

HIV and the Right to Health in Colombia

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Abstract

The first Colombian to claim a judicially enforceable right to health was a gay man living with HIV, who in 1992 claimed a violation of his constitutional rights on account of being denied antiretroviral therapy. Since then, HIV activists have been at the forefront of advancing both the judicialization and social reconstruction of health as a human right. However, their role—and its implications today—has been sometimes overlooked in the study of Colombia’s right to health. Based on semi-structured interviews with key stakeholders, we evaluate the HIV movement’s effect on the progression of the right to health and resulting health care reform, and analyze the reform’s success in addressing the needs of people living with HIV. While the landmark Constitutional Court decision T-760 and resulting health care reform are not the result of any one group, the HIV movement played a significant role in these developments, and its values are largely reflected in the country’s new sociopolitical conceptualization of the right to health. However, the movement has faced division over the issue of generic medication availability and among subpopulations who have not been strongly represented or consistent beneficiaries of its successes.

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Background

To a great extent, right-to-health litigation throughout the world—including in Latin America—emerged in the 1990s as a means of advancing health access for people living with HIV.¹ The courts of Costa Rica, Argentina, and Brazil have all authored notable decisions granting access to HIV-related care.² Moreover, these cases have often been a precursor to a growth in health care litigation generally, an expansion of the concept of a right to health, and sometimes (as in the case of Argentina) a degree of systemic change.³ The success of HIV activists in countries such as Brazil is directly correlated to litigation in pursuit of many other high-cost treatments that were not previously covered by government health plans; many contend that this litigation has disproportionately benefited wealthy individuals who have access to courts while damaging the financial stability of health systems.⁴ This phenomenon has been part of a larger trend in Latin America in which health care access has improved dramatically over the past half-century and yet continues to be marked by significant inequality.⁵

The HIV movement in Colombia has, to a great extent, relied on a right-to-health litigation strategy throughout its history and thus is squarely within this debate. Colombia's experience is unique, however, in the unprecedented degree to which its Constitutional Court responded to increasing health litigation by ordering widespread changes to the health care system in 2008 and forcing the government to adopt a human rights-based approach.⁶ While this decision has drawn much international attention, the HIV movement that was in many ways its catalyst has been less documented. Both the historic action of the court in 2008 and the degree to which Colombian HIV activists utilized right-to-health litigation as a central strategy make this an important story in the study of the judicialization of health. The purpose of this article is to document how, when, and with what impact the HIV movement used legal activism to advance the right to health, as well as to evaluate the relationship between the HIV movement in Colombia

and the expansion of the country's conception of the right to health.

Colombia's HIV prevalence of 0.4% is one of the highest in Latin America and equates to an estimated 120,000 adults.⁷ While this is sizeable enough to represent a significant public health and resource allocation concern, this population has remained marginalized. Furthermore, the epidemic reached Colombia during a particularly difficult time: in 1983, when the first case was diagnosed in Cartagena, the government was engulfed in conflict with left-wing guerrilla groups that emerged in the 1960s, new right-wing paramilitary organizations, and rising drug trafficking.⁸ Although significant progress has been made in achieving peace, Colombia still faces many challenges, with 28% of the population living in poverty and over six million people displaced by violence.⁹ Finally, the religious and conservative elements of Colombian society have created a difficult environment in which to address HIV given the stigma it carries with respect to sexual and cultural norms and the epidemic's disproportionate effect on sexual minorities, sex workers, and other stigmatized groups.¹⁰

At the start of the HIV epidemic, Colombia's health care system was one in which approximately 20% of the population had private health care coverage and the rest relied on the public health care system.¹¹ The current Colombian health care system was established in 1993 with the passage of Law 100, which created a universal health insurance scheme divided into contributive and subsidized packages, both managed by highly regulated but private companies.¹² The percentage of insured Colombians rose from 24% in 1993 to nearly 100% today, but the quality of care has often been criticized, particularly in the subsidized regime.¹³

Contrary to the broad epidemiological, clinical, and sociopolitical literature regarding HIV in Colombia, the study of legal and political HIV activism has been lacking.¹⁴ Furthermore, there has been much literature regarding general right-to-health litigation, particularly since the Constitutional Court's landmark T-760 decision of 2008 (outlined comprehensively by Everaldo

Lamprea in the introduction to his 2015 book), but most academic research regarding legal and political HIV activism in Colombia revolves around the Constitutional Court's impact on the health care system.¹⁵ Ana Cristina González Vélez and Juanita Durán have documented this impact on access to treatment for people living with HIV, and they and others have addressed the issues of priority setting and financing.¹⁶ This article will explain the role HIV activism has played in pursuing those changes.

