

# Between the constitution and the clinic: Formal and de facto rights to healthcare

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## Abstract

In no domain of global health has there been more talk of rights than in HIV/AIDS, yet little is known about how the right to HIV/AIDS care is mobilized at the clinic level. Drawing on interviews and field observations in the United States, South Africa, Thailand, and Uganda, we analyze the legal consciousness of caregivers in five HIV clinics. We identify three organizational factors—clinics' focus on the distribution rather than the adequacy of existing resources, the duties for caregivers that patients' rights create, and the dominant norms of exchange in healthcare—that help to explain the low penetration of *formal rights* talk into clinics despite its prevalence outside them. However, we also observe that within clinics, rights may accrue differently than public discourse about rights might lead us to expect. We find that patients often benefit from highly localized, tacit *de facto rights* that develop gradually over time with the support of state health infrastructure, clinic resources, and professional norms and commitments. These rights would be unlikely to stand up in a court of law but nevertheless have substantial impact on patients' access to care.

## INTRODUCTION: HIV/AIDS AND THE RIGHT TO HEALTH

The global fight against HIV/AIDS has long been intertwined with the fight for human rights. From the epidemic's outset, AIDS activists have drawn on the language of rights. The AIDS Coalition to Unleash Power (ACT UP), formed in New York in 1987, was especially effective in bringing attention to the epidemic. Its chants insisted that people with HIV deserved care, not as matter of charity but as a right: "Health! Care! Is a right! Healthcare is a right! Act up!" and "Drug treatment on demand! AIDS won't wait!"<sup>1</sup>

Over several decades, these demands diffused around the globe and became formally encoded in international treaties and declarations. Under pressure from activists, the international human right to health, first announced in the UN Universal Declaration of Human Rights in 1948 and elaborated in the International Covenant of Economic, Social, and Cultural Rights (ICESCR) in 1976, began to evolve to more clearly embrace the specific, positive right to HIV/AIDS care. In 2001, the United

<sup>1</sup>For a list of ACT UPchants, see <https://actupny.org/documents/newmem5.html>.

Nations passed the Declaration of Commitment on HIV/AIDS, setting forth ambitious global goals to combat the pandemic and explicitly recognizing access to HIV/AIDS medication as “one of the fundamental elements to achieve progressively the full realization of the right of everyone to the enjoyment of the highest attainable standard of physical and mental health” (UN General Assembly, 2001, p. 9).

Moreover, under the leadership of HIV/AIDS activists—most notably, Jonathan Mann—the field of “health and human rights” itself was forged (Stemple, 2008, p. S114). And just as HIV/AIDS activists merged disease fighting with human rights, a rights-based approach to tackling HIV also influenced the scientific community. Although in the late 1980s activists bitterly criticized the International AIDS Conferences for failing to address the social and political dimensions of the epidemic, by the late 1990s, conference organizers began to champion a human rights-based approach to fighting HIV/AIDS, with universal-access themes like “Bridging the Gap” (1998), “Breaking the Silence” (2000), and “Access for All” (2004) (International AIDS Society, 2020).

This human-rights approach to fighting HIV/AIDS greatly expanded access to lifesaving drugs, even though the ultimate goal of universal treatment remains unfulfilled. With the development of the first antiretrovirals (ARVs) in the late 1980s, and highly effective triple-therapies in the mid-1990s, the unprecedented social activism accompanying the global HIV/AIDS pandemic began to reshape international drug policy. The WHO Model List of Essential Medicines was forever altered in 1999, when patented pharmaceuticals, namely ARVs, were finally added to the list (Klug, 2008, p. 208). In 2000, the UN began negotiations with pharmaceutical companies to lower the price of ARVs for poor countries. In 2001, the World Trade Organization announced the Doha Declaration on Public Health, affirming the right of developing countries to buy or manufacture generic medications to combat public health crises like the HIV/AIDS epidemic. In response to this changing legal landscape of the global intellectual property regime (Chorev, 2012), a new cohort of transnational HIV/AIDS “access professionals” emerged to design and implement supranational solutions to expand access to ARVs (Nilsson, 2017). In 2002, the Global Fund approved its first round of \$600 million of grants for HIV/AIDS care in developing countries. And in 2003, US President George W. Bush launched the President’s Emergency Plan to For AIDS Relief (PEPFAR), allocating \$15 billion over 5 years in global aid to combat AIDS (US Department of Health and Human Services, 2016).

In tandem with these international moves, activists, and lawyers continued to prod national governments for access to drugs. In South Africa, for instance, lawyers and activists brought suits against both pharmaceutical companies, to gain the right to produce drugs locally, and the government, to force it to create a treatment program to prevent the transmission of HIV from mothers to babies (Heywood, 2009). In Brazil and other Latin American countries, the judicialization of health focused more on providing drugs for individual patients (Biehl et al., 2016; Rodríguez-Garavito, 2014).

By the early 2000s, then, rights talk had penetrated the world of HIV/AIDS activism, research, and policymaking. Yet despite the prominence of the human rights frame, scholars note, “many health professionals on the ground remain, to this day, unfamiliar with human rights” (Stemple, 2008, p. S117). Thus, even for HIV, a disease that might be considered the poster child for rights to health, we know relatively little about whether and how far rights consciousness has penetrated the world of HIV/AIDS treatment and even less about the barriers it encounters.

This article looks at rights to healthcare on the ground. In particular, it asks whether workers in HIV clinics, one of the main places where healthcare rights would be exercised, talk about such rights in their daily work of caring for people with HIV and conducting related research. Although others have studied the activists who worked to create or expand rights to HIV/AIDS care (Chan, 2015; Colvin & Robins, 2009; Epstein, 1996; France, 2016; Harris, 2017; Heywood, 2009), less research has examined what happens to rights once they are created. If real rights to health have been created or awareness of rights has increased, then we might expect staff members to reference these rights in their daily work, perhaps because their patients were asking for services not previously provided or because caregivers themselves were attempting to translate new rights into clinic routines.

Drawing on interviews and field observations in five HIV clinics in the United States, Thailand, South Africa, and Uganda, we analyze the rights consciousness of clinic caregivers and ancillary workers. We find, overall, a low penetration of rights talk in the clinics. We argue that three organizational factors—clinics' focus on the distribution rather than the adequacy of existing resources, the caregiver duties that patients' rights create, and the dominant norms of exchange in healthcare—help to explain why people are less likely to think and speak in terms of rights in the clinic than in the more public and politicized arenas of HIV activism, conferences, and commemorations.

We also observe, however, that within clinics, rights may accrue in a different way than public discourse and the world society literature (Meyer, 2004) might lead us to expect. Although both emphasize a top-down creation of *formal rights*, within clinics, patients often benefit from less formalized, tacit *de facto rights* that grow with the support of state health infrastructure, professional norms, and personal commitments. Although such rights would be unlikely to stand up in a court of law, they nevertheless have substantial impact on patients' access to care.

## LEGAL FOUNDATIONS OF THE RIGHT TO HEALTH: TRICKLE-DOWN VERSUS BOTTOM-UP RIGHTS

Sociolegal scholarship is replete with investigations of rights. Indeed, as Michael McCann stated in his Law and Society Association Presidential Address, “[p]erhaps no topic, short of law itself, has been more central to the sociolegal legacy of scholarly inquiry than that of *rights*” (McCann, 2014, p. 246). In the 1960s and 1970s, following the International Declaration of Human Rights and the Civil Rights Movement in the United States, many hoped that rights would alleviate human suffering and advance social justice. In this period, many empirical sociolegal “gap studies” examined how formal rights often fell short in practice (Gould & Barclay, 2012, p. 325; McCann, 2014, p. 246). This research powerfully illuminated the inconsistent, unequal, and contingent enforcement of rights (Gould & Barclay, 2012, pp. 326–328). Despite the well-documented shortcomings of rights (see, e.g., Horowitz, 1988), scholars have observed the remarkable staying power of rights discourse in American society (Milner, 1989) and around the world (Chua, 2015).

