17 The Juridical Hospital: Patient-Citizen-Consumers Claiming the Right to Health in Brazilian Courts

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Introduction

A retired bus driver, Edgar Lemos lives in a lower-middle-class neighborhood of Porto Alegre, the capital of the southern Brazilian state of Rio Grande do Sul. Dealing with significant motor difficulties, Edgar had to wait for more than a year for a specialized neurological appointment at a nearby public hospital. He was finally diagnosed with hereditary cerebral ataxia in November 2008. The neurologist prescribed the drug Somazina, which is not included on any governmental drug formulary.

Raised in a destitute family, Edgar had worked since the age of eight. He was proud of the gated brick and mortar house he had built himself on the top of a hill. Edgar's ataxia affected not only his mobility but also his sense of dignity and worth, as it made him dependent on the care of his wife and two adult daughters. Religion had become an important source of emotional sustenance and a complement to his pharmaceutical treatment. While Edgar felt that Somazina was helping to halt the degeneration of his motor abilities, he was also taking a variety of other drugs, from statins to antihypertensives and anxiolytics, to soothe additional symptoms.

During a conversation I had with him over his dining room table in August 2011, Edgar opened a box containing the five medicines that make up his regimen. As he held each one in turn, he said, "This one I don't judicialize, this one I don't judicialize. ... I only judicialize this medicine [Somazina] because I went into debt paying for it." A monthly supply of Somazina costs about US \$200.

After paying for the drug out of pocket for several months, Edgar had to take out a bank loan. Unable to keep up with house expenses and his loan interest, he had "no other alternative but to judicialize." He learned about the Public Defender's office (Defensoria Pública) from other patients also waiting for specialists' referrals at the public health post and filed a lawsuit to compel the state to pay for his medication. The Porto Alegre district judge issued a court injunction on his behalf, and Edgar received the medicine for several months, but then "the delivery stopped." He filed a new claim and won another injunction for three additional months of treatment.

As state attorneys were appealing the judge's decision, Edgar nervously anticipated having to renew the lawsuit again.

I asked Edgar why he was not judicializing the other drugs he was taking. "I know that the state cannot give everything to everyone," he stated. "I have to do my part and pay for whatever I can."

Across Brazil, patients like Edgar are seeking, and sometimes achieving, access to health care through the courts, a phenomenon that has been termed the "judicialization of health" (Biehl et al. 2009; Ferraz 2009; Marques and Dallari 2007). Though patients are suing the government to provide everything from baby formula to complex surgeries, a large number of lawsuits are for access to prescribed drugs (Scheffer, Salazar, and Grou 2005).

In this chapter, I explore how right-to-health litigation has become (in the wake of a successful universal AIDS treatment policy) an alternative for many Brazilians seeking to access health care, now understood as access to pharmaceuticals that are either on governmental drug formularies or are available only through the market. Throughout, I show how the relations between individual bodies, political subjectivities, medical technologies, and state institutions are compellingly rearranged along this judicialized front. Poor people are not waiting for medical technologies to trickle down; they are leveraging public legal assistance and a receptive judiciary to hold the state accountable to its mandate and to their medical needs, now. The chapter's ethnographic vignettes thus pave a path toward a relatively unexplored frontier of science and technology studies: that zone where technology, medicine, and law intersect in unexpected and deeply personal ways and where our ideas about the social life of technology and our notions about how medicalization and biopolitics operate from the bottom up must be rethought.

From the Right to Health to the Right to Pharmaceuticals

The 1988 Brazilian Constitution declared health a "right of all persons and the duty of the State" (Constituição Federal do Brasil, 1988), and the creation of the country's Unified Health System (SUS) extended health coverage to all citizens. Judicialization stems from an expansive definition of the meaning of the right to health and also, in part, from the passage of a landmark law in 1996 establishing free universal access to antiretroviral (ARV) therapies for HIV-infected individuals (Biehl 2007b). Ministry of Health policies and a 2000 ruling by the Federal Supreme Court further advanced the right to medicines as part of the constitutional right to health (Supremo Tribunal Federal 2000).