This paper also seeks to record the earlier years of the HIV movement. Two notable academic works specifically address the earlier years of the HIV movement in Colombia. Luis Cañón's 1995 book documents the movement's early years in the 1980s, although it does not analyze its impact.¹⁷ Lamprea broadly details the main characteristics of the movement in the 1990s and early 2000s, exploring the role of different stakeholders in the reconstruction of the health care system.¹⁸ This article bridges the gap in detail between the different periods of litigation, from the 1980s until the late 2000s, and offers an impact analysis of the HIV movement's role in the greater right-to-health movement in Colombia.

Methods

Between January 4 and February 5, 2016, we interviewed 46 representatives from 41 organizations. Participants originated from Bogotá (n=27), Cali (n=7), Medellín (n=5), Bucaramanga (n=3), Cartagena (n=2), Ocaña (n=1), Pasto (n=1), and Popayán (n=1). In total, we interviewed 16 women and 30 men from nine different professional fields: judiciary (n=3), medical providers (n=2), research institutions (n=3), nongovernmental organizations (n=9), activists (n=7), governmental officials (n=4), academics (n=13), and media (n=1).

Two sampling methods were used. First, we conducted a literature review of written and audio sources that referred to the right to health and social movements in Colombia, which we used to generate an initial list of desired participants. Our inclusion criterion for participants was any indi-

vidual who self-identified as having participated in or researched the HIV or broader right-to-health movements. Second, we conducted exponential, non-discriminative snowball sampling in which key stakeholders provided leads to other participants directly or indirectly involved in the HIV or broader patients' movements. Snowball sampling was necessary for hard-to-reach individuals, such as activists from the earlier periods of the movement who were not presently active.

This was an exploratory qualitative study conducted with data collected through in-depth, semi-structured interviews. The interview guide was composed of a basic socio-demographic background (age, gender, profession, years active in that profession, education level, and place of origin), as well as 15 questions related to the HIV movement and their involvement in it. All interviews were audio recorded and transcribed, and we undertook coding using QSR International's NVivo 11 program for the analysis of qualitative data. We used open coding, in which we read the transcripts without having developed themes beforehand and then established a number of themes based on this reading. Subsequently, we reread all transcripts, coding with the newly established themes.

The Harvard Longwood Medical Area Institutional Review Board approved this study in the United States. In Colombia, we convened a community advisory board for ethical review and approval of the study. The board concluded that the project complied with all appropriate ethical and methodological standards for a qualitative study of this nature, that the study was culturally appropriate, and that it posed no material risk to participants. All interviews were conducted at the preferred time and location of participants, all of whom agreed to be identified in the study and offered their informed consent.

Origins of the HIV movement

The 1980s constituted the beginning of the social movement of people living with HIV. As early as 1982, through news outlets and correspondence

with LGBTQ individuals in the United States and Europe, gay men in Colombia started to receive information on what was then known as the “cancer of homosexuals.”¹⁹ Although this would change later in the epidemic, the initiatives in the 1980s were led by the LGBTQ community, specifically gay men.²⁰ What is considered the first conference on HIV in Colombia was held in Bogotá on July 28, 1983, on International Gay Pride Day.²¹ That same year, the country’s first case of HIV was officially diagnosed and reported at the University Hospital of Cartagena.

The movement’s initial organization came in the form of support groups for patients living with HIV. These groups started to organize in medical centers, where patients with HIV-related conditions met.²² The main objectives were to create a space for patients to share experiences, help patients prepare for death, and accompany them during their terminal phase.²³ One of the first groups was organized at Seguro Social, the only such center then caring for patients with HIV.²⁴ With the help of physician Bertha Gómez, who offered palliative treatments and treatments for opportunistic diseases to HIV patients, a group called El Club de la Alegría organized support meetings every fortnight. Smaller groups in Bogotá, such as El Cartel de la Vida (a play on words from the drug cartels that were operating at that time), joined the meetings at Seguro Social. As more information made its way to Colombia, the support groups began offering information on topics such as nutrition and self-care. Similar groups in other cities also emerged, such as Vivir Mejor in Cali and Compartamos in Villavicencio.²⁵ The concept of support groups came naturally to the patients, but they were also influenced by information about similar activities in the United States.²⁶

