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ORIGINAL PAPER

"The freshness of irreverence": learning from ACT UP toward sociopolitical action in science education

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Abstract
This article explores ACT UP (AIDS Coalition to Unleash Power) through a Freirean lens of critical consciousness, dialogue, and transformation. The purpose is to draw from where there have been processes of engagement of sociopolitical action in science and how these spaces can become meaningful entry points to take toward making a "sociopolitical turn" in science education, as well as in science more broadly. Current practices in science education do not adequately prepare educators and students to challenge and interrupt injustices that we are emersed in. ACT UP is a well-studied example of when non-specialists engaged with science and scientific knowledge making to shift power and policy. Paulo Freire's pedagogy was developed alongside social movements. By examining ACT UP through a Freirean lens, I explore themes of relationality, social epistemology, consensus, and dissensus that emerged when a social movement engaged with science to achieve its goal. My intent is to add to the ongoing dialogues of approaching science education as a practice of critical consciousness and liberatory world making.

Keywords Science education · Paulo Freire · Sociopolitical action · Social movements · ACT UP

> Our being in the world is far more than just 'being.' It is a 'presence', a 'presence' that is relational to the world and to others […] that can reflect upon itself, that knows itself as presence, that can intervene, can transform, can speak of what it does, but that can also take stock of, compare, evaluate, give value to, decide, break with, and dream. – Paulo Freire, 1998, pp 25–26

> ACT UP always wanted the freshness of irreverence, and irreverence cannot come from consensus. – Anna Blume, Schulman 2010, p.17.

In this article, I begin by outlining ACT UP, followed by describing a Freirean approach to science education and social movements as spaces of critical pedagogy. Then, I provide

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recommendations for how science educators, researchers, and policy makers can engage with the ideas and practices of science making in ACT UP toward making a sociopolitical turn in science education. Finally, I analyze ACT UP through a Freirean lens of critical consciousness and social transformation.

ACT UP (AIDS coalition to unleash power) is an organization and social movement founded in 1987 in New York City in the USA with one goal: to end AIDS (acquired immunodeficiency virus). ACT UP emerged out of multiple institutional failures to appropriately respond to the HIV/AIDS pandemic that was primarily affecting and killing gay men (Epstein 1995). Building off the legacy of the Stonewall Riots and the lesbian, gay and trans liberation movements of the 1960s (Gould 2006) as well as the labor and civil rights movements in the USA, ACT UP became an international coalition that built grassroots power. They mobilized and fought for effective and affordable medical treatments and foundational human rights for people that were diagnosed with HIV/AIDS (Epstein 1995). The advocacy and strategies of ACT UP are a well-studied example of when non-specialists have engaged in participatory scientific knowledge making as a method to shift policy and direct research agendas toward sociopolitical action (Epstein 1995). They were motivated by a sense of urgency, "Unless we fight for our lives, we shall die" (Kramer 2005, p. 28). ACT UP was not only known for transforming scientific practices—they are also remembered for direct actions and street theater that forced people to pay attention. ACT UP pursued whatever was needed to place the conversation of AIDS into the national consciousness. In this article, I explore ACT UP as a case study, of how non-specialists engaged with science to shift policy and work toward liberation. I focus predominantly on the ACT UP New York chapter, because most of the early science knowledge making and activism in ACT UP was recorded by the New York chapter.

Paulo Freire (1970b) described critical and political consciousness *(conscientização)* as an essential path to liberation. Critical consciousness is achievable through the development of one's own awareness, identity, and dialectical relationship to the conditions of the world (Giroux 2010). However, consciousness alone is not enough to transform the world. One must continually *act* to transform the world and work against conditions of harm, erasure, and oppression. A Freirean approach in science education encourages such transformation by engaging with the problems that science makes or contributes to within society and explicitly (and often implicitly as well) inspiring engagement with actions that work against conditions of harm (Santos 2009).

To shift science education practices that take issue with the challenges of living in overlapping crises, we can employ a "sociopolitical turn" proposed by Rochelle Gutiérrez (2013) in respect to mathematics education and introduced into the science education discourse by Sara Tolbert and Jesse Bazzul (2017). All three scholars suggest a sociopolitical turn as a shift in scholarship. This shift moves the focus of science education in a different direction to center the political entanglements that we are already immersed in and possible actions to take in response to these entanglements (Tolbert and Bazzul 2017). Creating a sociopolitical turn remakes the bounds of the discipline and allows us to question what is worthwhile to study in science. Rochelle Gutiérrez (2013) also uses the term *turn* as in, a "turning something on its head" (p. 40). She gives an example of feminist scholars in the 1970s that aimed to "turn on its head" the ways that gender was researched in mathematics education, where most studies considered the best ways to make girls more successful in math was to make them act and think like boys. Tolbert and Bazzul (2017) also take up this dual meaning of turn to suggest that science education can turn from a hegemonic accumulation of knowledge toward a science that is a relational ongoing practice committed to making visible the sociopolitical inequalities that science is already submerged

within. By exploring ACT UP through a Freirean lens of critical consciousness, dialogue, and transformation, I examine this turning, both as a movement toward broader and more self-reflective scholarship and a turning of the current attempts in science education on its head. Taking this turn in scholarship and shifting a perspective that goes beyond the academy and into social movements, can offer support of how one might invite learners into worthwhile problem solving.

