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Social movement organizing and the politics of emotion from HIV to Covid-19

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Abstract

The Covid-19 pandemic has seen the rapid growth of collective organizing on the part of patient groups to address scientific and health inequities. This paper considers the emergence of Covid-19 activism as an embodied health movement that draws on and contributes to broader movements for racial, economic and gender justice. Recognizing the central role of emotion in social movements and in the bio-politics of Covid-19, I examine the key presence of the affective domain in social change through three Covid-19 social movement groups. These organizations draw upon anti-racist, feminist, and queer and HIV social movement organizing that position Covid movement building in intersectional histories and futures. I argue that Covid movement activists have built “archives of feeling”—or public cultures of trauma—of commemoration, Covid survivor narratives, and direct action that center affective feelings around grief, representation, and anger, respectively. I suggest that Covid-19 will become a key lens for articulating structural and social inequalities through which broader social movements will leverage their claims for justice—moving towards an integrated social movement. Social movement mobilizing will continue to play a critical role to ensure that the focus in the Covid-19 pandemic shifts from pathogen to society.

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KEYWORDS

activism, Covid-19, embodied social movement, emotion, HIV/AIDS, social movements

1 | INTRODUCTION

In June 2020, just months into the Covid-19 global pandemic, several dozen masked, socially distanced activists assembled alongside 30 body bags outside Philadelphia's City Hall with signs that read "Inaction = Death. Housing Saves Lives." The mood was somber as a diverse group affiliated with AIDS Coalition to Unleash Power (ACT UP)—the HIV/AIDS social movement group known as the AIDS Coalition to Unleash Power—gathered in light of recent Covid-19 deaths in the city, particularly among the unhoused, Black and Latino communities. Through its public demonstration of collective grief and anger laid bare on the steps of government actors—not insignificantly by the statue of Octavius V. Catto, a prominent nineteenth century African American leader in Philadelphia—this memorial expressed in the public domain what had until then been largely relegated to private forms of trauma felt in isolation and lockdown. By acknowledging the suffering of those who died of Covid-19 and those who remained to grieve their family and community members, this event represents what cultural historian Ann Cvetkovich has referred to as an "archive of feelings," or the public cultures that form in and around trauma (Cvetkovich, 2003). This moment, significant in itself, is also a reminder of the imperative of learning from history—in this case, the early days of the HIV pandemic, which still affects over 37 million people currently living with HIV around the world (UNAIDS, 2021).

This paper integrates social movement and queer cultural theory to examine the role of emotion in emergent Covid-19 mobilizing. I consider the emergence of Covid-19 activism as a health social movement, understood as a collective effort to address systemic inequities in health and medicine, that draws on and contributes to claims for racial, economic and gender justice of intersecting social movements. With the aim of contributing to social movements scholarship, the paper analyzes Covid-19 mobilizing as an "embodied health movement" that connects personal illness experiences to the broader political economic contexts that give rise to, and can prevent, states of disease (Brown & Zavestoski, 2004; Brown et al., 2011). Recognizing the central role of emotion as a source of social reproduction in the biopolitics of Covid-19, I examine the key presence of the affective domain in social change through three Covid-19 activist groups—*Marked by Covid*, *Body Politic*, and *ACT UP*.¹ Each of these organizations draws upon anti-racist, feminist, and queer social movement organizing strategies that position Covid movement building in intersectional histories and futures.

I argue that these organizations serve to center emotion in the public domain as a movement building strategy through creating an "archive of feelings" around Covid-19. An "archive of feelings" comprises the public culture that forms in and around trauma, which can assume varied forms, including performance, spoken word, written materials, and oral narratives (Cvetkovich, 2003). Because of the often "unspeakable and unrepresentable" nature of trauma, it is all the more imperative to tend to the forms of expression and creation (such as monuments and testimonies) that trauma gives rise to and that bring forward publics to witness them (ibid., p. 7). In this paper, I leverage "archive" as both a practice as I build an archive of early Covid-19 social movement practices, while also as an analytic stance that theorizes the presence of emotion-saturated cultural spaces, or "archives of feeling," of Covid-19 social movement building. This is key because these public cultures are "encoded not only in the context of the texts themselves but in the practices that surround their production and reception" (Cvetkovich, 2003, p. 7).

In this paper, I first examine the role of emotion in social movement organizing through the case of Covid-19, considering how archives of feelings allow for the expression of the collective trauma of the pandemic and its inequalities. I then turn to three Covid-19 early social movement organizations and argue that these three organizations each serves to create an "archive of feelings" for commemoration, Covid survivor narratives, and direct action that center affective feelings around grief, representation, and anger, respectively. Through their social movement building strategies, these organizations create repositories of feelings and emotions through which the individual and

collective trauma related to Covid-19 and its inequalities come to be expressed and negotiated in the public domain. In closing, I build upon health social movement theory to propose a framework for understanding Covid-19 as an *integrated health social movement*. I offer the framework of integrated health social movement as an embodied health movement that demands shifts in biomedical power to address scientific inequities and their structural determinants and impacts through drawing on the affective domain, while leveraging and contributing to broader intersectional social justice movements.