Other leading activists in the field began organizing more formally. Dr. Henry Ardila, who had been following the epidemic from the early 1980s, created the Colombian League for the Fight against AIDS in 1986 with the help of other activists and with the aim of providing assistance and information.²⁷ Nongovernmental organizations also appeared, such as Planeta Amor (then called Fundamor), which welcomed children living with HIV

with the goal of “offering a dignified death.”²⁸ Also important was Colombian Network of People Living with HIV, which offered support to and fostered connections among patients.²⁹

A key factor in the creation and cohesion of these groups was a reaction of self-preservation among their members, who were affected by deeply seeded stigma and discrimination. HIV was strongly associated with the LGBTQ community, which increased discrimination against both groups. Although in the future the LGBTQ movement and the HIV movement would mostly work separately, this gave the HIV movement an initial push, as LGBTQ organizations became involved in propelling the HIV cause during the late 1980s and early 1990s.³⁰

As these groups, organizations, and networks obtained information on treatments in the United States through personal connections and the media, and as these treatments arrived to Colombia through donations and individual purchases, the objective of the groups transitioned toward a fight for access to treatment.

Antiretroviral access through *tutelas* and the obligatory health plan

Law 100 of 1993 transformed Colombia’s health care system, which previously had a safety net comprising mostly public hospitals that provided low-income individuals with free or low-cost care.³¹ The new system was one of managed competition in which newly formed health insurance companies, known as *entidades promotoras de salud*, competed for patients under significant government regulation.³² These companies were divided into two categories: those to which beneficiaries and their employers contributed and those for minimum wage, informally employed, and unemployed people, which were subsidized.³³ The health insurance companies were required to cover only those treatments listed in the country’s obligatory health plan (Plan Obligatorio de Salud, or POS) for the contributory scheme (POS-C) or subsidized scheme (POS-S).³⁴ The POS-C was significantly more generous in its benefits than was the POS-S, and although both

excluded HIV treatment at that time, the POS-S also lacked many of the supplemental medications required by people living with HIV.³⁵

Since the antiretroviral medication AZT (azidothymidine) was not part of the POS, the only way to access it was to file a *tutela*, a device similar to a writ of protection that was introduced by article 86 of the 1991 Constitution.³⁶ A *tutela* could be filed as a simple plea, in theory by someone with no legal experience, citing a violation of a fundamental right. The claimant would then receive a response from the local court in which it was filed within 10 days. The first *tutela* to claim a violation of the right to health was T-484 of 1992, brought by a person living with HIV whose medication had been suspended by the public insurer Seguro Social de Tuluá.³⁷ The Constitutional Court held that the right to health—which was not itself considered a fundamental right—had to be protected given that it relates to the rights to life, personal integrity, and dignity: “[the right to health] can be identified as an immediate necessity to the right to life, so that to infringe upon the health of the people is equivalent to infringing upon their very right to life.”³⁸ The court therefore ordered the insurer to provide the medication. The connection between the rights to health and to life was particularly clear with respect to HIV, which at the time was marked by high mortality (particularly when untreated) and from which many patients died even while waiting the 10 days required for a *tutela*.³⁹ From that point on, HIV patients drew on the nexus between the rights to health and to life in their *tutelas*.⁴⁰ The use of courts to access ARVs was also occurring in other countries around this time.⁴¹

Support groups and organizations quickly became an incubator for the growth of *tutelas*. The very first HIV patients in Bogotá covered under Seguro Social had heard about the AZT treatment (approved by the United States’ Food and Drug Administration in 1987) and turned to patients’ organizations for help, as did a growing number of other patients.⁴² Germán Humberto Rincón Perfetti, a human rights lawyer who was volunteering for the Colombian League for the Fight against AIDS, composed the first legal strategy with patients from