SUS provides health services and medicines free of cost. As part of a broader process of decentralization and in an effort to improve the administration of SUS, the Ministry of Health divided responsibilities for pharmaceutical distribution among three levels

of government. Federal, state, and municipal tiers of government are responsible for purchasing and distributing medicines according to specific drug formularies. The federal health ministry continues to finance high-cost medicines they call "specialized medicines," which are distributed by state health secretariats. Municipal governments are responsible for purchasing low-cost "essential medicines," which are dispensed at local public pharmacies. State governments finance and distribute "special medicines" that their state residents require but that do not appear on either of the other two formularies. In addition, the federal health ministry funds strategic programs for the control of certain infectious diseases such as HIV/AIDS, tuberculosis, and leprosy as well as rare disorders such as Gaucher's disease.

Despite these laws, policies, and judicial rulings, the experience of patients in realizing access to medicines has been uneven. Today, about 200 thousand Brazilians take ARV drugs paid for by the government. At the same time, many citizens go to local public pharmacies only to find that essential medicines are out of stock and that the newer medicines they seek are not included in official formularies. Decentralization delegated responsibility but did not ensure sustainable funding and technical capacity at local levels. Regional and municipal governments have not been able to adequately budget and administer the growing complexity of medical needs and technological and infrastructural demands within an already complex health system.

With a population of about 200 million people and an economy on the rise, Brazil has one of the fastest-growing pharmaceutical markets in the world, with an estimated total value of more than US \$25 billion in 2012 according to a business association (SINDUSFARMA 2012). Public and private doctors increasingly prescribe and patients demand new medicines, some of uncertain benefit. Newer medicines, however, are often available only through private purchase. Unable to pay out of pocket (as in Edgar's case) or to find low-cost generics at public pharmacies, patients are increasingly suing the government to obtain what they need. People often use the expression *entrar na justiça*, "to enter the judiciary" or, literally, "to enter justice," to refer to their lawsuits.

Para-Infrastructures and Political Experimentation

For the past five years, I have been coordinating a multisited ethnographic study of right-to-health litigation in the southern Brazilian state of Rio Grande do Sul, which has the highest number of such lawsuits in the country. Implementing collaborative evidence-making practices, our research team moved across domestic, clinical, judicial, and administrative domains to track the interconnection of sites and the interplay of scales that the judicialization of health calls on and calls into question. Some of the core queries that guided our investigation included the following: Is the judicial

system an effective venue for implementing socioeconomic rights? Which social fields and practices of citizenship and governance are crystallized in the struggles over pharmaceutical access and administrative accountability? How is it possible to gauge the market's influence on medical demands and practices as well as on the public institutions of the world's sixth largest economy?

While examining the tense negotiations of the constitutional right to health in daily life, I often had a sense that social roles and political positions were out of place: the judiciary was a sort of pharmacy, the public defender was acting as a physician, the physician as an activist, the patient association as legal counsel, and the patient-citizen was becoming a consumer, among other translocations and displacements. I found Michel Foucault's (2008) tentative reflections on biopolitics and neoliberalism helpful as I tried to understand the form and reach of these novel medico-socio-legal realities, in particular his observations on the frugality of government in contexts where market exchange determines value. But these realities also contravened Foucault's reflections, as they underscored the importance of the juridical subject to late-liberal political economies.

In his 1978–1979 lectures at the Collège de France, Foucault argued that we can adequately analyze biopolitics only when we understand the economic reason within governmental reason, suggesting that the market shapes and even determines governmental logic. In Foucault's words, "The market constitutes a site of veridiction-falsification for governmental practice. Consequently, the market determines that good government is no longer simply government that functions according to justice" (2008, 32).

The ways and means of right-to-health litigation in Brazil reveal an intense experiential-political-economic field. Here the penetration of market principles in health care delivery is unexpectedly aligned with the juridical subject of rights. The rational choice-making economic subject (necessarily a consumer of technoscience) is also the subject of legal rights. The right to life is claimed in between the clinic, the court, and the marketplace. How are the interpenetrating domains of health, therapeutic markets, and the law emerging as implicit and explicit sites for claiming political rights and confronting political failures?