Likewise, the sociolegal literature on international human rights law has cataloged the unrealized promise of international human rights treaties—even in countries that are signatories (Cole, 2015; Hathaway, 2002). The International Covenant on Economic, Social and Cultural Rights (ICESCR), a multi-lateral treaty adopted by the UN General Assembly that came into force in 1976, is one of the key sources of the right to health globally. Implementation of state obligations under this key covenant is monitored by the Committee on Economic, Social and Cultural Rights, which considers availability, accessibility, acceptability, and quality (the AAAQ framework). Because of their focus on states' obligations, health law researchers have considered how treaty and covenant provisions like that of the ICESCR have been inserted into domestic legal documents (see, e.g., Backman et al., 2008; Perehudoff et al., 2016) but have not generally asked how a right to health filters down to the clinic level.

To be sure, a handful of researchers do ask what happens at the ground level. Anthropological work by Farmer (2001) on structural violence and global health inequality, Biehl (2007) on the pharmaceuticalization of governance and citizenship that accompanied the expansion of ARV access in Brazil, and Kenworthy (2017) on the socio-political death that accompanied HIV/AIDS treatment scale-up in Lesotho, particularly stand out. And public health law scholars have used the AAAQ framework espoused by the ICESCR to evaluate individual programs, as Sun and Amon (2018) do in appraising programs to reduce the impact of neglected tropical diseases. Yet as sociolegal scholars would argue, any assessment of the success or failure of international covenants such as the ICESCR must include a review of the gap between “covenant on the books” and “covenant in action”—and that means looking at the hospital or clinic level.

Early gap studies in the United States were criticized for focusing too much on “the top of the system”—rules and courts—rather than on “understanding the social role of law” (Gould & Barclay, 2012, p. 328; Trubek & Galanter, 1974, p. 1082). Similar critiques could be made of global gap studies, which have traditionally applied a US law-and-society paradigm to countries in the global South (Trubek & Galanter, 1974). The literature on the right to health rarely extends beyond cataloging links between global conventions and treaties and the constitutions and laws of individual countries. As both Engel (2012) and Merry (2006a, 2006b) suggest, we might expect some impact on transnational elites and NGO activists, who may be making rights activism their life’s work, without much expanded human rights subjectivity in the rest of the populace. Social scientists studying global actors have often taken a “vertical perspective,” investigating the links between local communities and the international human rights corpus (Engel, 2012). Even when scholars go further (e.g., Backman et al., 2008), they generally do not ask how right-to-health consciousness figures into ordinary social interaction (an exception is Levitsky, 2008, discussing Americans’ reluctance to claim health-related entitlements).

This article examines how the right-to-health discourse works on the ground by focusing on the clinic level. Despite the existence of formal rights to HIV/AIDS care in several jurisdictions we studied, we find that inside all of the clinics, the clinic-level rules, policies, and caregiver discourse gave precious little attention to patients’ rights to care. Yet, we find that in this silence, clinic patients nevertheless benefitted from highly localized, tacit *de facto* rights to HIV/AIDS care formed by clinic staff with the support of state health infrastructure, professional norms, and personal commitments.

Although this is not a finding anticipated by the human rights literature, which generally understands human rights to be anchored in global conventions and national constitutions and laws, several bodies of work acknowledge the importance of ground-level attention to rights, morality, and ethics. Sociolegal scholars, sociologists of science and medicine, scholars who study regulation, and organizational scholars all acknowledge the importance of discretion, noting both the opportunities and pitfalls it brings (Chiarello, 2019; Freidson, 1986; Hawkins, 1992; Heimer, 2011; Lipsky, 1980; Moody-Maynard & Musheno, 2003; Timmermans & Berg, 1997; Timmermans & Kolker, 2004). When front-line workers have discretion, they can (appropriately) adapt rules to fit the circumstances, but they can also (sometimes inappropriately) circumvent regulations. Discretion can bring the deviousness that undermines rules, but it also can bring the flexibility that makes rules work (Braithwaite & Braithwaite, 1995; Heimer & Gazley, 2012; McBarnet & Whelan, 1991). That flexibility is especially important in healthcare where tailoring treatments to patients is a core requirement.

In particular, we find that in the clinics discretion generally made moral decisionmaking into a matter of *favors* that physicians can give or withhold rather than *rights* that people can claim. In addition to asking when physicians use their discretion to give care that is in line with a right to health, then, we also ask what conditions allow for discretion to be enlarged sufficiently that patients can begin to make robust claims on their own behalf. This switch, we suggest, is how *de facto* rights might grow from the ground up.

## DATA AND METHODS

To investigate these questions about the right to health, we draw on ethnographic data and interviews gathered for a project on the legalization of medicine. With clinical guidelines, research protocols, and the other trappings of evidence-based medicine, HIV clinics are good places to study legalism, including how rights to health shape the daily life of clinics. The legal environment for clinic work is shaped by domestic law (national statutes, regulations, and guidelines), foreign law (mainly US law for the global South clinics), and international law (global conventions and treaties). In order to understand the effects of these disparate legal influences, the research was designed to include clinics in both the global North and the global South.

The ethnographic research was conducted in two HIV clinics in the United States (Robert Rafsky Clinic, where most patients were privately insured, and Bobbi Campbell Clinic, where public funds paid for treatment) and one each in South Africa (Gugu Dlamini Clinic), Thailand (Cha-on Suesum Clinic), and Uganda (Philly Lutaaya Clinic).<sup>2</sup> These countries varied in whether their citizens had a formal right to health (provided for via treaty, national constitution, or statute). All five clinics were engaged in both treatment and research, although the boundary between the two was often blurry and the balance between treatment and research varied somewhat across sites. In all of the clinics, though, research subjects were treated as if they were simultaneously patients and clinical trial participants. All of the clinics had hospital and university affiliations. All but Thailand's Cha-on Suesum Clinic received American government funds for treatment (as well as receiving funds from local sources) and all five clinics received some research funding (directly or indirectly) from the US National Institutes of Health (NIH), necessitating adherence to American government rules about both treatment and the ethical conduct of research. Because clinic researchers expected some research results to be used in drug approval processes, the clinics were also attentive to the rules of the US FDA.

In each fieldsite, one or two members of the team conducted the bulk of the research while others visited the site for brief periods. The fieldwork in the American clinics was of longer duration (nearly 2 years in Robert Rafsky Clinic; 13 months in Bobbi Campbell Clinic) but was less intensive (we were not in the field every day). We spent 4 months doing intensive fieldwork in Thailand, Uganda, and South Africa, with multiple 2-week visits before and after. We began fieldwork in Robert Rafsky Clinic in September, 2003, and last revisited our sites in Uganda, Thailand, and South Africa between June and August, 2007. The fieldwork thus took place during the first years of the UNAIDS, Global Fund, and PEPFAR global rollout of ARVs and contemporaneous locally funded programs.

We shadowed staff as they examined patients coming for treatment or for research study visits, made phone calls, attended meetings, and reviewed records with research monitors, site visitors, and accreditors. We gathered copies of clinic forms and policies. We talked with and observed staff in a variety of positions—physicians, principal investigators, nurses, administrators, social workers and counselors, receptionists, and data processors. We were able to observe the operation of both official rules and rules in action and to hear how clinic staff talked about their work.<sup>3</sup>

In addition to the ethnographic fieldwork and associated informal discussions, we conducted well over 100 formal interviews with clinic workers (e.g., physicians, research directors, pharmacists, nurses) and healthcare experts not directly affiliated with the clinics (e.g., government officials, NGO workers, health regulators). Interviews were audio recorded and transcribed. Fieldnotes and interview transcripts were coded using Atlas.ti.

In our effort to assess how rights to HIV/AIDS care were claimed, negotiated, or created in the clinics in a moment of international scale up of ARV provision, we inductively examined the clinic fieldnotes and interview transcripts coded for “rights.” And, to systematically examine the *absence* of rights talk where we would most expect it, we analyzed all clinic fieldnotes and interview transcripts coded for “lack of access to healthcare/treatment.” The material gathered outside the clinics is not formally analyzed in this article; we do, however, occasionally cite nonclinic informants to establish the national context and to draw contrasts with what we observed within clinics.

The clinics where we carried out our research could not be described as having a “human-rights approach” (Hunt, 2016) or even as being very oriented to a broad right to health—unlike, say, the clinics of Doctors Without Borders (Fox, 2014; Redfield, 2013) or Zamni Lasante, the Partners in Health's flagship community-based health project in Haiti (Farmer, 2001; Kidder, 2004). This is not to say that staff members in these clinics would not have endorsed a right to health, but rather that

<sup>2</sup>As a pseudonym, we assigned each clinic the name of a deceased AIDS activist whose work aligned with that clinic's ethos.