Seguro Social in 1994. The strategy, which he called Operation Wasp, was to file seven HIV *tutelas* in seven different courts to occupy the dockets of seven Bogotá judges for 10 days. All seven courts ruled in their favor, ordering Seguro Social to start providing AZT regimens to its patients.⁴³ Although the groups initially used *tutelas* to access AZT treatment, they quickly started to demand their right to comprehensive treatment, including the right to diagnosis, right to CD4 count, access to diapers, and non-discrimination in the workplace.⁴⁴ *Tutelas* for the right to comprehensive treatment increased rapidly, replacing AZT-specific *tutelas*.⁴⁵ These first years were followed by a large wave of HIV-related *tutelas* filed by the Colombian League for the Fight against AIDS, which by then consisted of 30 patients’ organizations and had become known as a “*tutela* factory.”⁴⁶

The avalanche of HIV-related *tutelas* was accelerated by the movement’s shift from primarily providing social support to individuals to providing technical and legal support for right-to-health claims.⁴⁷ Lawyers and activists travelled around the country organizing workshops and providing ready-made *tutela* forms, which were being filed by patients nationwide by the late 1990s.⁴⁸ The pressure in support of AZT treatment also came from other areas of civil society. For example, in 1995, the vice president of the Pan-American Association of Infectious Diseases published an op-ed in a national newspaper on the benefits of AZT and called for the government to add it to the POS.⁴⁹ Pressure was also mounted by physicians working within Seguro Social, such as Dr. Bertha Gomez, who had been supporting patients since the beginning of the epidemic.⁵⁰

For reasons that are unclear, AZT was added to both the POS-C and POS-S in 1997.⁵¹ Most academics and activists agree that the pressure from the numerous *tutelas* and from civil society played a significant role. Financially speaking, given that courts were ordering insurance companies to provide AZT even though it was not part of the POS, the money for the medication was coming out of a government fund called the Fondo de Solidaridad y Garantía.⁵² Earlier in 1997, the Constitutional Court held that the government was responsible for “cover-

ing the costs of non-POS services ordered by judges through a writ of protection,” and with the increasing number of *tutelas*, the government’s need to reduce the use of the fund was becoming evident.⁵³ Another factor was strong political support from Minister of Health María Teresa Forero de Sade, who steadfastly supported AZT’s inclusion, allegedly after a family member was diagnosed with HIV.⁵⁴

Finally, in December 1997, Agreement Number 83 was signed into law, adding comprehensive treatment for HIV patients to the POS.⁵⁵ This meant that new antiretroviral treatments and what is known as the “cocktail” combination therapy were included in both the POS-S and POS-C, and by 2000, treatments for HIV would be virtually standardized between the two schemes. However, new treatments were not automatically included, and many non-HIV drugs needed by HIV patients remained not covered by the POS-S, forcing many patients to continue relying on *tutelas*.

The high-cost patients’ movement

During the early 1990s, HIV had been classified as a catastrophic condition, along with other diseases, such as cancer, chronic renal failure, and transplants.⁵⁶ This classification was later changed to *pacientes de alto costo* (high-cost patients), defined as a condition with “high cost, low occurrence, high complexity of treatment and low cost-effectiveness.”⁵⁷ Inspired by the HIV movement’s successful use of *tutelas*, groups representing patients with other high-cost conditions began appearing in the late 1990s.⁵⁸ These groups soon began to work together, and in the early 2000s, HIV activist Nestor Álvarez formed a group called the Association of High-Cost Patients. Rincón Perfetti, the attorney noted above, described the organization as consisting of “technical and legal experts on the right to health ... regarding everything: for cancer, for AIDS, for dialysis, for everything.”⁵⁹

By 2005, 65% of high-cost patients were receiving treatment as a result of *tutelas* (versus paying out-of-pocket or using normal POS coverage).⁶⁰ In response, the government passed Law 972 of 2005, hoping to reduce the number of *tutelas*

and improve access for patients with nine identified high-cost conditions, including HIV.⁶¹ This law forced the health insurance companies to provide comprehensive treatment to these patients even if they, for any reason, lost their affiliation to that particular insurance company, in which case the company would be reimbursed by the government fund for care not covered by the POS. However, the law did not solve the problems that some identified with the semi-privatized system created by Law 100, including fragmentation, barriers to care, and a reduction in rights (even as the 1991 Constitution theoretically expanded them).⁶²

