather than impartial detachment" (99). In other words, Glenn's vision of archival work demands that feminist rhetorical scholars embrace an ethics of care—not just for the documents and ephemera we interact with, but also through careful attention to our own positionalities and the lives of those made both present and absent within an archive's holdings.

It is in this spirit that we outline how "care" functions as a critical tool that feminist-aligned rhetoric of health and medicine (RHM) scholars can employ as we enter medical archives. Along with gesturing toward a terrain that is all too familiar to RHM scholars—health care—care also indexes an ethical orientation toward the continual, transhistorical networks of labor that support our work in archives. "Care is work," reminds health humanities scholar Rachel Adams (2023), "an attitude toward others, and an ethical ideal" (19). As a critical tool for rhetorical histories of health and medicine, care not only shines a light on the often-invisibilized work done by the historical figures we study, but also on the transhistorical infrastructural networks of labor required to preserve historical materials and, importantly, the work that we as academics must do to produce our scholarship.

This short essay, therefore, positions care as a generative keyword for RHM historical work, conceptualizing it as an intellectual, embodied, and sensuous mode of archival engagement, a critical mode of intimate encounter with histories of both health and wellness and death and dying. In other words, we understand care as more than just a researcher's careful handling of historical materials with common tools like gloves, tweezers, and weighted page holders; we also see care as an epistemological and affective type of rhetorical *tending* to 1) discrete archival holdings, 2) the stories they tell, 3) the wider rhetorical and institutional ecologies within which they circulate, and, finally, 4) the potential histories researchers can co-construct with those materials. At base, then, caring for medical archives means taking archives on their own terms.

As we see it, the first step to taking medical archives on their own terms is setting our gaze on the material and institutional infrastructures that condition what types of information we encounter in our research. Below, we share formative experiences working in the archives of two US-based public health calamities: the polio pandemic and the AIDS crisis. Through theoretically informed mediations on our engagement with the material "vibrancy" (Bennett, 2010) of these archives, we show how caring for historical

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materials within RHM animates what has been lost in text, body, and the spaces in between. Not only can the careful tending to buried and forgotten stories help us better understand lived experiences of disease, it can also help prompt self-aware reflection on how we might produce rhetorical histories of health and medicine without retreating into mere recovery. Ultimately, we aim to demonstrate a way of caring for medical archives that engages them as repositories of knowledge as well as living entities that demand ethical, respectful, and critical interrogation.

## Archives and Erasure (Julie)

In my work on the polio epidemic of the 1950s in the US (Crowe, 2022), the archives I worked in for the project illuminated the power of absence, not just in the archive, but in the events of history the archive embodied. The project broadly sought to explore how the identity of the "potential victim" in public health campaigns was articulated, namely during the polio and HIV/AIDS pandemics in the US. I conducted this research during the first year of the COVID-19 pandemic as well, which made the topic not only more salient but also forced the project to rely on digital archival materials given the wide closures across the country. Using the Franklin Delano Roosevelt Presidential Library digital collection, I was able to locate materials from the National Foundation for Infantile Paralysis (later called the March of Dimes) and from the Roosevelt Warm Springs Institute for Rehabilitation.

The images and advertisements were telling - FDR on crutches with other polio patients at Warm Springs; children in wheelchairs with text saying "I could be your child"; and more. Many offered support for my argument that potential victims become constituted as subjects in pandemics, particularly in cases where one might not suspect their vulnerability and, as became evident, if the potential victims were white. Scholars like Naomi Rogers (2017) had already, of course, noted that polio became more and more of a "white disease" through the 1940s. FDR's facility only served white patients, March of Dime Posters largely only featured white children, and those clamoring for healthcare resources began to argue that Black people were immune to the disease when in fact, as Rogers notes, "Black polio cases were missed as the result of medical racism" (p. 785). In working with this archival material for the first time, the observable absence of Black people was so noteworthy, not just because of a lack of records or a simple incompleteness in materials, but because of how that archival absence signified a lack of diagnoses, care, and treatment for Black Americans.

