



Editorial

Contextualizing global TB advocacy: Lessons from three experiments in movement building



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The global TB community has, for a while, been wondering how they can replicate the successes of HIV movement. As patients suffering from TB fight for access to new drugs and diagnostics, it is imperative to closely study and fully understand the HIV movement as a sophisticated civil rights movement.

To have any meaningful conversation about the HIV movement, we'll have to start at the very beginning—at a lunch counter at Woolworth's in downtown Greensboro in North Carolina. On February 1, 1960, four African American college students sat down at a “whites only” counter and one of them politely asked to be served coffee [17]. His request was refused.

Thus began one of the three greatest experiments of civil rights movement in modern history.

In an article titled ‘Small Change’ in the *New Yorker*, Malcolm Gladwell writes, “Some seventy thousand students eventually took part. Thousands were arrested and untold thousands more radicalized. These events in the early sixties became a civil-rights war that engulfed the South for the rest of the decade—and it happened without e-mail, texting, Facebook, or Twitter” [5].

Thanks to the Internet, we now have several advantages over those who led the HIV movement in the 1980s. The TB activists of today have better tools and a better chance to collaborate globally and build a successful movement. However, with more tools & more expertise at hand, are communities now worse off when it comes to building movements? This paper is going to argue yes.

Back at that lunch counter in Greensboro, the four terrified students stayed put in the face of violence & started what would become the Mississippi Freedom Summer Project of 1964 [10].

In a paper titled, “Recruitment to High Risk Activism: The Case of Freedom Summer’ sociologist Doug McAdam studied the Freedom Summer movement to understand why some volunteers stayed while others dropped out due to the violence [13].

McAdam interviewed 720 volunteers who went to Mississippi and 241 ‘no shows’ - volunteers who dropped out. The study found that key difference between those who stayed & those who left – in face of violence- wasn't their commitment to the cause. In fact, all participants, including the ‘no shows’ were found to be highly committed supporters of the goals of the summer program.

What mattered more was ‘stronger and more extensive ties to other participants and a greater number of organizational affiliations’. Simply put, if your friends went out to protest, you are more likely to join it. McAdam's study found that participants were far more likely to go if their close friends were also going to Mississippi. High-risk activism, McAdam concluded, is a “strong-tie” phenomenon.

This was true for the four students who sat at the lunch counter. They were room mates and members of NAACP (The National Association for the Advancement of Coloured People). They prepared for a month before they sat at that lunch counter. They also received civil disobedience training from NAACP. They had strong ties.

In stark contrast, the type of activism enabled by the Internet is built on weak ties. This may not necessarily be a bad thing. Stanford Sociologist Mark Granovetter, examined the cohesive power of weak ties in a study titled ‘*The Strength of Weak Ties*’. He argues that weak ties are advantageous for certain things, especially for flow of information [6]. Granovetter's assertion is that more people can be reached through weaker ties; for example, weakly knit communities are good for making topics trend, sharing information democratically & quickly, organizing protests. But the *only way you can get someone you don't really know to do something for you* is by not asking too much.

Weak ties don't lead to high-risk activism.

Sociologists who study activism maintain successful movements have another deeper layer. The American civil-rights movement was not just strong-tie, high-risk activism. It was strategic too. The movement had clear targets and chain of command. Martin Luther King, Jr.

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was the leader and the movement was built with the black church at the heart of it.

It was not a democratic network but a hierarchy. When Dr King led the Montgomery bus boycott, by design he needed tens of thousands of people to boycott public transport. It sounds like an unreasonable demand-but the bus boycott lasted a *full year*. The leaders of movement organized free carpool service with dispatchers & pick up stations. By the time Dr King came to Birmingham, he had a budget of a million dollars, and 100 full-time staff members on the ground, divided into operational units.

The second great civil rights struggle came two decades later, in the form of the gay rights movement in 1960s. Not surprisingly, it was inspired by the American Civil Rights movement.