<sup>3</sup>Although we interacted with some patients while observing clinic activities, our IRB agreements did not permit us to gather information from or about patients.



such a perspective did not guide their work, which was instead much more organized around the standard practices of medical care and accountability both to their superiors in the healthcare organizations where they worked and to the entities that provided funding. Whether or not a clinic has an explicit human-rights approach, we can still ask whether the policies and practices of the clinics and its overall culture align with and support a rights-based approach to healthcare.

One additional methodological point bears mentioning. Our interviews were not explicitly about rights. Given that “[t]he aim of research on rights consciousness is to detect its presence or absence in the thoughts and actions of individuals across a range of social interactions,” Engel (2012, p. 434) argues, “[r]esearch that injects into the interview the very concepts whose existence is being researched would be methodologically self-defeating.” Rather than capturing researcher-directed conversations about rights, then, these interviews and observations, like the work of Ewick and Silbey (1998) on legal consciousness, capture the naturally occurring presence or absence of rights consciousness.

## RIGHTS TALK INSIDE THE CLINIC

Powered by a global human-rights movement and AIDS activism, the right to HIV/AIDS care took hold across the world in the 1990s and early 2000s. For our purposes, the right to HIV/AIDS care encompasses both the right to healthcare and to medicines, overlapping but distinct entitlements (Harris, 2017). As we show in Table 1, the right to HIV/AIDS care was formalized to varying degrees in the four countries we studied. Interestingly, despite impassioned HIV/AIDS activism and rights talk in the global North, the United States did not lead the way in formally codifying rights to HIV care. Instead, countries in the global South like South Africa and Brazil led the way, suggesting that rights do not always diffuse from richer countries to poorer ones.

In South Africa and Thailand, the right to HIV/AIDS care was formalized in international treaties, constitutional provisions, and domestic statutes (see Table 1). Importantly, in these countries, this formal right was bolstered by the statutory creation of a national health insurance scheme. Although Uganda ratified several international human rights treaties guaranteeing a right to health and its constitution guarantees access to health services, it lacked national legislation providing a right to healthcare (Mubangizi & Twinomugisha, 2010, pp. 121–122). Among the countries we studied, the United States had the weakest formal rights, lacking any constitutional or statutory guarantee of healthcare services for the general public, despite providing health insurance entitlements to limited sectors of the population through Medicare, Medicaid, Tricare, and SCHIP (Maruthappu et al., 2013, p. 15; Rosenbaum, 2003, p. 1547). More recently, the still-evolving and much-challenged US Affordable Care Act, signed into law in 2010, continued this trend by expanding Medicaid entitlements, increasing regulation of the insurance industry, and prohibiting discrimination (in Section 1557).

To understand how the global right-to-health discourse and formal rights to health in each country filtered into the legal consciousness of clinic workers, we analyzed all quotations coded for “rights” and “lack of access” among our clinic fieldnotes and interviews. We were struck by how little rights talk we found across these five HIV/AIDS clinics, even in countries (like South Africa and Thailand) where patients enjoyed a more robust formal right to health.

In a within-clinic comparison presented in Table 2, we examine rights talk in each clinic alongside lack-of-access talk. Those relatively common moments where patients’ gaps in coverage or access were noted by clinic workers (about 1.25–1.5 times per fieldwork or interview document in all of the clinics except Robert Rafsky) would seem to be logical occasions for providers to discuss rights to healthcare. And yet, even when discussing patients’ challenges obtaining HIV/AIDS care, these rough counts show that clinic workers neither invoked rights as a resource to increase patients’ access nor as an unfulfilled public promise. Rights of any kind were mentioned in only between 5% and 15% of the fieldwork and interview documents.

**TABLE 1** Formal rights to HIV/AIDS care, 2003–2007

Country	Treaty <sup>a,b</sup>	Constitution	Statute
<b>South Africa</b>	<ul style="list-style-type: none"> <li>• ICERD, ratified 1998</li> <li>• CEDAW, ratified 1995</li> <li>• CRC, ratified 1995</li> <li>• CRPD, ratified 2007</li> </ul>	Constitutional rights to access to healthcare services, emergency medical treatment, and basic healthcare for children, adequate medical treatment for detainees and prisoners <sup>c</sup>	National Health Act providing right to free primary care in 2004
<b>Thailand</b>	<ul style="list-style-type: none"> <li>• ICERD, ratified 2003 (but with reservations)</li> <li>• ICESCR, ratified 1999</li> <li>• CEDAW, ratified 1985</li> <li>• CRC, ratified 1992</li> </ul>	Constitutional provisions for the right to access healthcare and the right of the poor to free healthcare in both the 1997 and 2007 constitutions	National Health Security Act providing universal health insurance adopted in 2002, ART included in universal health coverage in 2006 <sup>d</sup>
<b>Uganda</b>	<ul style="list-style-type: none"> <li>• ICERD, ratified 1980</li> <li>• ICESCR, ratified 1987</li> <li>• CEDAW, ratified 1985</li> <li>• CRC, ratified 1990</li> <li>• ICRMW, ratified 1995</li> </ul>	Constitutional provision that state has duty to ensure access to health services	No national right to healthcare or universal insurance coverage
<b>United States</b>	<ul style="list-style-type: none"> <li>• ICERD, ratified 1994 (but with reservations)</li> <li>• ICESCR, signed 1977 (not ratified)</li> </ul>	No constitutional right to healthcare, with the exception of prisoners and detainees under Eighth Amendment jurisprudence <sup>e</sup>	No national right to healthcare or universal insurance coverage, but statutory provisions for coverage for special groups through Medicare, Medicaid, and Ryan White Programs

<sup>a</sup>CEDAW, The 1979 Convention on the Elimination of All Forms of Discrimination against Women; CRC, The 1989 Convention on the Rights of the Child; CRPD, The 2006 Convention on the Rights of Persons with Disabilities; ICERD, The 1965 International Convention on the Elimination of All Forms of Racial Discrimination; ICESCR, The 1966 International Covenant on Economic, Social and Cultural Rights; ICRMW, The 1990 International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families.

<sup>b</sup>Includes only international human rights treaties that recognize a right to health and were ratified by each country before 2007 (when our data collection ended). Does not include regional treaties recognizing a right to health that states may have been party to during this period. Country-level treaty data are available from the website of the UN Human Rights Office of the High Commissioner: <https://www.ohchr.org/EN/pages/home.aspx>.

<sup>c</sup>South Africa's constitution is available at: <https://www.gov.za/documents/constitution-republic-south-africa-1996>. South Africa's constitutionally based right to health was elaborated by the Constitutional Court of South Africa in *Soobramoney v. Minister of Health and Minister of Health v. Treatment Action Campaign* (Phillips, 2004, p. 11). In *Treatment Action Campaign*, South Africa's Constitutional Court interpreted ICESCR treaty obligations as mandating the country's provision of preventative HIV/AIDS treatment measures to all pregnant women (Phillips 2004, p. 11). In 1997, in *Van Biljon v. Minister of Correctional Services*, the Court held that the state had a duty to provide HIV/AIDS medication to prisoners (Mubangizi & Twinomugisha, 2010, p. 118).

<sup>d</sup>For a discussion of these laws, see Siraprasiri et al. (2016, p. 13).

<sup>e</sup>This right was first announced by the US Supreme Court in *Estelle v. Gamble* (1976).

In fact, these counts risk overstating the penetration of right-to-healthcare discourse in the clinics. As the examples below illustrate, when rights were mentioned by clinic caregivers, they generally did not refer to a right to HIV/AIDS care, but instead to other types of individual rights—namely, patients' rights to privacy, the rights of research subjects, or the right not to experience discrimination. And when clinic caregivers did raise issues of treatment access, they rarely referenced rights. In contrast, the comments of outside informants were much more closely aligned with the right-to-health discourse that is part of HIV/AIDS lore. We emphasize, though, that our finding about the lack of rights talk within clinics in no way indicates a failure of clinic caregivers, but instead suggests their implicit understanding about the lack of utility—the “lightness” (McCann, 2014)—of formal rights.