I was motivated to write about ACT UP based on my proximity to the AIDS pandemic growing up. Half of my childhood was spent with my father and his boyfriend. By 1991, HIV infection was the leading cause of death among men aged 25–44 years old in the USA (Centers for Disease Control 1993). Most of my father's friends tested positive and eventually died from complications of AIDS. This experience eventually influenced me to become a peer sex educator at Planned Parenthood to teach other youth about prevention and transmission of HIV. Being raised in a community during a time when my father's friends were sick with a virus that was more lethal politically because of their sexuality, race, and class than it was biologically, I became more aware that love is a political and radical act.

Why turn to social movements to expand science education?

In education science is constructed as a discipline, or a set of disciplines. Disciplines often isolate and remake the boundaries of study and people's identities that reinforce the "colonial matrix of power" (Mignolo 2009). Disciplines—and disciplinism—thrive within institutions to establish a professional identity. Within the discipline of science education, the hegemonic production and acquisition of scientific knowledge is the dominant discourse (Takeuchi et al. 2019).

Studying social movements can deepen and expand the epistemologies and method making in science education because they are a counterpoint to disciplines. Social movements are inherently supra disciplinary by placing people, collective action, and their needs in the foreground. Humans are *ipso facto* supra disciplinary. We are wholes, not parts. Being supra disciplinary is moving beyond the professionalization, standardization, logistics, and individualistic ideology that are often prioritized in liberal-based science education. For social movements to be effective, they move beyond the bounds of disciplines into processes (Muraca 2020). The word *movement* comes from the Proto-Indo-European root meaning "to push away," and The Latin, *movere,* "to move, or set in motion" (Harper n.d.). Historian Robin G. Kelly (2002, p. 44) taught us that "Social movements generate new knowledge, new theories, new questions. The most radical ideas often grow out of a concrete intellectual engagement with the problems of aggrieved populations confronting systems of oppression." Conjuring Paulo Freire and Myles Horton's adaptation of Spanish poet Antonio Machado's phrase: "We make the road by walking – se hace camino al andar" (1990, p. 6).

Social movements as critical pedagogy

Paulo Freire's critical pedagogy can be considered a pedagogy of social movements (Muraca 2020). He developed his ideas from Fanon, Gramsci, and Marx among others. Freire claimed that critical transformative actions are more effective in solidarity with

social movements as compared to actions of individuals directed in isolation (Mayo 1999). Many anti-colonial movements throughout the world have incorporated aspects of Freirean critical pedagogy to develop liberatory educational initiatives and literacy campaigns. Adult education campaigns of Movimento dos Trabalhadores Rurais Sem Terra (MST)/ Landless Workers Movement in Brazil developed their literacy programs using Freire's critical pedagogical approaches for the purposes of organizing landless peasants toward sustainability and land ownership (Meszaros 2000). Soon after the death of Amílcar Lopes da Costa Cabral in 1973, Freire was invited to Guinea-Bissau by the African Party for the Independence of Guinea-Bissau and Cape Verde (PAIGC) to collaborate on building political education programs that supported a newly independent Guinea-Bissau and Cape Verde (Freire 2021). Additionally, Kerala Sastra Sahitya Parishad (KSSP), a peoples' science movement in Kerala, India, incorporated aspects of Freirean critical pedagogy to design adult literacy campaigns (Fischer 2006). Relying on local and cultural knowledge and the raising of political consciousnesses, KSSP became mobilized through developmental models of participatory governance.

To consider moves toward liberation, Freirean pedagogy emphasizes and encourages a critical understanding and disruption of the social and political conditions that one lives under. For Freire, one attains critical consciousness, through one's own understanding of their reality (Santos 2009). This consciousness is not static but relational and unfinished—where one is made aware (and continually remade aware) of the dialectical conditions of the world. From here, these stages can be summarized as, "reading of the world, sharing the world with others, and constructing and reconstructing the world" (Santos 2009, p. 366).

Learning from ACT UP toward a sociopolitical turn in science education

> The classroom remains the most radical space of possibility in the academy…Urging all of us to open our minds and hearts so that we can know beyond the boundaries of what is acceptable, so that we can think and rethink, so that we can create new visions…" (hooks 1994, p. 12)

From a Freirean positionality, I suggest three essential questions for science education and science educators to consider:

(1) What are the epistemologies, practices, thematic (re)organizations, ways of being and phenomena that emerge when a social movement has engaged with science to achieve its goals?
(2) What can science educators, researchers, and policymakers learn from ACT UP to make a sociopolitical turn that is required at this moment in science education?
(3) How might students and teachers be supported to take such a turn?