Considering such erasures, Jackie James (2003) offers a relevant exploration of her work in the polio archives, though the absences she notes are those of documents and ephemera that erase the voices of those who still live with polio and its after-effects, which creates a false binary between a pre- and post-polio vaccine world. As such, she notes that, "Archives are a place where the bodies and lives of those who were not convenient, valued, or of interest in a given historical moment are often erased" (49). Extending her observations, though, historians and rhetoricians must not only account for what happened and wasn't recorded, but also attend to what *didn't* happen. In the case of the minimal archiving of Black individuals with polio, we must first recognize that it is not simply a lack of documentation of polio victims that erases them from historical narratives, but an actual lack of diagnoses and care in the first half of the twentieth century. Simply put, the records aren't there because the care wasn't there, either.

We are likewise pointed elsewhere – outside of the traditional archive – to notice the persistent erasure of Black bodies and voices in medical care. Through repeated narratives of insusceptibility to disease or suffering, absences in the archives permeate public consciousness and often serve as a smokescreen for denying medical attention. Consider, for example, racist narratives about Black mothers in labor - the denial of their pain and the erasure of voice has led to an abysmal maternal mortality rate in the US, where Black women are 2.6 times as likely to die from pregnancy-related complications than white women (Hoyert, 2021). We must, then, think about erasure as both part of and beyond the archive. In denying that the archive is just a traditional storage house of knowledge, Foucault (1972) maintains that the archive is instead a discursive practice and set of relations that "establish statements as events" (128) so that when we encounter erasure we can see that it is not just the physical absence of material and records, but an embodiment of and repeated denial of care and treatment. We, therefore, see within and without the archive, an erasure of pain or suffering through a "field of stabilization" (103) in a way that is not fully inscribed in detail in the text of the archive, but rather is noticeable in the "dark margin encircling and limiting every concrete act of speech" (Agamben, 1999, p. 144). For the medical rhetorician and historian, then, the care that the scholar must take in medical archives is not just about material attention to the archive's holdings, but also about the care extended into the margins, the absences, and in the writing of the histories of those who were not just denied space in the archive, but denied medical care as well.

The space in between text and the absences within an archive, ultimately, tell us about whose voices and bodies were valued and whose were not in the history of health and medicine. Foucault's and Agamben's work, though, in some ways, provides us hope for thinking about how we can reclaim these voices and lives and animate them anew. If we can see the archive as more than the text, pictures, and documents that we see in file boxes or digital collections, then we can likewise engage in modes of archival inquiry that interrogate the fascia holding archival artifacts together. Always incomplete, the archive still holds traces of lives ignored that scholars can reanimate, providing hope for glimpsing what once was forgotten. Such hope, of course, does not right the wrongs of denying care to Black Americans - rather, it can help us sort the remnants and traces of what remains so that we can better understand and honor those whose memories live among the lexical and visual absences within archives.

## Access, Infrastructures, and Intimate Relationality in AIDS Archives (Ryan)

The tragic loss of life caused by HIV/AIDS means that much of the "official" knowledge about the early years of the North American AIDS crisis comes to us through archives. To be sure, these archives perform the crucial task of preserving *some* of the ways that People with AIDS (PWAs) and their allies fought against social prejudice, medical neglect, and political apathy. Nevertheless, the materials contained in most institutional AIDS archives can perpetuate a problematic "founding narrative" of AIDS activism

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(Cheng et al. 1). This narrative disproportionately emphasizes the efforts of the white, well-connected, highly resourced, cosmopolitan gay men who mobilized in the 1980s and '90s while overshadowing the significant contributions that BIPOC, trans, disabled, poor, and women activists have made and, indeed, continue to make to various HIV/AIDS movements. Not only does the partiality of AIDS archives lead to the production of lopsided histories, it also hampers contemporary efforts to reduce the unequal burdens that HIV/AIDS imposes on minoritized communities. Lapses in preventive screenings caused by the COVID-19 pandemic, coupled with rising racism, homophobia, stigma, and poverty, have resulted in a troubling increase in new HIV diagnoses, particularly among Black and Latine populations (CDC). Thus, despite the availability of effective pharmaceutical interventions such as HAART and PrEP, HIV/AIDS remains a pressing public health, political, and social justice issue.