## South Africa

In Gugu Dlamini Clinic, nearly all of the staff discussion of “rights” concerned disclosure of HIV/AIDS status and employment discrimination. There, clinic counselors had to balance patients' constitutional rights to privacy with their legal duty to disclose HIV status to intimate partners in

**TABLE 2** Rights talk in the clinic

	Gugu Dlamini (South Africa)	Cha-on Suesum (Thailand)	Philly Lutaaya (Uganda)	Robert Rafsky (United States)	Bobbi Campbell (United States)
<b>Rights quotations</b>	13	3	6	8	6
<b>Lack of access quotations</b>	125	84	93	36	102
<b>Total documents</b>	87	58	73	167	66
<b>Rights quotes: Document</b>	0.15	0.05	0.08	0.05	0.09
<b>Lack of access quotes: Document</b>	1.44	1.45	1.27	0.22	1.55

certain circumstances. When discussing the HIV program's long history with patient user fees—an issue that directly bore on individuals' access to ARVs and other treatment—explicit rights talk was absent.

In contrast to the dearth of rights-as-entitlement-to-treatment talk inside the clinic, nonclinic informants in South Africa more often used rights frameworks in discussing HIV/AIDS medication access issues. For example, one nonclinic HIV/AIDS researcher praised the state for providing ARV access under South Africa's "human rights constitution." Informants who worked in the legal arena—where robust rights talk might be expected—also emphasized South Africa's constitutional healthcare entitlements. Noting the constitution's "transformative nature," one lawyer lauded "the express recognition in the constitution that the state has certain positive obligations in respect of all rights, whether socio-economic or otherwise" which "really allows you to create something new." Elaborating, he added that it was "not just that regulating medicine prices is a good thing because people then can get access to medicines, but government actually doesn't have a choice in the matter."

As this interview demonstrates, South Africans working on HIV/AIDS legal issues saw the formal right to health as a central resource in the fight for universal medication access. Indeed, when our South African informants invoked formal rights to HIV/AIDS care, it was not in the context of clinician-patient interactions or internal clinic discourse, but instead in relation to the impact of litigation undertaken by activist NGOs, such as the Treatment Action Campaign (Klug, 2008). This litigation against both international pharmaceutical companies and the South African government helped lower the costs of drugs, thereby expanding access to ARVs. Despite these successes, the rights consciousness of clinic healthcare workers and administrators had not expanded to include access to care, but instead had remained focused on other rights such as the right to privacy and the right to consent.

## Thailand

When Cha-on Suesum staff explicitly mentioned rights, it was only to comment on research subjects' rights in HIV vaccine clinical trials. This was true despite Thailand's 2004 expansion of access to ARVs through its nationwide "30 Baht" health insurance scheme and clinic staff's frequent discussion of patients' continued lack of access to ARVs, and especially second-line ARVs.

Some Cha-on Suesum patients still had to buy their drugs. Given the "shaky financing of ARVs and medical care," clinic staff believed that clinical trials remained an "attractive" avenue for access to medications for their patients. For some drug trial participants, post-trial lifelong access to study medications was guaranteed. But many patients who had received ARVs via research participation faced uncertainty about how they would get medications once studies ended. Despite recognizing these gaps, though, clinic staff did not invoke rights to healthcare. Instead, they attempted rudimentary needs testing and then filled gaps for the neediest. Social workers were tasked with "beating it



out of these patients, how much they can pay ...” Caregivers believed they could assess ability to pay by the patients’ appearance: “Looking at them, you see the nice shirt and nice watches. Some have cars, and they have new phones ... they can manage. We take care of the rest.”

In contrast to Thai clinic staff, nonclinic informants explicitly discussed the right to HIV/AIDS care, often mentioning formal entitlements to medications in the context of ground-breaking litigation over issuing compulsory licenses for HIV drugs.

## Uganda

Likewise at Philly Lutaaya Clinic, rights discourse did not focus on patients’ rights to HIV/AIDS care. Clinicians referred to breastfeeding as a right—a particularly poignant issue for HIV-positive mothers who feared transmitting HIV to their newborns. And, as in the other clinics we studied, Philly Lutaaya research staff discussed patients’ rights as research subjects, including their right to decline participation. The paucity of rights talk in the Ugandan clinic was especially notable given that patients faced significant obstacles in obtaining full access to HIV/AIDS care. Patients lived in extreme poverty, often requesting assistance in supporting their children or access to income-generating work. At the time of our study, access to ARVs was rare in Uganda—so rare that the clinic’s community health workers omitted discussion of ARVs in general HIV education programs in order not to create unrealistic expectations. Desperate mothers sometimes talked about “sharing pills” with children who had received ARVs through other programs.

Outside of the clinic, however, Ugandan informants were more likely to frame access-to-medicine issues as a matter of rights or lack thereof. Comparing Uganda with South Africa, the head of an HIV-related NGO emphasized that Ugandan HIV/AIDS patients enjoyed no formal right to healthcare. Uganda “faces no constitutionally-based pressure to provide ARV or to ensure equitable treatment,” he argued. “Yes, there’s a constitutional duty to provide healthcare but it’s a requirement *if* there are resources available. So you can’t sue the government for dereliction of duty as you could in South Africa.” Adopting a global, human-rights perspective the physician/director of a nearby health facility asserted that people have a right to healthcare. Without universal access to drugs, doctors were forced to “play God.” In his view, this denial of equal access to medicines amounted to genocidal treatment of the poor.

## United States

The United States was the only country where we studied two clinics—Robert Rafsky and Bobbi Campbell. Although these clinics had quite different patient populations, both had patients who struggled to obtain full access to HIV/AIDS care. In neither clinic, however, did caregivers discuss access to medicines as a matter of rights.

Affiliated with a private hospital, Robert Rafsky did not accept uninsured patients, although they accepted patients with Medicaid or Medicare, patients whose public aid was pending, and patients who could pay out of pocket. And they took on patients who qualified for participation in research studies, whether or not they had insurance. Prospective patients were screened by phone for ability to pay. When no funding source was available, prospective patients were referred to a public hospital in the same city. In some senses, then, Robert Rafsky sidestepped questions of rights by excluding patients who might need to make rights-based claims on clinic resources. Yet patients arriving with ample resources still could face challenges as their illness progressed. Nurses strategized with patients about how to keep their insurance and how to access care if they hit insurance limits. The greatest challenges occurred as uninsured research subjects navigated the period just after a clinical trial ended. Nurses worried about the discontinuity in care when research subjects lost the free medications and supportive nursing care they had received through research trial participation. Even in this

situation, though, providers spoke in terms of “discontinuity,” rather than a long-term lack of access to basic treatment or supportive services. And they certainly did not frame this discontinuity as a failure to honor patients’ rights to healthcare.

Indeed, “patients’ rights” were discussed at Robert Rafsky only in the context of research subjects’ rights. Concern for research subjects’ rights and wellbeing not only benefitted patients, but also ensured the future supply of research subjects by making patients feel good about research participation. Similarly, discussions about access to care often occurred in the context of clinical research. Rather than seeing research subjects as entitled to the same attentive care as they cycled off clinical trials, research staff instead talked about “weaning” patients from studies and lowering their expectations. When discussing the clinic’s international research, providers also described the supplemental care they would give Nigerian and Ugandan participants not as a right but as an adjunct to the clinical trials.

As noted, Robert Rafsky’s practice was to refer indigent patients to the neighboring public clinic. In contrast, the Bobbi Campbell Clinic was *the* public safety net clinic in its area. Bobbi Campbell was a Ryan White designee.<sup>4</sup> At initial financial screenings, clinic staff assessed whether patients qualified for any insurance program. If no payer could be identified, patients could not start therapy even if the provider had recommended starting ARVs that day. Clinic administrators enforced eligibility rules strictly. The sole exception was cases deemed “medically urgent”—and those had to be cleared by an attending physician.

Even in this public safety net hospital, care was neither free nor universally available. Insured patients were prioritized in scheduling appointments. Although once known as a “free hospital,” at the time of our research, the clinic faced a debt crisis and had imposed copays for visits and prescriptions. Although the \$3 visit copay might seem small and the \$2 prescription copay was capped at \$20/month, hospital administrators were so worried about patients’ reactions that they hired extra security during the copay rollout. Copays could be deferred only if patients were homeless or needed urgent care. Clinic records showed that a few patients were turned away each day because of the copay, and one provider reported being told that her patient did “not have fifty cents” for the copay.