A summary of the strategies and practices of ACT UP suggest multiple entry points for educators, researchers, and policy makers to take toward engaging in productive sociopolitical science. ACT UP as a socioscientific learning context would be a worthwhile project for science education. SSI (socioscientific issues) topics have been proposed as effective means of learning how the goals and practices of science are not neutral (Santos 2009). The extensive historical and ongoing cultural production of ACT UP provides an abundance of material for people to examine how similar issues interact with their lives today.

ACT UP was imaginative and outrageous (Blume and Schulman 2010). Their creative use of performance and art woven into science and activism discourse offers science education more disciplinary *turns* to engage in toward the political (Tolbert and Bazzul 2017) that expands on interpretation and expression. Studying how ACT UP organized themselves in decentralized groups based on commonalities, what they accomplished and where they fell short can add more depth and criticality to support current struggles (Emmer 2012) and productive discourse for science education. When reading through the narratives of ACT UP and the AIDS pandemic, there are straightforward connections to make to the COVID pandemic (government negligence, lack of access to health care, pharmaceutical company profits, etc.). ACT UP is a template for how to engage in science making for sociopolitical action, specifically in response to a pandemic.

Relational and social epistemology from ACT UP to science education

Learning from ACT UP means that we are prioritizing being in relationships differently with each other in science education spaces. A thread that is woven through the stories of ACT UP is the relational commitments that ACT UP members had between each other (Blume and Schulman 2010) from the way they were organized into decentralized affinity groups (Epstein 1995) to the ways that they cared for each other as well as through discourse and disagreements (Gould 2006).

An important function of social movements is the relationships and the role that emotions play in movement work (Gould 2006). Additionally, relationality and emotions are often in the background of science education, despite emotions being critical to learning (hooks 1994). A "constellation of emotions" (Gould 2006, p. 180) that people experienced are inseparable from the story of ACT UP. There was an abundance of joy, love, and deep comradery for each other, by being gay together, and pursing a common goal that was met with resistance (Blume and Schulman 2010). They successfully mobilized fear into action and turned internalized shame into collective political transformation (Epstein 1995). The community of ACT UP was driven by urgency and confidence, urgency because people were dying and confidence, which was required to make life and death decisions (Blume and Schulman 2010). The more science they learned together—the more they believed they could make a difference (Epstein 1996).

Turning toward science education, I discuss relationality as a method to be together and as a practice of science. I frame relationality from feminist philosophers of science that examine how *good* science can be made from different ways of considering of consensus (Potter 2006). Helen Longino (1993) argues the purpose of dialogue in science is not to come to an understanding of consensus, rather it is to engage in the scientific practice of revisions, corrections, knowledge sharing and model making with others. If a consensus occurs, it is because of the interdependent critical dialogue and inquiry that emerges from social interactions. Freire describes the creation of knowledge as a result of human interactions (Santos 2009). Scientific knowledge is a situated social epistemology (Longino 1993) because scientific knowledge is a result of communities who have similar values and beliefs (Potter 2006). Helen Longino (1993) defines social epistemology as a "shift in attention from the relationship between knower and known to the processes that mediate our interactions with others" (Wray 1999, p. 550). This contrasts with the dominant model of teaching consensus in science education as the least contentious, most agreed upon values and practices of science (Irzik and Nola 2011). Teaching the consensus model of science demonstrates a banking model, as proposed by Freire (1970b), where students receive

information about what has been pre-determined as correct and unchangeable. This model of consensus in science establishes a finished line of inquiry (Longino 1993) as opposed to a framing scientific inquiry that is an ongoing practice. We can turn our approach to consensus from a banking model of disseminating information to a commitment of social phenomena that occurs through collective action. Freirean methods of reflection, dialogue, and action can support us in creating the containers that are possible if we consider the blending of relational and intellectual scientific inquiry, social epistemology, and world making.

Political dissensus

A practice of dissensus is valuable in science just as much as a practice of consensus (Solomon 2007). Jesse Bazzul (2015) presents an argument for Jacques Rancière's concept of dissensus for science education to disrupt the ideas of consensus, citizenship in science education, and to position science education as "point of political contestation" (p. 221). Rancière's concept of dissensus is not about an argument or conflict of differing interests or opinions (Rancière and Panagia 2000). Instead, it is the tension between what is visible and what is invisible, and the questions that are required to ask to move toward radical equality (Bazzul 2015). ACT UP is an act of dissensus by making of the AIDS pandemic visible, being gay visible, and developing medical science that was not happening but was required in that moment to save lives (Epstein 1995). Their strategies and methods toward meeting their goal was to make the absurd disruptive to everyday life so that people took notice (Gould 2006). Additionally, Tolbert and Bazzul (2017) position Rancière's concept of "radical equality" in support of sociopolitical turnings in science education. ACT UP's self-learning and teaching each other medical science to shift power and effect policy change (Epstein 1996) demonstrates Rancière's concept of radical equality in education (Tolbert and Bazzul 2017). When considering practices of relationality, dissensus can support asking questions like, *what does it mean to belong? who belongs and who is left out?* Positioning both consensus and dissensus in the science classroom, supports the building of critical consciousness, dialogue, and action toward sociopolitical action.