2 | SOCIAL MOVEMENT ORGANIZING AND EMOTION IN COVID-19

Health social movements and the “patient groups” that animate them are theorized in social movement scholarship as “new social movements,” a term that denotes the growth of varied forms of collective action that focused on social identities and rights emerging from the 1960s (Buechler, 1995).² Health social movements are “collective challenges to medical policy, public health policy and politics, belief systems, research and practice” mobilized by formal and informal groups and their supporters (Brown & Zavestoski, 2004, p. 679). While health social movements are numerous and equally diverse in their forms and purpose, Brown and Zavestoski articulate a typology of three main forms of health social movement: (a) health access movements, (b) constituency driven movements (those addressing health inequities based on structural inequalities of racism, classism, sexism and homophobia) and (c) “embodied health movements” that challenge dominant biomedical understandings of illness, disease and disability (Brown & Zavestoski, 2004). While these are not mutually exclusive, social movement scholars have variously organized understandings of health social movements based on these articulated purposes (Epstein, 2020; Powers et al., 2021; Smith, 2020). Embodied health movements are organized by “patient groups” who are affected by the disease in question—in this case, those who are living with Covid-19 or long Covid (Callard & Perego, 2021; McCorkell et al., 2020)—and also include “proxies” for patients (Epstein, 1995, p. 504), such as those whose loved ones have died, and/or advocates and allies from health worker and activist communities. I harness this typology and consider Covid-19 organizing from the outset as an “embodied health movement” in part due to the central role of affected communities in initial mobilizing around Covid-19, as well as to further inform health social movement theory.

The impact of Covid-19 on social movements highlights its intersections with racial justice and #Black Lives Matter organizing (Bolsover, 2020; Godley et al., 2020; Hammonds, 2021) and global environmental justice, feminist and human rights mobilizing (Corpuz, 2021; Grant & Smith, 2021; Reyes, 2020). As Covid-19 has sharpened the lens on the contributing, pre-existing population health harms of global capitalism (Aguirre, 2020; Alsan et al., 2021; Bambra et al., 2020) and environmental inequalities (OECD, 2020; Perkins et al., 2021; Von Storch et al., 2021), social movements research has identified a decentralized, global “wave” of movements for social and economic justice organizing to fight capitalism and state power at a “moment of political suspension and heightened social confrontation” (Gerbaudo, 2020, p. 61).³ Covid-19 points to the critical intervention of the pandemic and the potential for future mobilizing around structural inequalities, and theorizing Covid-19 as a health social movement offers a key lens through which to view the historical foundations of and futures for pandemic social change.

The Covid-19 pandemic has seen the rapid growth of collective organizing on the part of patient groups to address the pandemic, both in person and online (Astor, 2021; Sprayregen, 2020). Diverse patient groups, including many organized by Black, Indigenous and People of Color (BIPOC), health-vulnerable, and/or low-income communities, have organized “archives of feelings” as strategic actions and expressions to frame and advance policy goals that address healthcare and vaccine access, and inequities in who is living and dying in the Covid-19 pandemic.⁴ In addition to the concrete actions and policy and educational efforts activists have moved forward, the pandemic has offered an opportunity for social movements to provide interpretive narratives of the social and economic crises underlying its disproportionate impacts—a “battlefield for alternative futures” (Pleyers, 2020, p. 14). For it is true that social movements, far from mere strategic mobilizations designed by rational actors for tactical purposes, are also

key sites for meaning making, even more critical at times of crisis. Yet how do social movements make meaning in a pandemic, with its vast swaths of loss, grief, life upended, and people changed?

I argue that emotion occupies a central role in emergent Covid-19 social movements for health in part through “archives of feeling” that mobilize Covid activism to address social and health inequalities through the affective domain. The role of emotion and the “affective domain”—or “bodily intensities, emotions, feelings, and passions” (Gould, 2009, p. 3)—in social movements has been of growing interest in the past 2 decades, presenting a more comprehensive view of the dominant analyses of political opportunities, frames and resources driving social movements (McAdam, 2001). Social movements scholarship has primarily focused on the rational processes that shape movements, however, understanding the role of emotions and expression in social protest is critical as we consider not just the effectiveness of social movements but the social processes and meanings that give rise to them and that they give rise to. Emotion is embedded in the daily operations and meanings of the political domain, despite the aspirations of the “rational” actors therein and understandings of emotion as constrained within, or to, individuals.

Emotion plays an integral role in social change in part through its re/framing of power: “by signaling that something is awry, that things could be and perhaps should be different, affective states can inspire challenges to the social order” (Gould, 2009, p. 26). Social movements and their varied visual, narrative, and direct-action policy strategies allow for the expression of those often “outlaw” or conventionally unacceptable emotions (Jaggar, 1989)—outrage, anger, grief, fear (to name a few)—that speak the unspeakable, see the unseen. As a cultural resource, emotion comprises a basis for social reproduction that replicates and/or challenges existing social structures and political alignments, as evidenced in the case of HIV/AIDS and other social movements (Gould, 2004; Jasper, 2011). As such, social movements provide a counter-hegemonic space for affective articulation, allowing for meaning-making and new ways of thinking about and acting through pandemic threats. As with its presence in much of the dominant social movement literature (Goodwin et al., 2001), theorizing emotion in Covid-19 movement building remains limited. However, the emotion-focused narratives of Covid that emerged from the earliest days of the pandemic echoed the grief and loss embedded in discourses of AIDS organizing and its insistence on turning grief into anger through the central organizing cry of “Silence=Death” coined by activist group ACT UP (Gould, 2004; Schulman, 2021).

This paper’s cultural and queer theoretical analysis locates emotion in varied “archives of feelings” harnessed by activists to mobilize the affective domain through Covid activism. In her work on queer trauma, Cvetkovich operationalizes a sociocultural frame for trauma as “a collective experience that generates collective responses,” moving beyond individual clinical symptomology to consider the ways in which traumatic events “refract outward to produce all kinds of affective responses” (Cvetkovich, 2003, p. 19). Neither an individual attribute nor necessarily sentimental in its tracings (Berlant, 2008), a critical socio-cultural analysis of trauma offers an optic into the intersections of the affective and political domain, and a challenge to the assumptions that these are indeed distinct. Far from individual clinical experience or diagnostics, trauma is foundational for creating those public spaces or “counterpublic spheres” where cultural formations render narratives of trauma and its histories by drawing on affective experience (Warner, 2002). In this way, understandings of what comprises—or should comprise—a public sphere are shifted, raising questions for the politics and practices of biomedicine at a time of the national trauma of Covid-19.