Not only was care not conceived as a right, but public programs like ADAP and Ryan White did not cover all of the services patients needed. According to caregivers, there was “[n]o way that Ryan White is going to pay one cent for things that are not ambulatory or in our center.” For example, Ryan White would not cover specialist services or basic dental care. Special approval was required for salvage therapy. Even insured patients sometimes got harsh reminders of the limits on what their payers would provide. When insurers declined to pay for expensive medications, clinic staff tried to get help from drug companies’ patient assistance programs. Any rights to care were further limited by geographical restrictions. Bobbi Campbell’s Ryan White funds covered only residents of the eligible counties.

In their daily work, Bobbi Campbell Clinic staff members gave ample evidence of their sophisticated understanding of the challenges facing indigent patients. They noted social and financial barriers to obtaining treatment, even suggesting that the 40% appointment no-show rate could partly be attributed to patients’ housing and transportation problems. And yet, despite their awareness of significant access issues, Bobbi Campbell providers rarely used the language of rights, even though they routinely distributed a “Know Your Rights” brochure as part of the Ryan White intake process. In fact, Bobbi Campbell staff did use a more political framing—but for matters outside the clinic. For instance, they seemed to see themselves as participants in a global healthcare rights struggle as they discussed boycotting a meeting of a pharmaceutical company that had recently increased the price of a “first line” HIV medication, affecting HIV programs worldwide. In addition, some doctors described themselves as advocates, fighting discrimination against people with HIV. Despite Bobbi

<sup>4</sup>The Ryan White Program, enacted in 1990, is the US safety net program for people with HIV (US Department of Health and Human Services, 2018). Through grants to healthcare facilities, it funds much of the care for uninsured HIV patients and fills gap when insurance coverage is inadequate. Its AIDS Drug Assistance Program (ADAP) pays for drugs.

Campbell caregivers' political sympathies and affiliations, a disconnect remained. HIV/AIDS care was not discussed as an entitlement in their own clinic-level discourse.

## ORGANIZATIONAL CONSTRAINTS ON CLINIC-LEVEL RIGHTS DISCOURSE

Despite the importance of rights talk in global HIV culture and the existence of formal rights to HIV/AIDS care in several of the jurisdictions where the clinics were located, in none of the clinics we studied did providers exhibit a right-to-health consciousness. This was so even as their patients encountered numerous obstacles in accessing treatment. What might account for the low penetration of rights consciousness in these HIV clinics?

One potential explanation of the paucity of rights talk may be the character of HIV/AIDS global health initiatives. Because the goal of achieving universal access to care has, in practice, placed a focus on biomedical management through ARVs, these interventions may have had a disenfranchising, depoliticizing effect on vulnerable populations, ultimately depressing rights discourse (see Kenworthy, 2017, p. 7). Moreover, this biomedical approach to HIV/AIDS care may be especially strong in clinics, like those studied here, that were involved in research. But in addition, we suggest that some general features of the social structure of healthcare provision may also help explain the almost complete absence of rights talk in clinics, though further research is needed on these points. Three organizational features of clinics—clinics' focus on the distribution of existing resources rather their adequacy, the additional demands on caregivers that patients' rights create, and the prevailing norms of exchange in healthcare—combine to help explain why formal rights do not penetrate into clinical settings, even when they exist in national constitutions, international treaties, and public discourse.

First, we find evidence that the clinic-level staff we studied were more concerned with stretching and distributing existing treatment resources than with the overall adequacy of those resources. In the workaday world of treating needy patients, these clinicians were eager to make good use of what they had on hand. This perhaps left little time for reflection on whether state-provided HIV/AIDS treatment resources, especially ARVs but also drugs for opportunistic infections, were adequate to meet patients' needs. When they did reflect on large-scale issues with treatment provision in formal interviews, clinic workers and administrators generally continued to discuss patient and clinic needs in pragmatic, mostly apolitical terms. Even in countries where patients enjoyed formal rights to healthcare, those rights often remained unusable in the clinics and staff did not mention them as resources that might be deployed to help meet immediate needs.

Second, we contend that common professional norms may make healthcare workers reluctant to cede too much control to patients. Patients' "rights" to medication and medical services may be perceived as autonomy threats by physicians, nurses, and pharmacists alike. A right to healthcare brings into being a new kind of client—one whom caregivers are obliged to treat, not by virtue of their professional training or oaths but by virtue of legal endowments created by the state. Among sociologists of professions, physicians are held up as a sterling example of a largely autonomous profession—respected for its expertise, permitted to set the conditions of its own work, and often allowed to regulate itself (Abbott, 1988; Freidson, 1970; Starr, 1984). Autonomy norms are undoubtedly less strong among other healthcare professionals, both because they are more closely governed by the rules of the healthcare organizations in which they are employed and because they are often subject to the authority of physicians (Chambliss, 1996). Because physicians, occupying roles as caregivers, scientists, and administrators, often set the tone and craft the rules of healthcare organizations, though, the professional norms about physician autonomy are especially influential in shaping clinic culture and practice. Although the professional dominance of physicians has been eroded somewhat with challenges from payers, healthcare organizations, ancillary professions, and even patients, sociologists agree that physicians nevertheless retain considerable authority and control (Halpern, 2004;

Wolpe, 1998). In the world of healthcare, then, public entitlements to minimum levels of care may continue to be negotiated with considerable respect for profession-specific autonomy norms. Because even guideline-based medicine has to respect variability among patients, rules necessarily apply in a different way to doctors than to other street-level workers.

Insofar as rights are conferred by governments as part of legal and political processes, they may translate more readily into claims on public resources (e.g., public funds, services provided by government agencies and government bureaucrats) than into robust claims on privately controlled resources (e.g., private funds, services provided in private healthcare organizations by private medical staff or independent service providers). But just as other civil rights have gradually expanded—often with nudging from legislatures and courts—so have rights to healthcare (see Rosenbaum, 2003). In the United States, that has brought some erosion of traditional deference to physicians and the “no duty to treat” principle, which once provided legal backing for the professional norm that medical caregivers made their own decisions about who they would and would not care for. Over time, the autonomy of both private healthcare facilities and physicians has been modestly whittled down.

Yet even with legal expansions in patients’ rights to healthcare services or medications, rights may nevertheless be experienced more as claims one has on a government or on a group of bureaucrats and less as claims on an expert caregiver to whom one feels vulnerable. In the “street level” encounter between a caregiver and a patient, then, caregivers retain considerable discretion to help patients (or not), to draw on their considerable skills and expertise (or not). Both because patients want individualized treatment and because responsible physicians cannot always adhere to guidelines, clinic-level caregivers, we contend, are somewhat different than street-level bureaucrats. Because other studies have found evidence that rights-consciousness develops in part through interaction with different professionals (Lejeune & Ringelheim, 2019, pp. 19–21), we might expect that clinicians’ professional orientation toward rights claims may ultimately impact how patients themselves think about their entitlements. As Levitsky observes, cultural norms and beliefs “mediate [e] between unmet social welfare needs and expectations for new social policy arrangements” (2008, p. 553). Changes in the legal environment may not immediately alter patients’ expectations about what their caregivers owe them.

Finally, the dominant norms of exchange in healthcare settings, shaped mainly by physicians, may help explain the low penetration of rights discourse into the clinics. Zelizer’s (1996, 1997) work on the social meaning of money can be usefully extended to the provision of healthcare services. Zelizer argues that how money is used varies with the nature of the relationship between the parties. In healthcare, we contend, services that are seen as entitlements, services categorized as gifts, and services provided in return for payments are culturally distinct. As in other spheres, these distinctions may serve “to create and maintain significantly different sets of social relations” (Zelizer, 1996, p. 487).

Because healthcare services are traditionally organized as gifts to the poor (i.e., as charity) or as consumer goods for the middle-class and wealthy (i.e., paid out-of-pocket or by insurers; provided in private hospitals), transitioning to the provision of healthcare-as-entitlement is socially awkward, at least without major changes to healthcare infrastructure, organization, and professional culture. Rights cannot easily be transplanted into healthcare settings where people are accustomed to thinking of care as a charitable gift or as a high-priced consumer good. Even where an entitlement structure of provision is put in place, patients may continue to find it socially awkward to make claims on caregivers. In healthcare, people do not want *only* what they are *entitled* to. Rather, they want thoughtful, attentive, individualized care. Particularism, not the universalism found “at the heart of human rights discourse” (McCann, 2014, p. 262), is valued especially highly in clinical settings.