LGBT movement

The HIV outbreak in San Francisco in the early 1980s was a perfect storm- a new virus doctors did not understand started infecting the gay community *just* as the long repressed community was coming out of the closet.

It was only in 1984, after the Ryan White case, that the mainstream society in America accepted that HIV could spread to straight people too [9]. Ryan White was 13 year old boy who got HIV following a blood transfusion [19]. When he returned to school, he had to fight AIDS-related discrimination and the story gained national attention. He became the face of public education about HIV in America.

However, despite mounting evidence, the mainstream society continued to blame the spread of HIV on an oppressed cultural minority- the homosexual community- when they needed urgent medical care & money for new science. This paper will focus on the strategies used by the leading advocacy group of the time ACT UP (AIDS Coalition to Unleash Power), which spearheaded the movement for right to access healthcare for HIV patients.

ACT UP came into being in 1987, when Larry Kramer, positive himself, made a speech focused on action to fight AIDS [8]. He began by having two-thirds of the room stand up and told them they would be dead in five years. ACT UP Co-founder Vito Russo was also HIV positive and boyfriend got sick with HIV as well. At 42, most of Russo's friends were dead or dying. So, Russo and Kramer threw themselves into the movement. Most people came into ACT UP with such grief- they had strong ties.

ACT UP's most successful demonstration was in October 1988, when it shutdown FDA for a day [2]. Around 1500 people stood outside FDA hoisting a black banner that read "*Federal Death Administration*". When police was called in, the officers were *wearing surgical gloves and helmets*. They arrested 120 protesters, and demonstration leaders said they were aiming for 300 arrests by day's end. A month later, on September 14, 1989, 7 ACT UP members infiltrated the New York Stock Exchange and chained themselves to the VIP balcony to protest the high price of the only approved AIDS drug, AZT [14].

Two months later, in December 1989, around 4500 protestors interrupted Mass at St Patrick Cathedral in New York, chanted slogans, & lay down in the aisles. 111 protesters were arrested [3]. Why? Because Cardinal's was homophobic.

In January 1991, ACT UP organized a protest called the 'Day of Desperation' when activists entered the studio of the CBS Evening News and shouted "AIDS is news. Fight AIDS, not Arabs" [15].

The next day, activists displayed two banners in Grand Central Terminal. One said "*Money for AIDS, not for war*" and "*One AIDS death every 8 minutes*." One of the banners was handheld and the other was attached to bundles of balloons that lifted it up to the ceiling of the station's enormous main room. This wasn't just a gimmick to attract attention. It was a great strategy, implemented theatrically.

As underdogs, the HIV activists of 1980s relied on theatre as tool to be effective- it allowed them to be non-violent, while being disruptive. In this civil rights movement, victims weren't identified by something

clear & definite like skin colour in the American South. Or religion in Nazi Germany. The HIV patients of the 1980s were judged by an invisible morality of the heterosexual society- the full force of their biases were brought to bear upon them.

It is not coincidence that ACT UP was influenced by the American civil rights movement. Much like Dr King's strategies in the 1960s, ACT UP also followed a committee structure- with clearly defined responsibilities. They had special committees for outreach, treatment and data, media, and housing - to find housing for people thrown out due to HIV related discrimination.

HIV activists of the 1980s *needed* to be that organized because leadership changed hands frequently and suddenly- people died. They also had "affinity groups"- with no formal structure, but were centred on specific events, like being called in to be a part of the "Day of Desperation" etc. What we have now- in campaigns for TB is just the 'affinity groups' - without the depth & clarity of an organized, hierarchical, strategic, strong tie movement.

While a lot is said about democratization of information flow, made possible by social media platforms like Twitter and Facebook, sociologists have found that hierarchical models work better while building movements. The third great civil rights movements -for India's independence- also followed a hierarchical model, with lawyer-activist Mahatma Gandhi at the centre [4].

All three movements also spent years in gestation.