3 | AN “archive of feelings”: SOCIAL MOVEMENT ACTIVISM IN THREE COVID-19 ORGANIZATIONS

In this section, I trace the saturation of emotion in Covid-19 activism from the earliest days of the pandemic, finding in these narratives a diverse embodied health movement fighting for alternative futures for this pandemic and beyond. This is evidenced in three archives of feelings centering in the public domain the collective trauma of Covid-19 through: commemoration, Covid survivor narratives, and direct action; evidenced in the emotions of mourning, recognition, and anger, respectively.

3.1 | Marked by Covid: Commemoration, mourning, and the biopolitics of grief

The formation of a collective identity in relation to Covid-19 emerged as a central form of mourning from the earliest days of the pandemic to express shared trauma at a time of impossible grief and restrictions on human contact. As such, in the face of a novel virus whose etiology, transmission, and treatment were still unclear, and with fear, uncertainty and stigma surrounding the virus, family members who had lost loved ones emerged as an early patient group in Covid-19. Covid survivors brought their grief and anger to the formation of online advocacy and support groups across global contexts of the pandemic (Astor, 2021; Sprayregen, 2020). These groups afforded a collectivization of individually felt trauma at a time of lockdown and isolation alongside the pandemic's re-structuring of everyday life—a constant reinstatement of trauma for those grieving Covid loss. Online groups served as an essential forum for shared experience and acknowledgment of the trauma of Covid-19 death; resource exchange concerning treatment options and health care access; and, as months of political inaction passed, a means for developing advocacy and policy responses to the pandemic. These efforts created shared avenues for the expression and cultural centering of emotion, from grief at the individual and collective losses suffered in the pandemic, frustration at the lack of recognition of Covid “long haulers” on the part of public health and medical institutions, and anger at biomedical systems and pharmaceutical industry in the face of increasing vaccine inequities.

Marked by Covid was founded in 2020 by Kirstin Urquiza, a queer Latinx organizer, after losing her father to Covid-19 in the United States. In what quickly became a viral accountability narrative of a politicized pandemic through the “honest obituary” she wrote for her father and her subsequent speech at the 2020 Democratic National Convention (Stevens et al., 2020), Urquiza held the Arizona governor and other state and federal leaders accountable for his death “due to the carelessness of the politicians who continue to jeopardize the health of brown bodies through a clear lack of leadership” (Urquiza, 2020). The drive to build this organization was partly based in the political context of the specific scientific silence at the hands of political leadership in the early months of the pandemic. Now a non-profit organization, *Marked by Covid* aims to connect people impacted by COVID to build a “COVID justice movement” through their coalitional, people of color and survivor led memorial events, and five-point policy plan for a data-driven national Covid response. The organization has focused most of its work to organize memorial events, including a Covid Memorial Day of over 120 grassroots events across the United States on 1 March 2021; a National Day of Action; a Week of Mourning; a Día de los Muertos Vigil; and a panel alongside the Lincoln Memorial Covid lighting underscoring “the importance of recognition” of Covid loss, to name a few (*Marked by Covid*, 2020).

Remembrance, memorialization, and the need for public sites of mourning are firmly embedded as one of the organization's policy objectives to “create space and forums for mourning and remembrance.” Supported by *Marked by Covid*, on 4 August 2021, Senator Elizabeth Warren with Senators Markey and Heinrich introduced a Senate Resolution, *Memorializing those impacted by and lost to the COVID-19 virus* (U.S. Senator Elizabeth Warren, 2021). This legislation is based in part on inscribing memory and equity in the political domain, not mere aspiration but a *resolve* given, “Whereas each life lost to COVID-19, each inequity and broken system brought to light, and each sacrifice made shall never be forgotten” (*Resolution: Memorializing Those Impacted by and Lost to the COVID-19 Virus*, 2021). The legislation proclaims a *never forgetting*, that continues with the charge: “Now, therefore, be it *Resolved*, That the Senate—(1) will memorialize those lost to the COVID-19 virus; and (2) recognizes the suffering of those who contracted the COVID-19 virus and survived but carry with them the unknown health side effects” (Ibid., p. 3). The resolution then proposes that the first Monday in March should become a COVID-19 Victims and Survivors Memorial Day.

Through insisting on the memorialization of Covid deaths and carving into the public domain the grief and irrevocable loss of Covid, organizers have woven Covid loss into the national fabric through change formalized in the political domain—an imperative that Covid loss should be felt by all. Integrating their efforts with broader social movements for racial, environmental and gender justice, this survivor-led, coalitional movement has centered the trauma of Covid through the need to memorialize the pandemic as a national tragedy. As an organizer points out, the role of this organization as a vehicle for mourning and shared experience is instrumental in addressing such trauma: “Validation

is huge for folks that have experienced horrific traumas. There's a deep understanding" (Barndollar, 2021). Through its collective call to imprint Covid-19 into the national public memory, activists have insisted on foregrounding the personal experiences and understandings of Covid-19 survivor communities—a key cornerstone of embodied health movements.

3.2 | Body Politic: Covid survivor narratives and the demand for recognition

Patient advocacy groups also formed early in the pandemic on the part of individuals living with Post-acute Sequelae of Covid-19 (PASC), or "long Covid" (Proal & VanElzakker, 2021). Long Covid is the term used to identify the condition of having ongoing symptoms that last for at least 4 weeks but often months past initial infection with coronavirus (Sifferlin, 2020). The formation of patient advocacy groups in the US on the part of Covid-19 "long haul" survivors can be understood as a *demand for recognition* considering a politicized pandemic that undermined scientific framing of the virus, collective trauma, and the unaddressed structural inequities and health vulnerabilities rendered through the pandemic. *Body Politic* was formed in 2020 by two of the founders of a queer feminist wellness collective at the intersections of wellness and social justice, when they experienced symptoms of long Covid. Facing a lack of resources and information for Covid patients in the early months of the pandemic, alongside the scientific silence on the topic of Covid long-haulers, they sought to build "a paradigm shift, where those who have been historically marginalized in health, medicine and wellness have the tools, relationships, and ... systems to serve as leaders and effective partners in their own care and well-being" (Body Politic, 2021). To do so, the organization of volunteer professional and community members has created a worldwide network of patients, allies, and healthcare advocates focused on peer support groups, patient-driven research, and community advocacy.