Moreover, clinicians, by virtue of their professional status, retain considerable discretion even where rights are robust and they are providing mandated services. How much discretion workers retain surely varies from one occupation to another, with physicians able to exercise more discretion than nurses, for instance. Discretion can cut either way—professionals can give exceptionally good care, going above and beyond what is mandated, or they can give perfunctory, unthinking care, or

(in some regimes) they can even refuse care on the grounds of conscience (Chiarello, 2019). Even when care is a “right,” then, residual variability in the social arrangements for care often mean that a right is diluted into being experienced as a gift, voluntarily bestowed or withheld and rarely “claimed.”

## DE FACTO RIGHTS TO HIV/AIDS CARE

Although clinic workers did not directly reference rights, they also did not stand by idly when their patients had trouble accessing lifesaving medications. In the five clinics we studied, physicians and nurses were deeply and humanely concerned with the welfare of their patients and research subjects. That meant they generally did use their discretion for the benefit of their patients and were attentive to the moral issues that arose in the course of caregiving and research. We did not encounter heartless, mechanical rule-followers, although of course caregivers were constrained by both internal and external rules, as Chambliss (1996) would suggest.

That said, the details of how caregivers used discretion varied from one clinic to another, responding to the constraints and opportunities of state policies, clinic resources, and clinic-level understandings of what caregivers owed patients and research subjects. By leveraging external resources provided by government programs and private actors (e.g., insurers, pharmaceutical companies), internal clinic-specific material resources (e.g., research grants), and nonmaterial cultural resources, over time each of the clinics developed highly localized, tacit *de facto rights* to healthcare, as we show in Table 3 and in the examples below. By calling these *de facto rights*, we mean that such rights to HIV/AIDS care have become so institutionalized in the policies and practices of organizations that people enjoy an entitlement to them, regardless of whether they are codified. Just as the exercises of discretion by street-level bureaucrats (Lipsky, 1980) made policy both in their individual interactions with citizens and clients and, when aggregated, in the behavior of agencies they worked for, so the individual and aggregated actions of clinic-level caregivers created *de facto rights*. Over time, as *de facto rights* are codified in clinic policies, we would expect that patients may become more comfortable about claiming these rights—tentatively at first, more forcefully later.

Generally speaking, rights allow people to press for goods and services in situations of conflict and to get what the other party might otherwise be unwilling to provide. In the clinics we studied, both assertion of rights and batting down of claims occurred in regularly occurring meetings of doctors and senior staff, not in interactions between patients and caregivers. No one came to blows, but they did often disagree, pointing out resource limitations and prohibitive costs to the clinic and to themselves personally as they argued about what they should, could, and would provide to patients.

## United States

In the midst of a budget crisis, for example, Bobbi Campbell Clinic’s providers felt obligated to make sure their patients still received care. Comparing their situation to that of much poorer countries, Bobbi Campbell staff felt that “that they [were] entering a ‘third world scenario,’” where everything “outside this building is like Haiti or Rwanda.” They would need to “cobble together” what they could for the patients. This meant that Bobbi Campbell workers helped patients prepare applications for public insurance schemes—Ryan White, Medicaid, Medicare, ADAP—to ensure continuous access to medications. And as in other fieldsites, Bobbi Campbell physicians used participation in research projects to obtain access to drugs for patients who had lost other coverage. To ensure that research participation actually worked to the advantage of research subjects, Bobbi Campbell required that all research subjects be assigned a separate primary care physician who watched for conflicts of interest but also acted as their advocate, seeking out needed resources.

**TABLE 3** De facto rights in five HIV clinics

	Gugu Dlamini (South Africa)	Cha-on Suesum (Thailand)	Philly Lutaaya (Uganda)	Robert Rafsky (US private)	Bobbi Campbell (US public)
<b>External material resources</b>					
<b>Public provision</b>	Varied over time: initially, public disability program though patients lost coverage when treatment effective; later, rollout of public ART	Public program: 30-Baht scheme, covering ART (although not when program first introduced)	No public program	Medicaid, though if no coverage through insurance or other funding source, patients sent elsewhere	Ryan White Program (available to patients but as clinic grant)
<b>Private provision</b>	“Medical aid” (insurance) but few insured patients; patients unable to afford co-pay referred to public hospital	Private insurance	No private insurance	Private insurance coverage for most patients	Most patients indigent and lacked private insurance
<b>Gap-filling programs (public and private)</b>	Not observed	Not observed	Not observed	ADAP & pharma company programs	ADAP & pharma company programs
<b>Internal material resources</b>					
<b>Clinic research program resources</b>	Research program in development	Very strong and varied research program	Very strong research program but limited number and variety of studies	Very strong and varied research program	Strong research program, fewer studies
<b>Clinic treatment resources</b>	Treatment programs funded	Treatment programs as research (observational study)	Treatment programs funded	No clinic-level funded treatment program	No clinic-level funded treatment program
<b>Nonmaterial cultural resources</b>					
<b>Rights culture</b>	Emerging right to care from political activism around HIV, though muted in clinic	Emerging right to care from political activism around HIV, though muted in clinic	Activism around HIV more “support group” than politics	Informed consent; nondiscrimination, but no broad “right to care.” Not clinic of last resort.	Informed consent taken especially seriously; nondiscrimination, but no broad “right to care.” Modified by status as clinic of last resort.
<b>Professional norms</b>	Committed physicians with interest in research and creating treatment policies. Physicians set the tone as heads of hospital, treatment program, and research program, but other professionals in	Committed physicians and scientists, with politicized understanding, but focused on their own position in global science and healthcare. Physicians set tone as overall head and director of research, but	Committed physicians and scientists with acute sensitivity to their own position in global science, healthcare, and regulation. Physicians set the tone as heads of clinic	Committed physicians and scientists. Strong belief in scientific solutions. Especially strong autonomy norms. Physicians set the tone as heads of clinic treatment program and HIV clinical research program, but other	Committed physicians and scientists. Especially sensitive to conflicts of interest. Physicians set the tone as heads of treatment program and research program, but other professionals in some gatekeeping



TABLE 3 (Continued)

	Gugu Dlamini (South Africa)	Cha-on Suesum (Thailand)	Philly Lutaaya (Uganda)	Robert Rafsky (US private)	Bobbi Campbell (US public)
	some gatekeeping roles. Professional roles tempered by religious commitments	other professionals in some administrative roles.	treatment program and research program, but other professionals in some administrative roles. Especially sensitive to creating professionally reputable systems.	professionals in some administrative roles.	and administrative roles.
<b>De facto rights</b>					
<b>Mechanism for creation or expansion of de facto rights</b>	Development of clinical protocols and clinic guidelines specifying package of clinic services to which patients were entitled	Creation of universal program for post-trial patients	Enlargement of group eligible for participation in treatment program	De facto rights depended on mobilizing external and internal resources	De facto rights depended on mobilizing external resources and advocacy by primary care physicians
<b>Overall conclusions</b>	<i>Intermediate de facto rights</i> included clinic policies re leniency on co-pays, (limited) access to resources of resistance study, and caregiver advocated generosity	<i>Strong de facto rights</i> included well-institutionalized clinic-level programs such as continued drug access through observational study created explicitly to increase access	<i>Intermediate de facto rights</i> included expanding care program to include family members, though not fully institutionalized	<i>Intermediate de facto rights</i> to help with ongoing access to drugs, more as matter of clinic and professional norms than explicit clinic policy	<i>Strong de facto rights</i> included clinic policies differentiation of research from treatment and provision of separate primary physicians for all research subjects

In an effort to remind patients that “drugs don’t just fall off trees,” the clinic educated patients about the history of the Ryan White program. One administrator argued that patients must understand that ARVs are “not aspirin,” and that, as part of their job, clinic providers should emphasize the cost and seriousness of taking these drugs. Nevertheless, this desire to *prevent* patients from seeing their drugs as an entitlement was, in our research, unique. It suggests that at Bobbi Campbell, at least, the near-universality of basic HIV/AIDS treatment had risen to the point of becoming a de facto right even for indigent patients.