These descriptions of relationality, social epistemology, consensus, and dissensus bring to the surface the function of having a worthwhile goal to pursue to work toward sociopolitical action. Social movements are formed in pursuit of a goal (Gould 2006). ACT UP had a goal—to end the AIDS crisis (Epstein 1995). Having a goal shifts our thinking from designing science *for* something to designing science *about* something (Longino 1993). Santos (2009) describes the importance of having a social and political goal in science that can transform us and build a new society based on equity and justice. Science education that works toward sociopolitical action would benefit from an explicit goal. Not necessarily a universal goal, but a goal local and meaningful that a learning community determines is worthwhile investigating (Potter and Alcoff 2006).

AIDS coalition to unleash power: a Freirean perspective

The first ACT UP meeting took place in 1987 at the LGBT Community Health Center in the West Village in Manhattan (Gould 2006). Those in attendance were either diagnosed with HIV or had loved ones diagnosed with HIV. Here, people expressed a concern that the lack of AIDS treatment and research was deliberate, homophobic, and politically motivated (Epstein 1995). The spark igniting the movement came from playwright and AIDS activist, Larry Kramer, who asked the packed room, "Do we want to start a new organization

devoted to political action?" (Gould 2006, p. 12). The stigma of AIDS publicly shaped the collective identity of gay men during this time (Epstein 1995). The epidemiological construct of AIDS is entangled with narratives that only *certain* people with *certain* lifestyles and behaviors contract AIDS. If the people most affected were not already oppressed or ostracized the connections between identity and disease might have had little significance (Gould 2006). "Dehumanization, which marks not only those whose humanity has been stolen, but also (though in a different way) those who have stolen it, is a distortion of the vocation of becoming more fully human" (Freire 1970b, p. 44). Vito Russo, an activist, and member of ACT UP who was well known for writing the Celluloid Closet, a book about homophobia in film gave a speech called "*Why We Fight."* In this speech (Russo 1988), he explained exactly what he thought was killing him:

> If I'm dying from anything, I am dying from homophobia. If I am dying from anything, I am dying from racism. If I'm dying from anything, it's from indifference and red tape, because these are the things that are preventing an end to this crisis. If I'm dying from anything, I'm dying from Jesse Helms. If I'm dying from anything, I'm dying from the President of the United States. And, especially, if I'm dying from anything, I'm dying from the sensationalism of newspapers and magazines and television shows, which are interested in me as a human-interest story—only as long as I'm willing to be a helpless victim, but not if I'm fighting for my life.

ACT UP's activism was directed toward a wide range of institutions that maintained power in directing AIDS research in the USA—The Centers for Disease Control (CDC), National Institute of Health (NIH), and the Federal Drug Administration (FDA). The direct actions of ACT UP were designed to be public and overt, so that people and the media took notice and understood the urgency of the crisis (Gould 2006). There was already a built-up distrust of medical institutions that AIDS activists had due to racism, and the maltreatment of women, trans, and gay people (Epstein 1996).

ACT UP frequently targeted the media, the Catholic Church, politicians, and those who continually stood in the way of AIDS research and treatments. The rhetoric from these groups established the public perception and stigma of AIDS. For example, Jesse Helms, the US Senator from North Carolina from 1973 to 2003, fought against any federal funding for AIDS research, treatment, and blamed being gay for the spread of AIDS (Epstein 1995). In response, ACT UP staged a creative, well-planned-out action to get his attention in the hopes that he would stop his attacks. They inflated a 15-foot giant nylon condom around his house with a banner across it that said, "Condoms to stop unsafe politics. Helms is deadlier than a virus." National media was contacted in advance to ensure that people across the country would see this on live television. There were elements of ACT UP that had to be outrageous to make an effect. I will provide more examples throughout this article demonstrating how ACT UP interrupted daily life to put AIDS in the national consciousness. Anna Blume explains, "ACT UP understood itself as acting […] saw itself as meaningful in its ability to express and externalize the *id* of HIV expression—or it knew it needed to be out of control if it was going to exist at all" (Blume and Schulman 2010, p. 47). This action hints at the general flow of ACT UP campaigns. First, pressure was placed on researchers, scientists, and policymakers to better study the pathogenesis of HIV and to create more varied, accessible, and affordable treatment options (Harrington and Schulman 2003). In cases where lobbying efforts and communications failed, ACT UP moved to public performances and direct actions—ever mindful of Paulo Freire's observation that, "Freedom is acquired by conquest, not by gift" (1970b, p. 47). For members of ACT UP, freedom meant not just political and social freedom, also freedom knowing that what you

are doing is worthy because it improves people's lives (Gould 2006) and must be done over and over until freedom is achieved.