Even as the high-cost patients’ movement was taking shape, divisions were forming around the issue of generic drug access. The pharmaceutical industry had allied with some members of the HIV movement in the late 1990s, and industry interest grew as the movement expanded beyond HIV patients to include others with high-cost conditions.⁶³ The companies saw patients’ groups as a means to broaden the market for high-cost medications and thus supported these groups with funding and pharmaceutical samples.⁶⁴ However, with the success of the *tutelas* and subsequent reforms improving access, some activists did not feel comfortable working with the pharmaceutical industry, which they saw as the reason for Colombia’s unusually high costs of care. As certain HIV and right-to-health groups started to raise the issue of pharmaceutical pricing, others quickly splintered off. Additionally, the Association of High-Cost Patients—which had merged with another patients’ group to form Pacientes Colombia in the early 2000s—survived for only two years before splitting back in two for the same reason.⁶⁵ The disunity was also driven by the opinion held by many HIV activists that HIV was actually not a “high-cost” condition and that in a properly regulated system, life-saving treatment for HIV would not be exorbitantly expensive.⁶⁶

The T-760 decision and resulting reform

By 2008, the number of annual health care *tutelas* had swelled to over 100,000, all but forcing the Con-

stitutional Court to seek a systemic resolution.⁶⁷ Juanita Durán, who worked on the case as a *magistrado auxiliar* (auxiliary magistrate, a position similar to an indefinite clerkship), said that the HIV movement was “the pioneer, the most important [actor] leading the path” to T-760.⁶⁸ Because T-760 resulted not from a single lawsuit but rather from 22 separate *tutelas* selected by the court, it cannot be said that any one group prompted the decision.⁶⁹ But in framing the right to health in the same way that the HIV movement had done for years, the court not only addressed most of the movement’s longstanding goals but also popularized its conceptualization of health as a human right.

First, T-760 and the policies that followed made the POS more generous, more equitable between the contributory and subsidized plans, and less arbitrary in determining exclusions. In keeping with the court’s orders, the government equalized the POS-C and POS-S in 2012.⁷⁰ By 2017, the POS will pivot from being a list of covered treatments that excludes anything not enumerated to a list of excluded treatments with coverage otherwise presumed.⁷¹ This reversal of defaults should mean a reduced need for advocacy around the inclusion of new HIV treatments. The court also ordered that measures be taken to prevent the arbitrary denial of covered services, including discriminatory denials against people living with HIV.⁷² Although T-760 permitted the government to reduce nonessential benefits in merging the plans, those in the subsidized plan will ultimately have greatly enhanced coverage.⁷³ This includes many treatments that, while not directly related to HIV, are required to treat conditions that are complicated by HIV. The significance of this problem for HIV patients was noted by Aquiles Arrieta, an auxiliary magistrate with the court who worked on the decision.⁷⁴

Second, the decision represents a reduction of the need to use *tutelas* for HIV treatment. In many countries, the judicialization of health rights has been criticized as exacerbating inequities because the most marginalized groups have difficulty accessing courts.⁷⁵ Many of our interviewees felt that the evidence was mixed in terms of whether *tutelas* had improved health equity, noting that *tutelas*

could be completed without the help of an attorney (unlike in many countries) but at a lower rate of success.⁷⁶ The patients’ groups may have eased inequity by providing assistance to those who were unable to file *tutelas* on their own.⁷⁷ Nonetheless, some felt the system overwhelmingly benefited the privileged.⁷⁸ Only a few interviewees felt strongly that local court access was reasonably equitable.⁷⁹ Even if this is true, those in the subsidized regime were still at a disadvantage because they had to fight more exclusions than their counterparts in the contributory scheme.⁸⁰ Additionally, it was hard to enforce *tutelas* ordering the provision of HIV medications in the POS-S pharmacies because these pharmacies often did not have such medications in stock.⁸¹ Therefore, T-760 can be seen as addressing a fundamental limitation of the *tutela* system as a means of achieving the movement’s goals.