Body Politic exemplifies many of the key components of embodied health movements, forming a group of over 25,000 people with Long Covid and their allies within months to draw on their illness experiences to inform scientific research and public health policy. This group brings a critical lens to the process and practices of scientific research—even considering which subjects are "worthy" of study or not (such as long Covid). At the same time, it ultimately aims to contribute to a body of scientific knowledge through conducting "credible" research informed by personal experience. In this way, this organization illustrates the tensions faced by many health social movements as they both draw upon and contest biomedicine (Brown & Zavestoski, 2004). *Body Politic* illustrates the ways in which embodied health movements center the affective domain, not merely through a focus on the experiential dimensions of individual health experiences but through an understanding that these operate at a collective level.

Through several campaigns, including "Voices of the Virus: Body Politic and Covid 19 long haulers," *Body Politic* strategically centers individual illness narratives (Kleinman, 1988) that foreground patient narratives of Covid-19 long haulers and survivors to move forward patient advocacy goals. Illness narratives are a form of meaning making that foreground lived experiences of illness, situating the illness and its processes in the context of the patient's social and structural conditions and interactions with institutions of medicine (Jurecic, 2012). In the context of Covid long haulers, these stories highlight the dimensions of bodily and emotional pain, suffering, fear, and the concrete impacts of a Covid-19 diagnosis for those who live with it. Through their advocacy goals and consumer support, *Body Politic* provides advocacy captions that serve as a call for recognition in light of the failure of biomedicine to adequately address or even acknowledge the illness. By mobilizing human suffering, these narratives serve as a challenge to the biomedical sphere. For example, one of the advocacy prompts states: "Due to the lack of health authority recognition, many symptoms are not yet recognized by medical practitioners or the general public, causing a lack of medical support for patients" (Body Politic, 2021). Through collectivizing individual experience into organized survivor narratives that convey the media, research and advocacy goals of the movement, these patient narratives serve as much as a call for recognition on the part of a newly forming patient group as they are an acknowledgment of a politicized pandemic. Rather than *who* is being recognized, the questions then become, *why* is recognition necessary and *how* are these new patient groups shaping meanings of the pandemic?

3.3 | ACT UP: Anger through direct action

Body bags, masked activists, and the call “Inaction = Death” proclaimed on signs and spoken on the mid-pandemic steps of Philadelphia’s city hall in June 2020—these are classic assemblages of ACT UP direct-action activism, mobilized recently by ACT UP groups that have coalesced around Covid-19. ACT UP activism around Covid-19 is driven by the related injustices of global vaccine and treatment apartheid driven by pharmaceutical monopolies, need for accountability of government leaders in particular in the US, and disparate impacts on BIPOC, lesbian, gay, bisexual, transgender and queer (LGBTQ) and low-income communities (Modak, 2021). The Philadelphia action took place on the 18th straight day of protests worldwide after the police murder of George Floyd in May 2020, demonstrating accumulated outrage at the persistent legacy of racist police murder of Black men and women in the United States. The pandemic served to illuminate long-standing racial/ethnic inequalities, while online organizing mobilized global networks efficiently in protest against racial violence. Drawing on the movement tactic of the “die in” leveraged in HIV/AIDS activism, as well as the movement leadership of patient groups themselves, this action created an archive of feelings to convey the unspeakable losses of Covid-19 that had been so far relegated to the private domain.

In calling forward a public for the expression of Covid death in the context of its political, economic and racial inequities therein, this archive of feelings leverages unspeakable loss into rage at racial injustice, poverty and Covid-19. A collective image of the (many) dead alongside its cause, simply stated—*Inaction*—becomes a political act of grief-turned-*rage* and accountability for a community that has experienced sweeping COVID loss, alongside the inability to see or care for loved ones as they died. More than memorial, this action served to shift the more palatable emotion of mourning loss to that of anger at its causes, a change traced in histories of early ACT UP organizing that saw queer activists insist upon “militancy over mourning” (Gould, 2009). ACT UP activists brought visual and narrative demands that articulate deep anger at the structural inequities of housing access, poverty, and racism at the root of Covid-19 deaths. As such, they have effectively reframed Covid-19 from novel coronavirus to a pandemic not just of racial and economic injustice, but of government neglect.

The points of continuity and change between HIV social movements and their salience for COVID-19 organizing have been well articulated by activists, academics, and health professionals alike (Epstein, 2020; Gandhi, 2021; Hargreaves et al., 2020; Modak, 2021; Specter, 2021). In these recent histories, HIV activists mobilized public displays of grief and anger to demand change to the processes and outcomes of HIV/AIDS scientific research and treatment, building what sociologist Steven Epstein has referred to as “lay expertise” (Epstein, 1995). In the late 1980s and early 1990s, ACT UP staged public displays of anger and street mobilizations from Wall Street to the headquarters of the Food and Drug Administration as strategies for confronting institutionalized homophobia and political and bureaucratic inaction in light of the HIV pandemic.⁵ In “die-ins,” HIV activists leveraged clear demands on pharmaceutical companies, politicians, in strategic and visible spaces in full view of broader publics to reveal the disjuncture of societies marked by racism, poverty and homophobia and how they are sustained by global biopolitics.⁶