Mahatma Gandhi went to South Africa in 1893 as a barrister. By 1896, Gandhi had established himself as a political leader in South Africa, where he refined the idea of non-violent resistance as a representative of the Indian community in apartheid South Africa. He came back to India in 1914 & started a three decade long freedom struggle [18].

By the time Dr King starts seeing results, he had already spent some 10 years [21] building the civil rights movement. In case of the HIV movement, the gay community already had a network in place- from their fight against an anti-gay legal system in the 60s. In 1965, a man called Adrian Ravarour set up the Vanguard, an LGBT gay liberation youth organization in San Francisco [20]. He taught LGBT youth volunteers, philosophical & historical principles of their rights to equality with examples of Gandhi and Dr King so the movement would gain a philosophy and become a force of its own. When the HIV patients started being diagnosed in the 1980s, they relied heavily on the networks set up by the LGBT community during the 1960s and 1970s.

TB movement

In contrast, the TB movement remains limited to only 'affinity groups'. This paper will focus on India, which shoulders the highest TB and DR TB burden in the world. Out of the 10.4 million new cases in 2016, 2.8 million live in India [22]. A staggering 147,000 are resistant to medicines that can cure them due to high prevalence of anti-microbial resistance in the country [16].

This is, yet another, a perfect storm. The Indian health ministry's response to this monumental challenge has been glacial. In fact, two key drugs required to treat India's growing DR TB crisis are available only to 1000 patients [11]. Only 81 patients have access to Delamanid, as of December 2017.

TB activism in India is fragmented, with fierce rivalry between approximately six groups.

Over interviews conducted anonymously, activists from each group accused the others of being 'petty', 'chasing funding and credit' without focussing on patients.

In January 2018, father of an 18-year old girl suffering from DR TB took the Indian government to court [7], over access to new treatment regimen. The case was an opportunity to mainstream the conversation about entitlements of the TB community. However, in contrast with the HIV movement, which galvanized the community around emblematic cases (e.g. Ryan White), India's leading TB activists kept a low profile

throughout the court case- limiting themselves only to speaking with the journalists who approached them.

Much like the Freedom Summer study by McAdam showed, the friction among activist groups is not a reflection of their commitment to the cause. In fact, all groups are highly committed supporters of the rights of TB patients and wrote separately to the Health Ministry, demanding relief for the girl's family. However, the methods were in contrast with the strong-tied, strategic campaigns led by ACT UP activists during the HIV movement.

In February 2018, the Indian government allocated Rs 600 crore for nutritional support to TB patients [1]. The plan included a cash benefit of Rs 500 per month to each patient for nutritional support- which all TB activists privately agreed was not enough to provide the required nutritional support to a patient suffering from tuberculosis. The statements made to the media however were opposing.

An article in *The Indian Express*, widely shared within TB community, on the subject said, “while activists like Chapal Mehra, convenor of NGO *Survivors against TB*, has termed the budgetary allocation as a patient-centric and empathetic move, others have raised questions about the inadequate cash incentive. Blessina Kumar, CEO of *Global Coalition of TB Activist*, said “how will the government ensure people who need it the most get the benefit,” Kumar asked [14].

To replicate the success of the HIV movement, the fundamental requirement within the TB community is of stronger ties, more co-operation and high-risk strategies that define successful, non-violent civil disobedience movements. That the HIV epidemic is no a longer a public health emergency, is testimony to what the movement achieved.

A careful examination of the sophistication of HIV movement could help India's TB community immensely, as the global battle against TB will be won or lost in India, home to most TB patients in the world.