Third, the decision led to an unprecedented public debate on health care and to a reconceptualization of health as a human right. An unexpectedly large and diverse group of patients, providers, and the general public rallied in support of the Constitutional Court and in opposition to then president Álvaro Uribe, who opposed the decision.⁸² The public essentially embraced what the HIV movement had argued for years: that health was a fundamental right that the health care system of Law 100 had systematically violated. Many of our interviewees considered this symbolic shift to be the most important direct impact of the court’s decision, especially since the long-term effects of health care reform remain to be seen.⁸³

Despite the fact that the decision addressed these three significant goals of the movement, there remains a need for *tutelas*: in recent years, 27% of people living with HIV have still claimed being denied some form of care, and the deep fragmentation that marks the system causes some to be unable to successfully navigate the care to which they are entitled.⁸⁴ Finally, the court’s ruling did not resolve two critical issues cited by activists: the fight within the movement over whether to push for increased availability of generic medications, and the degree to which the movement has not been fully inclusive of the needs of vulnerable populations.

Kaletra, pharmaceuticals, and the fight for the inclusion of generics

The division that had begun prior to 2008 over whether to fight for generic access or insist on brand-name drugs culminated with the campaign of pro-reform activists to lower the price of Kaletra, an HIV medication patented by Abbott Laboratories for patients with resistance to older HIV medications.⁸⁵

By 2010, nearly 6,000 patients were being treated with Kaletra, including 500 beneficiaries of the subsidized regime.⁸⁶ The annual per-patient cost of Kaletra was approximately US\$4,000, compared to US\$1,110–1,300 in other South American nations.⁸⁷ Four organizations—the IFARMA Foundation, the Health Mission Foundation, the Colombian Network of People Living with HIV, and the Committee of Organizations Working on HIV—contacted attorney Rincón Perfetti, who had initially led the *tutela* movement, to try to lower costs. These groups argued that the government was justified under the international compulsory licensing agreement (TRIPS) to issue a compulsory license for a generic version of Kaletra because the drug's price was hindering public health efforts.⁸⁸ The government denied the demand but nonetheless negotiated with Abbott and forced the company to reduce the price to US\$1,067 in 2009. This was seen as a partial victory, but the movement still took the matter to court. In September 2012, the Administrative Tribunal of Cundinamarca ruled against the government in a class-action suit and ordered further negotiation with Abbott, which led to a price reduction to US\$670.⁸⁹ Additional success was achieved in 2014, when the national Industry and Commerce Superintendence issued Abbott a fine of approximately US\$1 million for inflating Kaletra's price by up to 66%.⁹⁰

Although the groups never succeeded in seeing the government issue a compulsory license for HIV drugs, the HIV movement's success helped prompt the government to begin broader negotiations with the pharmaceutical industry, including the regulation of 8,600 medications in 2012, and ultimately creating a regulatory scheme to control prices.⁹¹ For the patients' movement, their initial work with price regulation gave them a special role in these

subsequent negotiations led by the government. In the future, they would be consulted on medications and generics, giving them a space in the national debates on price regulations.⁹²

However, broader organizations dedicated to medication control, such as ObservaMed, also consider the success against Abbot Laboratories as having “kaletrized” the issue.⁹³ ObservaMed contends that the HIV movement's involvement in the issue began and ended with Kaletra, rather than being a sustained effort for reform.⁹⁴ Therefore, the Kaletra issue not only finalized the split within the HIV movement but also failed to unify the pro-generics HIV groups with the pro-generics movement itself.

Activism among vulnerable populations

From the beginning, Colombian activists have strived to do more than file individual cases, instead using litigation as a strategy to build a network and produce systemic change that would benefit everyone. Most of our interviewees agreed that there have nonetheless been challenges in maintaining diversity in terms of who composes and leads the movement, as well as who benefits from its successes. Intersecting forms of discrimination and stigma have ensured that those who stand to benefit most from a human rights approach to health have, to date, benefited least.

This is perhaps most notable with respect to women. Since its early days, the HIV movement has been led mostly by men.⁹⁵ Advocates for Colombian women living with HIV began organizing separately in 1997 with the first National Meeting of Women Living with HIV, followed by the first Latin America and Caribbean Regional Seminar of Women Living with HIV in 1999.⁹⁶ They created the Sunflower Project, now the National Foundation of Positive Women, to foster women's empowerment. While many interviewees understood the concept of the feminization of HIV—that is, the global shift in which the epidemic no longer affects mostly men who have sex with men and now affects men and women equally—no interviewees could say whether the HIV movement had changed to re-

flect this demographic shift, and some suggested a need for additional study. Many interviewees raised issues faced by Colombian women living with HIV relating to the unique biases, stereotypes, and marginalization they experience, which sometimes result in different needs that have not been addressed by the movement's successes to date.⁹⁷ Heterosexual married women are generally excluded from the national HIV plan of action, further segregating efforts to end the epidemic among women from the broader HIV movement.⁹⁸ Most women receive HIV testing only if they become pregnant; even then, only two-thirds receive testing and only two-thirds of those with a positive result are given comprehensive mother-to-child transmission prevention.⁹⁹ A recent study found that 70% of Colombian women living with HIV had been surgically sterilized, which is said to discourage testing, thus nullifying for those women the gains won by the movement.¹⁰⁰