Strategies of queer mobilizing have been foundational in the Covid-19 health movement, through direct action strategies mobilizing the rage of many thousands dead to centering an understanding of the shared political and economic roots underlying these pandemics. In the words of former ACT UP organizer Asia Russell, “we only make our efforts to challenge the AIDS crisis stronger by mobilizing to confront Covid-19 inequities at the same time” (Modak, 2021). This is being evidenced from direct action mobilizing to bring anger to the streets to the online activist work of *Act Up- Fight Covid-19!* a group of ACT UP activists and allies founded in March 2020. This online group mobilizes primarily around issues of vaccine access and pharmaceutical accountability to “unite and empower grassroots HIV and health activists and allies, including front-line researchers, to fight the Covid-19 epidemic by sharing information and ideas for strategic, informed, ethical and compassionate community responses and solutions” (Rosenhaus et al., 2021). As such, queer and BIPOC social movement activists are leveraging the affective domain to mobilize Covid-19 organizing both on the streets and online. In the words of epidemiologist and former ACT UP member Gregg Gonsalves, “AIDS activists are back in the game for COVID-19... This is a political problem right now. We can beat COVID globally if we have the political will to do so” (Gonsalves, 2021).

By centering emotion in the HIV social movement, HIV activists have powerfully set the stage for further social movements, such as Covid-19, to adopt tactics and strategies that aim to shift power similarly through leveraging the affective domain. While some of the organizers across queer and HIV and contemporary Covid social movements are the same people, I posit that the centering of emotion in earlier movements as an ethos and commitment has underscored these as specific strategies to achieve varied movements' goals, therefore transmitting these key sources of information across movements over time.

4 | TOWARD RACIAL AND ECONOMIC JUSTICE: COVID-19 ACTIVISM AS AN INTEGRATED HEALTH SOCIAL MOVEMENT

This piece considers the role of emotion in the formation of Covid-19 health social movements, namely those activist and advocacy efforts that have developed to challenge and change the course of the pandemic's health inequities and the biomedical systems that contribute to them. Patient groups have formed to express the grief, frustrations, and anger of growing numbers of people who experienced or faced the devastating loss of a family member to Covid-19, or who themselves had Covid or Long Covid. The paper argues that the collective trauma of Covid—its histories, disparities, and constituencies—is expressed through “archives of feelings,” or the public cultures that have formed despite (and because of) pandemic restriction and fear. These forms of expression draw on HIV and queer social movement strategies, with their commitments to those “outlaw” emotions that “unravel hegemonic ideologies” (Gould, 2009, p. 41). I frame Covid-19 social movement activism as an embodied health movement, identifying three archives of feelings in public spaces of memory, Covid survivor narratives, and direct action through which cultural expressions of mourning, representation and anger are expressed to fight for change. Just as the AIDS pandemic rendered new forms of mourning and activism, I argue that Covid-19 is seeing new forms of mourning as well as activism.

Tracing the felt presence of emotion in emergent Covid-19 activism allows us to understand the necessity of considering the co-presence and production of the affective with the structural domain in social movements. In this regard, the role of emotion in mobilizing responses to Covid-19 presents an opportunity to bring forward the collective trauma underlying the pandemic—necessary to re-frame current injustices with alternative narratives and therefore futures. While there are many lessons to be learned from pandemic histories for our contemporary experience of Covid-19, including from the early years of the HIV epidemic, pandemic patterns are less about the pandemics themselves—each a “shock and disruption of its own distinct kind”—but more in the political responses to them (de Waal, 2021). Our understanding of the patterns of political response requires a careful lens on the extra-political collectivities mobilized to affect change. Embodied health movements underscore the ways in which structural and social inequities underlie the major health issues of the late 20th century, and the fact that scientific inquiry is, by itself, not able to address these issues (Brown & Zavestoski, 2004).

Covid-19 patient groups have drawn on the legacies and ongoing struggles of racial justice, feminist and queer organizing. This suggests that Covid-19 will become a key lens for articulating structural and social inequalities through which broader movements for racial, economic and gender justice—including #BLM, environmental justice movements, and HIV/AIDS activism will leverage their claims for justice—moving towards what I call an *integrated health social movement*. I operationalize an integrated health social movement as an embodied health movement that demands shifts in biomedical power to address scientific inequities and their structural determinants and impacts through drawing on the affective domain, while leveraging and contributing to broader intersectional social justice movements. As such, I find that Covid-19 social movement organizing reflects an embodied health movement that also encompasses key commitments to health access and formations of constituency driven movements. Given the focus of Covid-19 mobilizing on issues of health access and equity, alongside embodiment and patient-driven movement strategies, we must consider how health social movements at this time in the Covid-19 era are becoming “integrated health social movements.” The construct of an *integrated* health social movement aims to retain theoretical utility of

considering typologies of social movements for analyzing health movements, at the same time as to overcome the ways in which categorizing these movements can result in a simplification of the diversity therein (Epstein, 2008). It is also a reflection of the increasing recognition on the part of social actors of the interconnected nature of economic, racial, environmental and health inequalities.

As an integrated health social movement, Covid-19 mobilizing brings together a range of social actors with a broad array of demands, informed by and informing other social movements that span multiple calls for justice—reflecting a call for social change based on integrating the affective with the structural. As such, I argue for the necessity of considering the co-presence and production of the affective with the structural domain in social movements. As Covid-19 continues to exacerbate global economic and racial inequities through the creation of vaccine classes, I believe that Covid-19 activism offers the potential to help advance the goals of varied economic and racial justice social movements.