Addressing the intersecting social, political, and material demands of HIV/AIDS undoubtedly requires renewed attention to how we write histories of the epidemic. However, writing more robust histories involves more than merely incorporating the overlooked contributions of marginalized activists into existing AIDS timelines. As Cindy Patton points out in her foreword to Jih-Fei Cheng, Alexandra Juhasz, and Nishant Shahani's important edited collection, *AIDS & The Distribution of Crises*, "It is not simply [enough to say] that histories of AIDS have ignored women, or Black individuals, or children, as if inserting these groups into the founding narrative resolves the issue" (ix). Instead, emerging critical AIDS scholarship must account for how archiving practices themselves—acquisition procedures, processing protocols, indexing techniques, and storage methods—continue to hinder more equitable and just forms of AIDS activism. As Marika Cifor has recently warned, "Framing AIDS and its archives as relics of a distant past defangs contemporary AIDS crises in the United States." Cifor contends that responding to the crises that surround HIV/AIDS requires scholars to self-consciously resist the "depoliticization" that results from the "simplistic historicization" of the epidemic and instead begin interrogating the archival infrastructures that preserve what are only ever provisional AIDS histories (5).

Guided by these insights, I suggest that rhetorical historians of health and medicine might resist such simplistic historicizations by attuning ourselves to the different institutional and affective practices that care for the materials housed in AIDS archives. Reflecting on an experience when I inadvertently accessed an early AIDS activist's unredacted medical records, I consider how this failure in infrastructural care allowed for an excessive degree of access that compelled me to develop a responsive sense of intimacy with the activist. By problematizing the dynamics between infrastructural access and care, I outline how intimacy—as an ethical and methodological orientation—creates opportunities for writing more comprehensive rhetorical histories of health and medicine without violating patients' rights to privacy.

# The Event

In the fall of 2019, I visited a small, queer-run AIDS archive. I was interested in studying the discursive negotiations that took place as early AIDS educators, the majority of whom had minimal practical medical experience, accommodated technical information about AIDS. I had come to this archive to review the records of one particularly influential AIDS educator who frequently collaborated with members of the mainstream medical establishment. Working through the collection, I found ample evidence of this activist's rich correspondence with doctors and public health representatives alike. I had that wonderful feeling that everything was falling into place.

Halfway through my visit, I opened a folder containing pages and pages of un-redacted sensitive medical and financial documents. I was looking at lease statements, bank account ledgers, disability applications, papers that noted his social security number, and perhaps most shockingly, medical discharge papers that detailed specific diagnoses, insurance information, and payment plans. What lay on the table before me was overwhelming evidence of the harrowing tolls of AIDS. I had proof of the activist's disabled body, his economic precarity, and the sheer scale of the assault that AIDS waged on his personhood and security. The information I uncovered added textured nuance and uncharacteristically acute vividness to my mental construction of the activist.

To be sure, the comprehensiveness of the collection was exciting, and I pulled out my camera to begin taking pictures of what I had found. However, before I could focus my lens, I realized that I had not only stumbled upon a massive HIPAA (Health Insurance Portability and Accountability Act) violation but I had also been given tremendous access to intimate details about this man's life that made him vulnerable to exploitation some quarter of a century after his death.

# HIPAA, Infrastructural Access, and Historical Intimacies

HIPAA regulations, as Susan Wells and Nathan Stormer (2018) have argued, make historical work in the rhetoric of health and medicine particularly difficult (27). While restrictions have loosened significantly since the US Department of Health and Human Services approved the so-called Final Rule in 2013, which removes legal protections for people who have been dead for over 50 years, the documents I viewed that day fell outside of that exception. Upon recognizing this, I was put into a tricky situation. In the intervening years, I have not, and will not, use any of this information in any publications. And yet, I still find myself seduced by these documents. I wonder what types of histories I *could* tell if I wasn't ethically and legally obliged to disregard this information. I think about the power of this type of information to illuminate the unimaginable vulnerability of many of the earliest AIDS activists. I also think about how an awareness of this vulnerability underscores the material weight of medical records more broadly, how affect and feeling open up different avenues for accessing medical archives.