Similar to the situation with women, the LGBTQ community has a complicated history of inclusion in the movement. LGBTQ people bear a disproportionate burden of HIV, as well as stigma and discrimination, in every society.¹⁰¹ This includes Colombia, where recent progress has been made on LGBTQ rights but where many problems remain that exacerbate challenges related to HIV.¹⁰² Furthermore, the medical community has failed to demonstrate cultural competence regarding LGBTQ individuals.¹⁰³ While the movement has always been driven by gay activists, transgender people have been largely absent and their activism occurs in a separate sphere. This is partially because transgender individuals—unlike the gay men who were at the helm of the HIV movement and led its litigation strategy—have lacked the means by which to set their own community's agenda.¹⁰⁴ Instead, international donors set priorities, which are not always in line with those of the transgender community.¹⁰⁵ While internationally funded projects have made street-based rapid testing available to transgender women, these women are not connected to services that would enable them to gain insurance or enter into care.¹⁰⁶ Furthermore, transgender men lack what limited visibility that

transgender women have achieved and are not seen as at risk for HIV.¹⁰⁷

Additionally, Colombia's sex workers, many of whom exist at the intersection of gender-based and gender-identity-based marginalization, have been a notable exception to the general story of the movement told herein. Sex work is legal under certain conditions and in designated "tolerance zones" in Colombia, but a large, mainly street-based illegal market remains.¹⁰⁸ Our interviewees were not aware of sex workers playing a significant role in the movement despite their high rates of HIV. As they have with the transgender population, international donors have played a significant role in directing HIV funding for sex workers; in fact, because there is so much perceived overlap between communities of transgender women and sex workers, many programs are aimed at the combined population of both groups.¹⁰⁹ The HIV movement's success in adding treatments to the POS has not included preventive products and medication that advocates said would most benefit sex workers, who lack the bargaining power to request condoms during sex and could thus benefit more from female condoms and PrEP, which are generally unavailable through health insurance companies or otherwise.¹¹⁰ Many sex workers see HIV testing as pointless because they feel that adequate and inclusive care is out of reach, which means that the movement's gains have had a limited impact on this community.

Finally, some interviewees raised concerns that the changes brought about by the movement and T-760 have not reached incarcerated persons, who face high levels of HIV exposure due to regular sexual relations with guards and other inmates combined with limited access to condoms.¹¹¹ Many prisons have a cell block designated for people living with HIV, within which it is possible to receive some HIV-related care for those who are willing to go public with their status.¹¹² However, inmates usually need help from outside the prison in order to access HIV medications despite such access being theoretically guaranteed by T-760 and the inclusion of the drugs in the now-merged POS. Much of this is blamed on the only health insurance company that is permitted to operate in

prisons, which is allegedly ineffective and corrupt; T-760 did not change the policies on eligibility that would have allowed incarcerated persons to select another plan or to stay with the plan they had prior to incarceration.¹¹³ These issues are now being taken up primarily by those advocating for the rights of the incarcerated rather than by the movement.

Conclusion

This work outlines the history of HIV activism in Colombia—from its start with creating safe spaces for HIV patients in the 1980s, through its development of right-to-health litigation as a primary strategy for improving medication access, and to the fight over generic medication access that caused its division. The movement's success in expanding access to medications—first through *tutelas* and now through expanded health benefits—has not equally benefitted certain marginalized groups, despite the new health care law's guarantee of “equality of treatment and opportunities accessing promotion, prevention, diagnosis, treatment, rehabilitation, and palliation for everyone.”¹¹⁴ However, Colombia's story shows that reframing health as a human right can have a transformative and mobilizing effect on society, and potential remains for a rights-based approach to health to further improve the lives of Colombians living with HIV.

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