From science literacy to knowledge making and policy intervention

The science activism within ACT UP originated from a subcommittee called the Science Club (Harrington and Schulman 2003). The Science Club morphed into the Issues Committee, then into the Treatment and Data Group (T&D). Some members of T&D split off and started the Treatment and Action Group (TAG), which is now an international, independent organization that works at the intersection of HIV research, policy, and advocacy. The Science Club met weekly to learn and discuss experimental drug developments, the pathogenesis of HIV, and the inner workings of how the NIH and FDA operated (Harrington and Schulman 2003). They utilized their newfound science knowledge to get into the doors of the NIH and FDA, as well as any other institution that had power in directing HIV research agendas. Learning science legitimized them in front of establishment scientists. The more science that T&D's members learned, the more ambitious and effective their efforts became (Epstein 1995).

One of the first projects T&D worked on was translating relevant terms from medical and scientific languages they didn't understand into a language they could use to transform research. To know the issues they were fighting against, they needed to understand the language the issues were written in. To get here, they studied medical dictionaries, textbooks, drug manuals, and research papers (Harrington and Schulman 2003). They made glossaries of these translations to distribute to the broader ACT UP community. They held teach-ins to discuss how each government agency operated—e.g., the FDA oversaw drug testing: the NIH conducts drug testing (Harrington and Schulman 2003). Teaching the institutional language and scientific concepts of government organizations outside of T&D was to equip everybody with basic science talking points in preparation for the demonstrations, beginning with the FDA (Epstein 1996).

The FDA was one of ACT UP's earliest and most successful large-scale direct actions with over 1000 people who showed up to shut down the FDA in Rockville, Maryland (Crimp 2011). This action, which resulted in over 300 arrests, was a turning point in AIDS activism and planted ACT UP firmly in the national consciousness. ACT UP began to be taken seriously by stakeholders, institutions and agencies that controlled the available treatments offered for people living with HIV and AIDS (Harrington and Schulman 2003). ACT UP prepared for months prior to the demonstration and T&D had an essential role in supporting the chapter. T&D assembled a press kit that was given to the ACT UP Media Committee, who then scheduled media appearances, provided the journalists with a background of ACT UP and a list of demands (Crimp 2011). All major news outlets were invited to the demonstration. When the press showed up to the demonstration, they were reporting on a story that had already been written by ACT UP members. ACT UP made HIV/AIDS visible during a time when many lawmakers, media, and individuals wanted them to be invisible. ACT UP took control of the story of AIDS and humanized the experiences of people who were affected by HIV and AIDS.

Re defining AIDS. One of the first policy changes produced from science that originated out of T&D was changing the clinical definition of AIDS (Ward et al. 1992). Members of T&D were some of the first to advocate that AIDS and HIV was expressed differently between men and women. This was highly significant, as the working clinical definition was very narrow, and did not reflect symptoms or disease progression that was

predominantly experienced by women (Epstein 1995). For example, it was not common for women to develop Epstein Barr Virus, as compared to men. Women were more likely to develop bacterial and pelvic infections, sometimes leading to cervical cancers, but at the time medical professionals were not looking at bacterial infections. AIDS trials were no different than other drug medical research trials at the time where the subject populations mostly consisted of middle-class white men (Gould 2006). This resulted in limited drug trials, HIV trials, and access to treatment options. ACT UP's advocacy successfully pressured the CDC to change the definition of AIDS from: "any 1 of 21 opportunistic infections including some cancers" to "a measure of immunosuppression (a CD4+T-lymphocyte count < 200/μL or CD4 + percentage < 14)" (Ward et al. 1992, p. 9) and three clinical conditions (pulmonary tuberculosis, recurrent pneumonia, and invasive cervical cancer). This change in the clinical definition resulted in increased access to screening and treatment, particularly for women (Harrington and Schulman 2003). Through T&D's continued advocacy, the CDC established a Women's HIV and AIDS Health Advocacy Center to specifically address women's health care, which included everything from treatment options to nutrition and housing.

On the effects of researching your community. The public was limited to the findings of the researchers and scientists studying AIDS in laboratories as well as limited by the time it took to run the studies. No research was being conducted during the 1980s and early 1990s on how to stop infection, part of the consequence of AIDS being erased and politicized (Harrington and Schulman 2003). Members of ACT UP and T&D were closer to the pathogenesis of AIDS than most scientists working in laboratories. This proximity became critical to their awareness and advocacy. Mark Harrington, one of the founding members of T&D and TAG tells this story in the *ACT UP Oral History* project: "The evidence was all around us" (Harrington and Schulman 2003, p. 21). Harrington goes on to describe the observations that were possible by being insiders of the community that was being studied. They observed in their own community men who, despite repeat exposure to HIV in the 1970s and 1980s, never contracted HIV.