Researchers at Robert Rafsky primarily leveraged their numerous clinical trials (40 concurrent studies at one point) to help patients continue on their medications after any particular study ended. To the chagrin of administrators, physicians sometimes “generously” failed to bill for professional services when their salaries were already covered by research projects (Heimer, 2008). They also acknowledged an obligation to care for patients when they were sick even when such treatment was not explicitly included in research protocols.

Even in the absence of a formal right to HIV/AIDS care, then, patients in the US clinics could expect to receive ongoing treatment, whether or not they had been participants in clinical trials. In both clinics, staff members were able to draw on extensive external and internal material resources to create quite robust de facto rights to treatment, although the de facto right to healthcare was stronger at Bobbi Campbell than at Robert Rafsky because of the greater external resources (e.g., Ryan White) available to indigent patients and the more complete institutionalization of mechanisms to ensure adequate care (e.g., designated primary care physicians).

## Uganda

Patients at the Philly Lutaaya Clinic enjoyed no formal right to healthcare, yet once they became clinic regulars by virtue of participation in one or another clinic program, they could expect staff members to help them get care. Many Philly Lutaaya patients relied on funded research or treatment programs to access care. When it was a child who was enrolled in the program, the clinic worked to make “some exceptions” so they could provide ARVs for sick mothers who might otherwise be “sharing [the child’s] pills” in an attempt to keep themselves healthy enough to care for their children. This was said to be a “case-by-case decision.”

Over time, though, the clinic policy evolved as staff came to believe that, in light of the drug shortages, it was neither appropriate nor feasible to treat one family member without providing care for other family members. For that reason, they developed the MTCT + treatment program, with the + signaling the inclusion of other family members in a program that had initially been designed for mothers and infants. Because family is often defined broadly in African societies and obligations to kin are strong, the clinic struggled with their definition of family. Given the program’s objectives and the reality that child participants were often AIDS orphans, clinic staff felt compelled to emphasize caregiving arrangements rather than blood ties. So an “auntie” caring for a target child, would be included in the “family” entitled to care, as would other members of the household. Thus, although Philly Lutaaya Clinic was unable to compensate for the lack of formal rights by providing full de facto, clinic-based rights to healthcare for all prospective patients, they were able to create an institutionalized program to expand care for people who could claim a familial tie to a child or mother already receiving treatment.

## Thailand

Cha-on Suesum’s unfolding program provided an especially clear example of how de facto rights are created. From the outset, Cha-on Suesum staff committed to discussing “matters about drug affordability and accessibility” with each newly enrolled patient. Initially, their obligation was limited to providing *information* about where patients could obtain low-priced or completely free ARVs; the clinic did not directly provide these drugs.

Over time, however, clinic staff came to understand their responsibilities somewhat differently. Some clinicians reported reaching into their own pockets during the early days when “there were not drugs” and “you just spent time being a counselor” because there was little else to offer. “[A]ctually I personally funded many patients and I think most doctors do too, because it’s very hard to watch,” one physician confided. Recognizing that they could not personally fill all the gaps, Cha-on Suesum clinicians worked to ensure access to medications by using the clinic’s own funds or by finding other funding sources. Providers were sometimes able to draw on a “drug fund” for patients who qualified by going through arduous means-testing, including a committee review and consultations with social workers at the public hospital.

When a study budget ran out or the national healthcare system failed, Thai physicians tapped “spare” research monies to ensure that patients’ needs were “provided for.” Cha-on Suesum’s researchers had wisely banked some portion of their research grants to create internally funded programs. Thus, the clinic was able to leverage its research program to develop entirely new studies, including one whose main objective was to ensure patients’ access to medications after clinical trials ended. This follow-on observational study became their ticket to long-term treatment. Although this new observational study provided significant benefits to patients and was essentially research in service of treatment, it was created as one element of the clinic’s suite of internally funded programs, not as additional “compensation” for research subjects or as a result of bargaining with them.

Acknowledging their responsibility to ensure drug access, clinic staff taxed their externally funded research projects so they could transition from stop-gap measures to a more reliable, equitable means of providing care. By creating a post-trial research program for patients to maintain their medication, Cha-on Suesum Clinic was able to institutionalize a group-level entitlement to treatment—a de facto right to care for people who had now become part of the clinic community. Later, after carefully considering the adequacy of clinic resources, they instituted a policy of providing pap smears for all of Cha-on Suesum’s women patients and research subjects.

## South Africa

Gugu Dlamini Clinic drew on a diverse set of external and internal resources to generate de facto rights to certain services. At the front end, the HIV testing program was the route into the clinic and testing positive made a person a member of a category with some rights: the right to be retested and to have CD4 counts rechecked and the right to clinic help in securing prophylaxis until ARVs were needed. Like the Thai clinic, the South African clinic had an emergency fund. Both physicians and administrators told us that this fund could pay the monthly user fees of especially needy patients. But such funds were available only for the short term and only after a needs assessment. Gugu Dlamini administrators allowed patients to defer payment for a month or two, but those who remained unable to pay their user fees were transferred to the nearby government clinic, where they had (undiscussed) rights to care. So although administrators articulated a clear sense of obligation to struggling patients—“we won’t allow a patient to not get their drugs”—the limits of such generosity were equally clear—“[w]e’ll sign one month.” Moreover, these discretionary acts of generosity were limited to patients who had some realistic hope of being able to pay in the not-too-distant future:

I mean, like that lady ... she’s probably working, is getting paid at the end of the month, she’ll come pay. But ... if somebody comes to me and they don’t know where they’re going to get the money from, then I refer them through to one of the counselors or social workers, so that they can reassess their situation. Because we can’t really carry over two months or three months; we have to transfer that patient to the government.

Not everyone was comfortable with Gugu Dlamini’s user fee policy. For example, one member of a team engaged to assess the clinic’s performance explained that although people might value care more if they had to pay for it, he thought there were advantages to removing barriers, making it “really easy for people to be consistent about taking their drugs.” He was skeptical of the claim that people were never denied treatment just because they could not pay and suggested that sometimes “if you had a debt ... you might just give up and not come” to the clinic. He spoke approvingly about another clinic whose program focused on removing structural barriers to patient care. In contrast, the hospital superintendent felt that she and other physicians had probably been “a bit too

soft,” disrupting the “fine balance” between meeting the needs of impoverished individuals and keeping the hospital afloat. She suggested that misuse of discretion had “ripple effects upon the viability of the hospital’s sustainability of services.”

Gugu Dlamini physicians often reported a “moral responsibility to do HIV care.” Describing their work as a duty or “calling” rather than simply a job, they used their discretion to offer care in ways that did not quite comport with the rules. Occasionally, Gugu Dlamini clinicians would temporarily take on “charity cases,” for instance providing urgent care to an infant born to an HIV-infected mother until a transfer to the government clinic possible.

Gugu Dlamini clinicians, like their counterparts at other clinics, also sometimes used research studies to ensure access to ARVs and lab tests. For example, a physician working with the drug-resistance project told a patient that, assuming she was “motivated to take her medications properly,” he would “make an exception and include her in the study” so the 2000 rand resistance test would be free.

Thus, at Gugu Dlamini Clinic, perhaps more than in other sites, institutional mechanisms permitted staff to exercise case-by-case discretion and provide short-term care to indigent patients. But this did not create a *general* claim or an entitlement for most patients, despite the widespread sense, articulated by an eminent South African HIV researcher, that the “human rights constitution” permitted people to “demand” rights in constitutional courts and win their cases. In this South African clinic, any *de facto* rights were narrow and applied to a subset of testing and treatment services, rather than the full spectrum of HIV/AIDS care. That began to change somewhat, though, as the government ARV rollout commenced just as we left the field.

## COMPARING FORMAL AND DE FACTO RIGHTS TO HEALTHCARE

As these examples show, healthcare organizations like HIV/AIDS clinics leverage external and internal material and cultural resources to institutionalize care for patients even in the absence of formal rights to healthcare. Although *de facto* rights would not be honored in traditional legal forums, they nevertheless are quite consequential for patients’ access to care, particularly in the short run. In Table 4, we map the differences between formal and *de facto* rights in more detail.