Undergirding all these considerations, however, is an acute awareness that a violent rupture in the archive's infrastructure is what allowed me access to this abundance of sensitive information in the first place. Nathan Johnson (2018) suggests rhetoric scholars working in archives ought to embrace what he describes as an "infrastructural approach" to medical artifacts. This approach attends to knowledge-making as

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an embodied process that moves through pre-existing design, classification, and storage practices. The often "mundane" practices that allow for archival research weave dense infrastructural webs that "connect users with the shared networks of standards, classification, protocols, and algorithms that provide the dependable background of knowledge work" (63). For feminist rhetoricians composing rhetorical histories of health and medicine, thinking infrastructurally allows for considering how medical archives toggle between logics of visibility and invisibility, access and inaccessibility. What is compelling about the mundanity of archival infrastructures is their capacity to obscure themselves. Per Johnson, "When infrastructures are working well, their components work together seamlessly and are unnoticed." When something goes awry, when an element of an infrastructural system fails to achieve its intended purpose, the infrastructure becomes visible, and "massive interruptions in knowledge work" ensue (63).

This is precisely what happened in the queer history archive I was working in. The infrastructural safeguards established by HIPAA had broken down, and information meant to be hidden became immediately visible. As a researcher, I was forced to consciously reflect on my affective orientation toward both the archive and the activist. I could no longer take my role as a disinterested knowledge worker for granted. Instead, I needed to reflect on how to handle this material with care in the hopes that I might protect both this activist's legacy and the archive that helped preserve that legacy. Because of this infrastructural failure, I had to contemplate how, why, and for what purposes I accessed this activist's information. I had to determine how I might protect the feelings of care that encountering this sensitive material had engendered in me, which, in effect, meant extending my care for archival materials to a care for this activist and his right to privacy and dignity.

When joined, these dual concerns—access and care—facilitated a reckoning with how an archive's material infrastructure facilitated a type of *transhistorical intimacy*. Ara Wilson (2016) argues that experiences of intimacy (understood generally as a mode of "relational life" that extends across public/private, official/ vernacular, and local/historical distinctions) are, in fact, infrastructural accomplishments (251). For Wilson, "Understanding how infrastructures enable or hinder intimacy is a conduit to understanding the concrete force of abstract fields of power by allowing us to identify actually existing styles rather than a priori structures" (248). Infrastructures, put more simply, lubricate specific experiences of connectedness and relationality at the expense of others.

Notably, tracing the intimate pathways that emerge through an archive's infrastructures gives momentary form to diffuse, transhistorical systems of power that make minorized communities vulnerable to violation, abuse, and exploitation. In my case, a breach of institutional protocols helped me recognize the importance and limitations of HIPAA protections. Encountering information legally designated as private made my relationship with this activist more immediate and intimate. I was able to feel how institutional protocols, the very same ones invisibilized by archival infrastructures, continue to put queer people at risk. I could, if only imaginatively and momentarily, grasp the structural, emotional, and institutional vulnerability that PWAs experienced as they demanded attention and resources.

# **Caring for Medical Archives**

It has been a quarter of a century since Wendy Sharer (1999) wrote that rhetorical historians "cannot afford to ignore the various processes...that affect the corpus of the historical record on which we may be able to construct diverse and subversive narratives that challenge previous, exclusionary historical accounts" (124). Sharer's call to action remains particularly important for RHM scholars, given our close attention to sensitive textual traces of pain, suffering, and trauma. "[T]he listener to trauma," notes Dori Laub (1992), "comes to be a participant and a co-owner of the traumatic event" (62). Carefully tending to the archival practices that preserve and continue to enact traumatic medical events helps rhetorical historians of health and medicine interrogate and manage what KJ Rawson (2018) has described as "the rhetorical power of the archive" (331).

By positioning care as a tool that feminist RHM scholars might use to steer our historical projects, we have operationalized care as *both* a means of ethical engagement *and* a critical intervention into the material practices that sustain the archives in which we work. As we step back from these two accounts, we are reminded of Jacques Derrida's argument that "...the question of the archive is not a question of the past...It is a question of the future, the question of the future itself, the question of a response, of a promise and of responsibility for tomorrow" (1996, 36). Above, we have shown how care might be employed as a framework that rhetorical historians of health and medicine can use to respond to past medical abuses and work toward more just health futures. As we have argued, an initial step in caring for RHM histories means tending to archival materials themselves, the stories they tell, their infrastructures and ecologies of circulation, as well as their potential to construct new histories. In approaching medical archives with care, feminist RHM researchers might ensure that those lives living within archives are reanimated so that they, too, might be cared for once and for all.

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