T&D successfully pressured the NIH to study how people could be exposed but unaffected. From these studies, NIH concluded that some people did not acquire a second receptor that was a result of a silent gene mutation (Harrington and Schulman 2003). Those that inherited the silent gene mutation from both parents, would have an almost zero percent chance of contracting HIV, despite repeated exposure to the virus (Harrington and Schulman 2003). Around this time and independent from the work of T&D and NIH, similar findings were being reported within the Marengo Observational Cohort Study of sex workers in Nairobi, who despite repeated expose to HIV did not become infected (Bandeware, Kamani and Lavery 2010). Researchers determined that these individuals had achieved cellular immunity by producing enough killer T-cells that could destroy cells infected with HIV before multiplying.

Studying the drugs. In the beginning, AZT (azidothymidine) was central to the science advocacy of ACT UP. Still, in 1991, the main drug treatment for AIDS was AZT (Epstein 1995). ACT UP members observed each other suffering from toxic side effects of AZT, particularly anemia. Observing other's symptoms was easy, due to the proximity they had to one another. From these observations, they inferred that they were being unnecessarily and aggressively over prescribed drug interventions (Harrington and Schulman 2003). They continued to watch an overwhelming amount of their community die from AIDS, even though they were doing everything they were told to do by doctors and researchers, including taking the prescribed amounts of AZT (Blume and Schulman 2010). Additionally, AZT did nothing to prevent infection. Members of the Pathogenesis Group began to

study dosages of AZT and the effects that changing the dosage had on people's symptoms (Blume and Schulman 2010). They read studies that suggested that a lower dose of what was typically prescribed, was *more* effective and less toxic. Members of T&D wrote to and applied pressure to key people at the NIH and the FDA. Then they wrote to a journalist they had built a relationship with at the *New York Times* who wrote a cover story about these effects (Harrington and Schulman 2003). As a result, NIH lowered the recommended AZT doses.

AZT was the most expensive drug on the market at $10,000/year (Blume and Schulman 2010). Not only was Burroughs Wellcome profiting off people with AIDS, AZT was also unaffordable to the majority of people with AIDS (Blume and Schulman 2010). The campaign targeting Burroughs and Wellcome became a major demonstration that shut down the NY Stock Exchange. "Release the drugs" and "Drugs not bodies" became the central slogans of these campaigns (Crimp 2011) Shortly after the demonstration, the FDA announced it would shorten its drug approval process from nine years to two years. Around the same time, the NIH lowered the dose of AZT, and Burroughs Wellcome reduced the cost of AZT to $3000/year (Harrington and Schulman 2003). During the campaign to lower the cost of AZT, T&D built another campaign to speed up drug trials to make drugs more readily available to people. The average amount of time that federally run drug trials lasted was nine years (Epstein 1995). In 1987, many people who were diagnosed with HIV or AIDS did not live for nine years to see a drug approved (Harrington and Schulman 2003). Additionally, T&D began to write research proposals about single drugs to submit to the NIH. To develop research proposals, members were placed in small groups of "drug buddies" and given specific drugs to investigate (Harrington and Schulman 2003). Research into specific drugs involved calling investigators at research laboratories to learn more about the trials and presenting their findings to the whole group for critique, then making revisions as needed and submitting the proposals to the NIH.

Fact making is often prioritized by the top down (Epstein 1995) from government, media, industries, and education. In the case of ACT UP, fact making, and knowledge production came from the activists on the ground. They used their newly acquired knowledge to advocate for and negotiate with medical researchers for broader and more effective treatment options (Harrington and Schulman 2003). Thus, ACT UP activists slowly established themselves as legitimate forces that became part of the culture of medical science, which enabled them to do some bottom-up decision making.

Affinity groups as spaces for dialogue and transformation

A lot of the success (and fragmentation) of ACT UP has been attributed to its decentralized organizational structure (Epstein 1995). ACT UP was made up of independent, tightly connected affinity groups. Members of affinity groups were typically connected by similar backgrounds, identities, or by common motivating interests. Some of these groups included: Invisible Women, Dos Locos Radicales, The Non–Toxics, The Power Tools, and W.A.R. (Wipeout AIDS and Racism), along with many more (Harrington and Schulman 2003). Affinity groups focused on specific issues they were interested in or wanted to learn about. The Non–Toxics focused on alternative health methods for treating HIV and AIDS (Blume and Schulman 2010). The Power Tools were an ad hoc affinity group that organized an eight-month campaign in 1987 to pressure Burroughs Wellcome (the manufacture of AZT) to lower the cost of the drug.