Perhaps only time will tell to what extent a discrete Covid-19 social movement may emerge, however I posit that this will depend on the ability of Covid-19 to organize around the unique “emotional habitus” of illness and suffering in the Covid-19 pandemic (Gould, 2009, p. 32). With vaccines so rapidly developed, and yet so differentially distributed in a failure of global governmental and scientific responsibility to the most vulnerable communities, the moral compass has shifted from understanding death from Covid-19 as caused by a novel virus to death caused by neglect. At this juncture in the pandemic, this work suggests that social movement mobilizing will continue to play a critical role to ensure that the focus in the Covid-19 pandemic shifts from pathogen to society—illuminating and intervening in the social and structural patterns that render some populations more vulnerable to Covid-19 than others. I can only hope that these archives of feelings will continue to build social movements to center the lives of the 6.06 million people who have died of COVID-19 worldwide (WHO, 2022), whose voices were not heard in their final hours. It is for them that these archives of feelings must continue to circulate until the power and pain embedded in their narratives are needed no more.

CONFLICT OF INTEREST

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ENDNOTES

- ¹ It is important to note that the analysis of these specific organizations and their Covid-19 activism is selective and draws from a review of media representation and online organizing efforts, as well as close knowledge of Covid survivor organizing, from the outset of the pandemic in the US to consider the role of emotion in Covid-19 activism. This analysis is not intended to be representative of the many and varied forms of activism that have developed in response to Covid-19 throughout very specific local contexts, including but not limited to anti-vaccination and anti-masking mobilizing, and the many specific anti-government protests in contexts of national and lockdown and political oppression or mandates. The case examples selected here allow for a lens on considering emotion in social movements that may be salient in other contexts, and further work on a broader range of social movement organizations is warranted.
- ² The demarcation between new social movements and their “allegedly new... issues, tactics, and constituencies” (Calhoun, 1993, p. 385) and “older” social movements prior to the 1960s has been noted to be an artificial one (Calhoun, 1993; Young, 2002). However, it is generally agreed upon that a defining characteristic of new social movements is the way in which they are not centrally organized labor movements and theorize “historically specific social formation as the structural backdrop for contemporary forms of collective action” (Buechler, 1995, p. 443).
- ³ Far from becoming stagnant in a time of social isolation, restrictions on public movement, and shifts in the private domain, social movements have been found to have maintained and even bolstered activity during the Covid-19 pandemic (Pleyers, 2020). Activists quickly adapted to the pandemic by taking organizing activities online and have in fact found there to be the potential for long term strategies useful for mobilization that will persist even as the pandemic shifts (Pinckney & Rivers, 2020).

- ⁴ COVID-19 disproportionately affects BIPOC communities in the US, tracing long-standing impacts of structural racism on health in the United States. Black and Latinx people are 2.8 times more likely to be hospitalized with Covid-19 and two and 2.3 times more likely to die of COVID-19, respectively, than whites (CDC, 2021). American Indian/Alaska Native individuals are the most disparately affected, and are 3.5 times more likely to be hospitalized with Covid-19, and at one point the Navajo nation had a higher infection rate than all of New York State (CDC, 2020). Further, racial/ethnic disparities are evident in vaccine rollout (Walker et al., 2021).
- ⁵ (Epstein, 1995). These histories are often misrepresented as primarily involving white, middle class gay men living with HIV, overlooking the central role of activists of color and women, as per Schulman's recent historical accounting of ACT UP NY (Schulman, 2021).
- ⁶ This activism paved the way for the development of a new type of antiretroviral medications that turned the tide on the HIV pandemic from one of likely death to a chronic manageable illness. HIV related deaths plummeted by 60% within 2 years once these medications were on the market as activists put their own health on the line to fight for a fast-tracked research process (Centers for Disease Control and Prevention, 1998). In so doing, HIV activists rendered the scientific domain and community expertise as one and the same.

REFERENCES

- Aguirre, M. (2020). The impact of the coronavirus crisis is due to inequality. *Social Research: International Quarterly*, 87(2), 223–227.
- Alsan, M., Chandra, A., & Simon, K. (2021). The great unequalizer: Initial health effects of COVID-19 in the United States. *The Journal of Economic Perspectives*, 35(3), 25–46. <https://doi.org/10.1257/jep.35.3.25>
- Astor, M. (2021, March 17). How 535,000 Covid deaths spurred political awakenings across America. *New York Times*. <https://www.nytimes.com/2021/03/17/us/politics/covid-survivors.html>
- Bambra, C., Riordan, R., Ford, J., & Matthews, F. (2020). The COVID-19 pandemic and health inequalities. *Journal of Epidemiology & Community Health*, jech-2020-214401. <https://doi.org/10.1136/jech-2020-214401>
- Barndollar, H. (2021, September 2). Reminded every day: New Englanders turn to online support groups after losing loved ones to COVID. <https://eu.providencejournal.com/in-depth/news/2021/09/02/covid-online-facebook-support-groups-helping-grief-pain-loss/8150621002/>
- Berlant, L. (2008). *The female complaint*. Duke University Press; JSTOR. <https://doi.org/10.2307/j.ctv1131c7k>
- Body Politic. (2021). *Body politic*. Body Politic. <https://www.wearebodypolitic.com/>
- Bolsover, G. (2020). Black Lives Matter discourse on US social media during COVID: Polarised positions enacted in a new event. *ArXiv:2009.03619 [Cs]*. <http://arxiv.org/abs/2009.03619>
- Brown, P., Morello-Frosch, R., & Zavestoski, S. (2011). *Contested illnesses: Citizens, science, and health social movements* (1st ed.). University of California Press. <https://doi.org/10.1525/j.ctt7zw1q9>
- Brown, P., & Zavestoski, S. (2004). Social movements in health: An introduction. *Sociology of Health & Illness*, 26(6), 679–694. <https://doi.org/10.1111/j.0141-9889.2004.00413.x>
- Buechler, S. M. (1995). New social movement theories. *The Sociological Quarterly*, 36(3), 441–464.
- Calhoun, C. (1993). "New Social Movements" of the early nineteenth century. *Social Science History*, 17(3), 385–427. Cambridge Core. <https://doi.org/10.1017/S0145553200018642>
- Callard, F., & Perego, E. (2021). How and why patients made long Covid. *Social Science & Medicine*, 268, 113426. <https://doi.org/10.1016/j.socscimed.2020.113426>
- CDC. (2020, August 19). *CDC data show disproportionate COVID-19 impact in American Indian/Alaska Native populations*. Centers for Disease Control and Prevention. <https://www.cdc.gov/media/releases/2020/p0819-covid-19-impact-american-indian-alaska-native.html>
- CDC. (2021, September 9). *Risk for COVID-19 infection, hospitalization, and death by race/ethnicity*. Centers for Disease Control and Prevention. <https://www.cdc.gov/coronavirus/2019-ncov/covid-data/investigations-discovery/hospitalization-death-by-race-ethnicity.html>
- Centers for Disease Control and Prevention. (1998). *HIV/AIDS surveillance report* (2 No. 10). <https://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-report-1998-vol-10-2.pdf>
- Corpus, J. C. G. (2021). COVID-19 and the rise of social activism in Southeast Asia: A public health concern. *Journal of Public Health*, 43, e364–e365, fdab063. <https://doi.org/10.1093/pubmed/fdab063>
- Cvetkovich, A. (2003). *An archive of feelings*. Duke University Press; JSTOR. <http://www.jstor.org/stable/j.ctv113139r>
- de Waal, A. (2021). *New pathogens, old politics: Two hundred years of war on disease and its alternatives*. Polity Press.
- Epstein, S. (1995). The construction of lay expertise: AIDS activism and the forging of credibility in the reform of clinical trials. *Science, Technology & Human Values*, 20(4), 408–437. <https://doi.org/10.1177/016224399502000402>
- Epstein, S. (2008). Patient groups and health movements. In E. J. Hackett, O. Amsterdamska, M. Lynch, & J. Wacjman (Eds.), *New handbook of science and technology studies* (pp. 499–539). MIT Press.