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References

- [1] Bhatial I. UP hails Rs 600 crore for nutritional support to TB patients. *The Times of*

- India 2018. Retrieved from <https://timesofindia.indiatimes.com/city/meerut/up-hails-rs-600-crore-for-nutritional-support-to-tb-patients/articleshow/62747182.cms>.
- [2] Crimp D. Before occupy: how AIDS activists seized control of the FDA in 1988. *The Atlantic* 2011. Retrieved from <https://www.theatlantic.com/health/archive/2011/12/before-occupy-how-aids-activists-seized-control-of-the-fda-in-1988/249302/>.
- [3] Deparle J. 111 held in St. Patrick's AIDS protest. *The New York Times* 1989. Retrieved from <https://www.nytimes.com/1989/12/11/nyregion/111-held-in-st-patrick-s-aids-protest.html>.
- [4] Gandhi, M. (2012). *The essential Gandhi: an anthology of his writings on his life, work, and ideas*: Vintage.
- [5] Gladwell M. Small change. *The New Yorker* 2010. Retrieved from <https://www.newyorker.com/magazine/2010/10/04/small-change-malcolm-gladwell>.
- [6] Granovetter MS. The strength of weak ties I A2 - Leinhardt. *Samuel social networks*. Academic Press; 1977. p. 347–67.
- [7] Grover A. Multi-drug resistant TB: what the court ordered. *The Hindu Business Line* 2017. Retrieved from <https://www.thehindubusinessline.com/specials/pulse/multidrug-resistant-tb-what-the-court-ordered/article9589765.ece>.
- [8] Handelman, D. (1990). Act up in anger. <https://www.rollingstone.com/culture/features/act-up-in-anger-19900308>.
- [9] Health Resources & Services Administration. Retrieved from <https://hab.hrsa.gov/about-ryan-white-hiv-aids-program/about-ryan-white-hiv-aids-program>; 2016.
- [10] History.com. Freedom summer. 2009. Retrieved from <https://www.history.com/topics/black-history/freedom-summer>.
- [11] Krishnan V. Extreme TB: Centre yet to push for cheaper versions of two crucial drugs. *The Hindu* 2018. Retrieved from <http://www.thehindu.com/sci-tech/health/extreme-tb-no-licence-to-heal/article22920634.ece>.
- [12] Mascarenhas A. Union Budget 2018: 'will vulnerable TB patients get benefit?'. *The Indian Express* 2018. Retrieved from <http://indianexpress.com/article/cities/pune/union-budget-2018-will-vulnerable-tb-patients-get-benefit-5048410/>.
- [13] McAdam D. Recruitment to high-risk activism: the case of freedom summer. *Am J Soc* 1986;92(1):64–90.
- [14] NYC LGBT Historic Sites Project. ACT UP demonstration at the New York stock exchange Retrieved from <https://www.nyclgbtsites.org/site/act-up-demonstration-at-the-new-york-stock-exchange/>; 2017.
- [15] Plamper J. *The history of emotions: an introduction*. OUP Oxford; 2015.
- [16] Revised National TB Control Programme. India TB report 2018 2018. Retrieved from <https://tbcindia.gov.in/showfile.php?lid=3314>.
- [17] Rothstein E. Four Men, a counter and soon, revolution. *The New York Times* 2010. Retrieved from <https://www.nytimes.com/2010/02/01/arts/design/01museum.html>.
- [18] South African History Online. Mohandas Karamchand Gandhi. 2011. Retrieved from <http://www.sahistory.org.za/people/mohandas-karamchand-gandhi>.
- [19] The Gayly. Remembering Ryan White. 2018. Retrieved from <http://www.gayly.com/remembering-ryan-white>.
- [20] *The LGBT Religious Archives Network*. Profile: Rev. Adrian Ravarour. 2008.
- [21] The Martin Luther King Jr. Research and Education Institute. Major king events chronology: 1929–1968. King encyclopedia. Stanford University; 2018 <https://kinginstitute.stanford.edu/king-resources/major-king-events-chronology-1929-1968>.
- [22] World Health Organization. Global TB report 2017 2017. Retrieved from <http://apps.who.int/iris/bitstream/handle/10665/259366/9789241565516-eng.pdf;jsessionid=5FF63FC0D315565D5809EDA9701D0348?sequence=1>.

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