The effectiveness of affinity groups increased when people worked collectively to achieve the same goal—in their own ways and dictated by their own terms and interests. Often affinity groups would split up due to conflict or deferring interests and disband to form new affinity groups (e.g., Treatment Action Group) (Harrington and Schulman 2003). Through these multiple separate groups, strategies, and interests—people came together, felt powerful, and exacted that power. Affinity groups had their own ideas and participated in their own decision making (Epstein 1996). Affinity spaces were places where new knowledge could emerge as new ways of knowing the world, as a relational space for pedagogical theories and practices to emerge. Ultimately, affinity groups became transformational spaces, involving an overlapping web of consciousness, dialogue, and action (Freire 1998). Weekly meetings and affinity groups were a mix of emotions and experiences. For some activists, meetings are what kept them going and filled them with inspiration (Epstein 1995). For others, meetings were overwhelmingly hostile events where nothing ever happened (Gould 2006). Members shared experiences, but did not necessarily reach agreements. ACT UP's goal required fellowship and solidarity, not consensus. Additionally, affinity groups fueled the development of a larger social and political consciousness, as people who might not have ever met before were now sharing their lives with one another, introducing each other to new food, art, and ways of being in the world (Elbaz 1997).

The work of affinity groups extended into care work, where members made medical decisions and arranged funerals for those whose families had abandoned them for being gay and having AIDS (Gould 2006). Affinity groups and chapter meetings were spaces for coming together to share narratives of grief and anger. Avram Finkelstein described his experiences at chapter meetings, "Fear and grief faded away when I discovered action" (Gould 2006, p. 184). Transmitting grief and anger into action became a way to reframe the narrative for people to feel powerful by speaking their story. "If it is in speaking their word that people, by naming the world, transform it, dialogue imposes itself as the way by which they achieve significance as human beings" (Freire 1970b p. 88). The dominant narrative as told by politicians, the media, and The Catholic Church was that people die of AIDS because of their sexuality and lifestyle. ACT UP *turned* this narrative into: People are dying of AIDS because of government negligence, hatred, and ignorance.

Youth activism in ACT UP

Public school teachers and youth that were already activists in ACT UP became motivated by a 40% increase in reported HIV + cases among youth from 1987 to 1989 (DiClemente, 1992). They established an affinity group called Youth Education Lifeline (YELL) to develop sexual education programs to "save lives" (Elbaz 1997, p. 12). In 1989, there was a lack of compressive sexual education and prevention programs that would go beyond abstinence-based teaching in NYC public schools (Andersen 2019), even though there was evidence that high school students were sexually active, and that using condoms was highly effective in preventing transmission of HIV (Solomon and DeJong 1989).

The organizers of YELL developed their sexual education programs based on critical pedagogy (Elbaz 1997). They did not depend on public health experts to teach about HIV transmission, who would simply come to schools and distribute information on what is required to know (the banking model, Freire 1970b) about disease transmission. Most of YELL's education programming focused on peer education. Workshops would pivot from technical demonstrations of how to put on a condom to dialogical conversations about why people with AIDS are discriminated against (Elbaz 1997). The pedagogical practices of

YELL reflected Freirean methods of establishing environments in which learners could feel safe, and be themselves. This established openings for dialogical transformations and facilitated participants' critical understanding of their sociopolitical conditions (Freire 1970b). Youth organizers of YELL purposely replaced shameful language and judgment about sex and drugs with humor, art, and performance to establish an environment for learners to share personal stories and ask questions regarding HIV/AIDS transmission (Elbaz 1997).

Outreach extended to distributing condoms and creating and passing out pamphlets with information about transmission and prevention of HIV (Anderson 2019). YELL's postmodern approach was effective and popular among teachers and students. However, they were met with considerable pushback, specifically from religious conservatives, most notably the Christian Coalition. These religious groups out-mobilized YELL and ACT UP with more resources and more political clout (Elbaz 1997) and successfully pressured school boards that parents should have the right to determine if condoms are provided to students.

ACT UP as supra discipline

People from ACT UP became activists because they or their loved ones were dying, and they were motivated to do something about it (Kramer 2005). They learned science because they wanted to stop dying. Most of the authors and scholars cited and quoted in this text were active in ACT UP or in AIDS activism more broadly—Douglas Crimp, Steven Epstein, Deborah Gould, Mark Harrington, Vito Russo, Sarah Schulman, etc. Many were writers prior to their activism or became writers as practice of activism. Anna Blume, fashion designer, activist, and scientist described, "ACT UP communicated to me on the level that I existed on" (Blume and Schulman 2010, p. 44). Kiyoshi Kuromiya, an author, civil rights activist, and member of the ACT UP Philadelphia Chapter wrote the first culturally competent medical guidelines on taking care of people with HIV (Emmer 2012). Garence Franke-Ruta co-founded Countdown—18, a project to put pressure on pharmaceutical companies to study opportunistic infections that were killing people with AIDS (France 2012). Thousands of individuals in ACT UP had similar stories and took up types of initiatives that mattered to them and worked to make a difference in environments that they had influence in. The extensive archived history and cultural production of ACT UP narratives, storylines, happenings, events, conflicts, artistic and cultural production demonstrated, as a collection of memoirs, that any activist can be a historian of their own stories and their friends' stories. The history of ACT UP cannot be told chronologically (Blume and Schulman 2010) but rather as relational and reflective process of what happens when thousands of people tell a story in a multitude of expressions of their experiences.