- Epstein, S. (2020, June 11). COVID-19 and the politics of knowledge (science, knowledge, and technology). American Sociological Association. <https://www.asanet.org/news-events/footnotes/may-jun-2020/research-policy/covid-19-and-politics-knowledge-science-knowledge-and-technology>
- Gandhi, M. (2021). Four ways HIV activists have saved lives during Covid. *Knowable Magazine | Annual Reviews*. <https://doi.org/10.1146/knowable-041221-1>
- Gerbaudo, P. (2020). The pandemic crowd: Protest in the time of COVID-19. *Journal of International Affairs*, 73(2), 61–76.
- Godley, B. A., Schoenbach, V. J., & Adimora, A. A. (2020). Racial justice and HIV in the United States: Now is the time. *Journal of the International AIDS Society*, 23(10), e25625. <https://doi.org/10.1002/jia2.25625>
- Gonsalves, G. (2021, July 26). Epidemiologist Gregg Gonsalves: “3 Things Biden Can Do Right Now to Stop COVID and Save Lives.” In *Democracy now*. KPFA. https://www.democracynow.org/2021/7/26/covid19_pandemic_vaccination_masks_gregg_gonsalves
- Goodwin, J., Jasper, J. M., & Polletta, F. (Eds.). (2001). *Passionate politics*. University of Chicago Press. <https://press.uchicago.edu/ucp/books/book/chicago/P/bo3640435.html>
- Gould, D. (2004). Passionate political processes: Bringing emotions back into the study of social movements. In J. Goodwin & J. M. Jasper (Eds.), *Rethinking social movements: Structure, meaning, and emotion*. Rowman & Littlefield Publishers.
- Gould, D. (2009). *Moving politics: Emotion and act up's fight against AIDS*. University of Chicago Press, 2009.
- Grant, P. R., & Smith, H. J. (2021). Activism in the time of COVID-19. *Group Processes & Intergroup Relations*, 24(2), 297–305. <https://doi.org/10.1177/1368430220985208>
- Hammonds, E. (2021). A moment or a movement? The pandemic, political upheaval, and racial reckoning. *Signs: Journal of Women in Culture and Society, Feminists Theorize Covid-19*.
- Hargreaves, J., Davey, C., Hargreaves, J., Davey, C., Auerbach, J., Blanchard, J., Bond, V., Bonell, C., Burgess, R., Busza, J., Colbourn, T., Cowan, F., Doyle, A., Hakim, J., Hensen, B., Hosseinipour, M., Lin, L., Johnson, S., Masuka, N., ... Yekeye, R. (2020). Three lessons for the COVID-19 response from pandemic HIV. *The Lancet HIV*, 7(5), e309–e311. [https://doi.org/10.1016/S2352-3018\(20\)30110-7](https://doi.org/10.1016/S2352-3018(20)30110-7)
- Jaggar, A. M. (1989). Love and knowledge: Emotion in feminist epistemology. *Inquiry*, 32(2), 151–176. <https://doi.org/10.1080/00201748908602185>
- Jasper, J. M. (2011). Emotions and social movements: Twenty years of theory and research. *Annual Review of Sociology*, 37, 285–303.
- Jurecic, A. (2012). *Illness as narrative*. University of Pittsburgh Press. https://scholar.google.com/scholar_lookup?author=Jurecic%20A.&title=Illness%20as%20Narrative&publication_year=2012
- Kleinman, A. (1988). *The illness narratives: Suffering, healing and the human condition*. Basic Books, Inc.
- Marked by Covid. (2020). Marked by Covid. <https://www.markedbycovid.com>
- McAdam, D. (2001). *Dynamics of contention/Doug McAdam, Sidney Tarrow, Charles Tilly*. Cambridge University Press.
- McCorkell, L., Assaf, G., Davis, H., Wei, H., & Akrami, A. (2020). Patient-led research for COVID-19: Embedding patients in the long COVID narrative. *OSF Preprints*. <https://doi.org/10.31219/osf.io/n9e75>
- Modak, R. (2021, August 12). “We Have To Change the Rules”: What AIDS activists can teach us about the Covid pandemic. *In These Times*.
- OECD. (2020). Urgency of inequality and climate change raised by COVID-19. In *Development co-operation report 2020*. OECD. <https://doi.org/10.1787/081f1e8d-en>
- Perkins, K. M., Munguia, N., Ellenbecker, M., Moure-Eraso, R., & Velazquez, L. (2021). COVID-19 pandemic lessons to facilitate future engagement in the global climate crisis. *Journal of Cleaner Production*, 290, 125178. <https://doi.org/10.1016/j.jclepro.2020.125178>
- Pinckney, J., & Rivers, M. (2020). Sickness or silence: Social movement adaptation to COVID-19. *Journal of International Affairs*.
- Pleyers, G. (2020). The pandemic is a battlefield. Social movements in the COVID-19 lockdown. *Journal of Civil Society*, 16(4), 295–312.
- Powers, M., Brown, P., Poudrier, G., Ohayon, J. L., Corder, A., Alder, C., & Atlas, M. G. (2021). COVID-19 as eco-pandemic injustice: Opportunities for collective and antiracist approaches to environmental health. *Journal of Health and Social Behavior*, 62(2), 222–229. <https://doi.org/10.1177/00221465211005704>
- Proal, A. D., & VanElzakker, M. B. (2021). Long COVID or post-acute sequelae of COVID-19 (PASC): An overview of biological factors that may contribute to persistent symptoms. *Frontiers in Microbiology*, 12. <https://www.frontiersin.org/article/10.3389/fmicb.2021.698169>
- Resolution: Memorializing those impacted by and lost to the COVID-19 virus. (2021) (Testimony of Elizabeth Warren). <https://www.warren.senate.gov/imo/media/doc/WIL21831.pdf>
- Reyes, E. (2020). Body politics in the COVID-19 Era from a feminist lens. *Development*, 63(2–4), 262–269. Sociological Abstracts. <https://doi.org/10.1057/s41301-020-00266-w>
- Rosenhaus, J., d'Adesky, A.-C., Hannay, M. L., Bauer, B., Lunceford-Stevens, At, & Danzig, A. (2021, October 2). *About act up—fight Covid 19!* <https://www.facebook.com/groups/2635737100084778/about>