Formal rights to healthcare are created through political processes and codified as law—in treaties, constitutions, statutes, or regulations. They give individuals or entities rights to or against something (e.g., rights against workplace discrimination, rights to a jury of one’s peers). They are, at least theoretically, legally enforceable. If individuals or entities feel that formal rights have been violated, they may bring claims for enforcement to legal forums such as domestic or international courts or administrative agencies tasked with hearing such claims. Formal rights can be cheap to create, often existing only on paper, and a storied tradition of sociolegal scholarship points out the inevitable gaps between law on the books and law in action (Gould & Barclay, 2012). In part because of their “lightness” (McCann, 2014, p. 248), formal rights are portable. They travel relatively easily across borders and are legible to a broad range of actors across cultures and nations.

In contrast, *de facto* rights are created by local actors, such as physicians and other staff in clinics and other healthcare organizations, and are less likely to be fully codified. If they are institutionalized, it is generally in the policies and practices of particular healthcare organizations where services are provided. More than formal rights, *de facto* rights are in sync with norms of professional autonomy and the norms of exchange common in healthcare settings. *De facto* rights do not generally belong to or adhere to individuals but instead are created to solve problems for groups, although they of course may be utilized by individuals. In the case of a *de facto* right to HIV care, such a group might be “HIV positive individuals with single-digit CD4 counts,” a group entitled to be fast-tracked into treatment at Gugu Dlamini; “indigent patients cycling off a clinical trial,” a group

**TABLE 4** Comparing formal and de facto rights

	Creation and institutionalization	Possession	Enforceability	Forums for claims	Resource requirements and time frame for creation	Range
<b>Formal rights</b>	Created and adopted by political bodies; codified in treaties, constitutions, statutes, regulations	Individuals and other entities (incl. people, states, corporations)	Legally enforceable	Courts, administrative agencies, arbitration	Low, but protracted process	Portable, wide-range
<b>De facto rights</b>	Created and adopted locally, for example, by clinic or other healthcare workers; institutionalized in policy and practices of service-providing organization	Groups of people	Not generally enforceable, though decisions can sometimes be appealed	Individual service-providers and organizational decision makers	High, but compressed time frame	Localized, contextually dependent

entitled to help in locating alternative sources of free drugs at Robert Rafsky; or “co-residing immediate family of an HIV treatment program participant,” a group entitled to HIV treatment at Philly Lutaaya. Because such policies are created locally to solve local problems, because they are generally seen as adhering more to groups than individuals, and because they are not fully institutionalized, de facto rights are not enforceable in traditional legal forums. Claims based on de facto rights may sometimes be made, but at a very micro level, through appeals directly to service providers themselves or to organizational decision makers (such as policy councils or heads of organizations).

Unlike formal rights, de facto rights can be created by a relatively small number of actors and so can develop relatively quickly. But they are almost always expensive to create, especially when they are rights *to* something, such as healthcare. They often exist only in practice, generally not being fully committed to paper, in part because they often grow by accretion—as individual uses of discretion solidify into collective norms—rather than by formal policy-making processes. They require changes in organizational routines and, in some cases, a steady supply of material objects, like medications. In short, de facto rights are “heavier”—they are highly context-dependent. Generally they exist and can be used only very locally, for instance within a single clinic.

De facto rights are entitlements that grow from the bottom up as caregivers use their discretion, professional expertise, and knowledge of the local packages of resources to create programs and policies that meet patients’ needs. Crucially, unlike formal rights which may entail externally imposed obligations, de facto rights are more likely to arise when groups of professionals impose obligations on themselves, preserving a sphere for professional autonomy. But policies assigning a primary care physician to protect the interests of each research subject (at Bobbi Campbell), enrolling post-trial research subjects in an observational study to ensure ongoing care (at Cha-on Suesum), and offering care to families because pediatric AIDS patients cannot be treated effectively unless their parents’

health is also protected (at Philly Lutaaya) all create distinctive local rights to healthcare. Crucially, these homegrown rights have bubbled up from local understandings of patients' needs rather than filtering down from more theoretical understandings of human rights.

This conceptual disaggregation helps to demonstrate that de facto rights are not simply the implementation of formal rights. De facto rights may exist completely independently of formal rights; there is no necessary relationship between the two. But de facto rights also may build on a foundation of material resources (e.g., lower drug prices, state funding for healthcare services) and cultural resources created by formal rights. Therefore, an expansion of formal rights generally reduces the cost of creating de facto rights and may support their development over time.

In sum, our data reveal that de facto rights to health may exist independently of formal rights or alongside them, but in either case, the full realization of a right to health depends on significant changes to healthcare infrastructure, organizations, and professional cultures—in effect, on both formal and de facto rights. In today's highly unequal global health landscape, the struggle for a universal right to HIV/AIDS care is critical. Our results demonstrate both that formal legal rights are just the beginning and that patients and providers can commence the project of making rights real as they await the arrival of formal rights.

## CONCLUSION

Although HIV now can be treated quite effectively and infection can often be prevented, the decades old epidemic continues to wreak havoc around the world. Along with the devastation, though, HIV has also brought a dramatically increased awareness of the importance of rights to healthcare and a frequently noisy and efficacious activism to pressure for such rights. One need look no further than the biographies of Robert Rafsky, Bobbi Campbell, Gugu Dlamini, Cha-on Suesum, and Philly Lutaaya—the five activists whose names serve as pseudonyms for the clinics we studied—to understand the role the right to healthcare has played in global HIV culture. Like many others, these five people eloquently advocated for the rights of people living with HIV, including the right to testing and treatment, the right to participate in setting scientific agendas, and the right to inclusion in the full round of social life, free from the stigma that has often accompanied HIV.

Yet although public HIV/AIDS discourse draws on and feeds human rights talk, in this article, we find that discourse does not cross the threshold into the clinics where HIV treatment and research occur. Clinic staff do not actually employ a language of rights as they care for patients and conduct research. This low penetration of right-to-health discourse in the very places where the main work of managing the epidemic occurs raises important questions about what human rights law and HIV activism can accomplish. Our clinic-level observations and interviews suggested a mismatch between how patient needs were framed in HIV clinic culture and in the public discourse on health rights, including both the horizontal public health approach of health rights advocates and the more single-minded, disease-focused, vertical approach of HIV activists. Both rights approaches have blind spots (Crane, 2013; Farmer, 2001; Nguyen, 2010), and neither speaks very directly to clinic-level needs. Where rights approaches would suggest that caregivers have a legal obligation to provide needed care, the professional norms of doctoring suggest instead that autonomous professionals, altruistic though they may be, retain considerable discretion about when, how, and to whom they provide care. Likewise, where a rights approach would suggest that patients have an entitlement to care, the exchange norms of healthcare settings instead frame care as a voluntarily provided charitable gift or an individually negotiated service.

But that did not mean that clinic staff were insensitive to patients' needs for care. Where rights to care either did not exist or had failed to meet patients' needs, clinic staff sometimes developed novel ways to ensure that patients received care. Over time, some of these ways of filling gaps



solidified into clinic-level norms, policies, or programs—not quite the rights to care that the law might envision, but nevertheless something local patients could count on.

Like other sociolegal researchers, we too found a gap between law on the books and law in action, perhaps less surprising when the legal right to healthcare is not itself fully spelled out. But we also found a quite different gap, where de facto rights seemed to be sprouting up, often without being tethered to the constitutional provisions, statutes, or court decisions that create the legal right to healthcare. We note that this particular development is also not easily accounted for by world society theory (Meyer, 2004), which would instead anticipate a different kind of disjuncture, namely the diffusion of essentially ceremonial talk of rights decoupled from meaningful practices. What we observed instead was the development of de facto rights without the ceremonial rights talk.

We find this intriguing because it suggests both that rights can grow without a corresponding rights consciousness grounded in formal human rights law and that gaps between law on the books and law in action can be diminished in more than one way. In particular, our research on de facto rights suggests that gaps can be reduced either by the adoption of legal norms and a deeper penetration of legal discourse or by more careful attention to indigenous norms within the settings where gaps are observed. Bohanan (1965) noted that law often “double institutionalizes” existing rules and norms, adding legal force to what was already there. But such double institutionalization requires that legal actors actually become familiar with those pre-existing norms. In the case of rights to healthcare, our discoveries about de facto rights tell us something useful about the indigenous norms that might profitably be double institutionalized by a formal right-to-health regime. In this encounter between two powerful professions—law and medicine—gaps might shrink more quickly with movement from both sides.

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