A critical history

The telling of history is central to the survival of AIDS activism, intergenerational collective memory making and queer futures (Emmer 2012). The history of ACT UP is continually being remade, especially as activists critically reflect with others and younger generations on where they fell short and what can be learned from ACT UP's activism and engagement with science to support current struggles (Gould 2006). Critical reflection that moves in-between dialogue and action is necessary to be in the world (Freire 1970a). Emmer (2012) argues that it is important to avoid the mythologizing of ACT UP to be in support and relevant for current struggles.

Many ACT UP chapters shut down due to internal conflicts (Gould 2006). The main reasons for internal conflicts were reflective of the same conflicts that existed within the world at large, racism, misogyny, and classism (Gould 2006). The New York chapter of ACT UP was dominated by gay, white men from middle-class backgrounds who had built political power from the lesbian, gay, and trans liberation movements, and they knew how to fundraise (Elbaz 1997). This allowed them to rise in leadership even within a decentralized organizational structure and then to steer the direction of the research agendas. For example, people within ACT UP who had more access to resources, higher class status were generally more concerned about drug development (Epstein 1996). People without that economic power were more focused on housing, food, and ensuring that people with AIDS had basic resources (Epstein 1995). Erik Sayer, the co-founder of Housing Works, an organization that emerged from ACT UP activism that focuses on supporting people living with AIDS and experiencing houselessness, argued "Ninety-seven percent of people living with AIDS in the world have no access to the drugs at all. For them nothing has changed" (France 2012). Some chapters took notice of what was happening and attempted to do something different. ACT UP in Philadelphia created a Treatment Education Activists Combating HIV (TEACH) to develop activist leadership that focused on political organizing in Black and Brown communities, treatment science, and building self-autonomy in communities in Philadelphia who were most affected by HIV (Emmer 2012).

In 1991, Treatment Action Group (TAG) split from ACT UP mostly due to the increase in participation within institutions as compared to pressuring these institutions from the outside (Epstein 1995). Others began to question the narrowing of ACT UP's treatment science to research exclusively being conducted on drug treatments as opposed to expanding access to health care. ACT UP was able to gain access to the dominant scientific knowledge and bend the arc of HIV/AIDS treatment and research. They blurred the boundary between science and the public. Through their activism, advocacy, scientific knowledge making, science practices and cultural production, they expanded treatment options for people who were diagnosed with HIV/AIDS, decreased the cost of AZT, expanded the clinical definition of AIDS, and established needle exchanges. They increased treatment options for women, people of color, as well as others who were often left out of treatment and care (Epstein 1996). Due to their work, members of ACT UP are now voting committee members on boards at the NIH and the FDA (Epstein 1995). However, ACT UP did not fully disrupt the gatekeeping and hierarchical knowledge structure of dominant science and its institutions.

Conclusion

For Freire, the practice of education as a practice of liberation is not an exercise to reproduce what has already been done (Darder 2011). Instead, education as a liberatory process is based in the social responsibility of fresh and critical imaginative pursuits of people to intervene in the transformation of their own social and material conditions (Freire 1970b). Looking toward ACT UP's engagement with science demonstrates how science can be used to organize people in ways that are powerful to them and make turns toward social political action—however small those turns might be. Freire believed in solidarity across differences, especially regarding class struggle (Darder 2011). ACT UP organized across differences through affinity groups and the sharing of a common goal. This allowed ACT UP to be more effective and creative in working toward ending AIDS and improving the

social and material conditions of people affected by HIV and AIDS. I started writing this article during the weeks that high school student walkouts were happening in New York City, Chicago, and many more cities in the US in response to the inadequate and unsafe learning conditions that youth experienced due to the COVID-19 pandemic (Timsi 2022). I finished writing this article months later when youth activism is fueled by transphobic and homophobic school policies in multiple regions across the United States (Mack 2022). Young people are at the forefront of international climate and environmental justice movements (Han and Ahn 2020). Youth activism is already happening and will continue to happen. The work is to be critically conscious to support people in using their own voice to disrupt the "culture of silence" (Freire 1970a, p. 2) that perpetuates these conditions. To transform the world, requires meeting the world where it is. Building containers of relational and intellectual scientific inquiry, social epistemology, and world making within science education involves the sharing and developing of common goals and meeting each other where we are. We can get here through dissensus by making what is hidden visible as a dialogical practice. This moves science teaching and learning outside of the bounds of science as a discipline toward a responsive and relational process of liberatory education.

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