- Schulman, S. (2021). *Let the record show: A political history of ACT UP New York, 1987-1993*. Farrar, Straus and Giroux. <https://us.macmillan.com/lettherecordshow/sarahschulman/9780374185138>
- Sifferlin, A. (2020, November 11). How Covid-19 long haulers created a movement. *Medium Coronavirus Blog*. <https://coronavirus.medium.com/how-covid-19-long-haulers-created-a-movement-24313746833a>
- Smith, N. C. (2020). How can stigma contribute to our understanding of the formation and mobilization of collective identities in health social movements? *Sociology Compass*, 14(6), e12796. <https://doi.org/10.1111/soc4.12796>
- Specter, M. (2021, June 7). How ACT UP changed America. *The New Yorker*. <https://www.newyorker.com/magazine/2021/06/14/how-act-up-changed-america>
- Sprayregen, M. (2020, November 13). *This support group is helping launch a Covid-19 patient advocacy movement*. *Forbes*. <https://www.forbes.com/sites/mollysprayregen/2020/11/13/this-support-group-is-helping-launch-a-covid-19-patient-advocacy-movement/>
- Stevens, M., Paz, I. G., & Medina, J. (2020, August 18). Kristin Urquiza, whose father died of Covid, denounces Trump at D.N.C. *The New York Times*. <https://www.nytimes.com/2020/08/17/us/politics/kristin-urquiza-dad-covid-trump.html>
- UNAIDS. (2021). *Global HIV & AIDS statistics—fact sheet*. <https://www.unaids.org/en/resources/fact-sheet>
- Urquiza, K. (2020, July 6). Mark Urquiza obituary. *Arizona Republic*. <https://www.legacy.com/us/obituaries/azcentral/name/mark-urquiza-obituary?id=2188298>
- U.S. Senator Elizabeth Warren. (2021, August 4). Warren, Markey, Heinrich introduce resolution memorializing those lost to and suffering from COVID-19. <https://www.warren.senate.gov/newsroom/press-releases/warren-markey-heinrich-introduce-resolution-memorializing-those-lost-to-and-suffering-from-covid19>
- Von Storch, L., Ley, L., & Sun, J. (2021). New climate change activism: Before and after the Covid-19 pandemic. *Social Anthropology*, 29(1), 205–209. <https://doi.org/10.1111/1469-8676.13005>
- Walker, A. S., Singhvi, A., Holder, J., Gebeloff, R., & Avila, Y. (2021, March 5). Pandemic's racial disparities persist in vaccine rollout. *The New York Times*. <https://www.nytimes.com/interactive/2021/03/05/us/vaccine-racial-disparities.html>
- Warner, M. (2002). *Publics and counterpublics*. MIT Press.
- WHO. (2022, March 17). *WHO coronavirus (COVID-19) dashboard*. <https://covid19.who.int>
- Young, M. (2002). Confessional protest: The religious birth of U.S. National Social Movements. *American Sociological Review*, 67, 660. <https://doi.org/10.2307/3088911>

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How to cite this article: Mackenzie, S. (2022). Social movement organizing and the politics of emotion from HIV to Covid-19. *Sociology Compass*, e12979. <https://doi.org/10.1111/soc4.12979>