Jonathan Spencer has written about anthropology's difficulties in "drawing bounds round 'the political'" (2007, 29). While classic anthropology limited politics to formal and functional analyses (a "politics without values"), the anthropology of politics that emerged in the 1980s and 1990s as a necessary and invigorating corrective (as exemplified by subaltern studies) "deliberately exclud[ed] the state from the domain of authentic politics" (Spencer 2007, 23). In the intervening decades, the anthropology of politics has moved to include a consideration of the state and development (Ferguson 1994), of transnational politics and neoliberalism (Comaroff and Comaroff 2011; Ong 2006), and of the affective domains and subjective experiences of political

life (Biehl, Good, and Kleinman 2007). And while much recent anthropological and STS scholarship has productively applied Foucault's concept of "biopolitics" to a variety of contexts (Tironi and Barandiarán, this volume; see also Fassin 2007; Nguyen 2010; Ong and Collier 2005; Rabinow and Rose 2006), we are only beginning to capture the fluidity and fragility of biopolitical processes and their entanglement with the market as a testing ground for techniques of governance and self-fashioning (Edmonds 2010).

Clearly, anthropologists and STS scholars have stayed attuned to politics—even as the substance of what is considered "political" has varied with disciplinary conversations—whether as activists concerned with the inequalities of the field or in their theoretical concerns with such issues as postcolonial disorders, structural violence, social suffering, and biopolitics (Comaroff and Comaroff 2011; Das 2007; Farmer 2003; Good et al. 2008; Scheper-Hughes 1992). Most compellingly, anthropologists have begun to examine the politics involved in the formation of "para-infrastructures" such as humanitarian interventions and therapeutic policies (Biehl and McKay 2012, 1210; Fassin and Pandolfi 2010; McKay 2012).

While Stephen Collier (2011) has explored how Soviet urban infrastructures reveal political and economic rationalities and negotiations over the form of the (post)social state, other scholars such as Nikhil Anand (2012) and Hannah Appel (2012) have shown how infrastructures (such as water networks and oil enclaves) form critical sites of engagement and negotiation for corporations and states and their subjects (or citizens) in everyday life. However, with the term *para-infrastructure*, I mean to call attention to, and account for, the interstitial domain of political experimentation that becomes visible in people's case-by-case attempts to "enter justice" in Brazil. There is no predetermined strategy of control in the judicial para-infrastructure. Norms are constantly in flux, and numerous parties—state and market institutions as well as experts, legal representatives, and citizens—can manipulate levers of access. While laying claims to life, facing off over and disputing responsibility, evidence, and costsbenefits, these various parties bide their time and become at once empirically present and permeable.

Although precarious, para-infrastructures such as the judicialization of health significantly inform the ways of living that people take up in the context of ailing or inadequate public institutions as well as the scope and reach of governance in real time. Attention to such "intermediary power formations," as I considered them elsewhere (Biehl 2007b, 94), and to the growing "judicialization of politics" (Comaroff and Comaroff 2006) presents new ethnographic quandaries. They compel us to engage and think through the ambiguous political subjectivities and social formations that crystallize amid the blurring of distinctions between populations, market segments, political movements and constituencies, and collective objects of intervention or disregard.

Moving across various scales of anthropological analysis, this chapter brings into view lives and living forged across exceedingly complex and often contradictory institutions. The experiences presented here of lawyers, patients and their families, doctors, advocates, policy makers, and judges do not and cannot perfectly cohere. I try to describe the entanglements of the judicialization of health without claiming that it is seamless. Instead, I urge readers to consider how this new political phenomenon compels sick persons, laws, experts, officials, and commodities to shuttle between the home, the hospital, public offices, and the courtroom, remaking those spaces and themselves.

Ethnographic realities can help us to refine, complicate, and even dislodge totalizing assumptions about neoliberal structural adjustments, market-driven societies, and technology transfer (see Marques, this volume). In the Brazilian judicialization of health, rather than seeing a top-down biopolitical model of governance in which population well-being is the object of knowledge and control, we see instead a struggle over the utility and purpose of government by multiple private and public stakeholders. At stake here are the ways in which government (qua drug regulator, purchaser, and distributor) facilitates a more direct relationship, in the form of technology access, between atomized and ambiguous political subjects of rights and interests and the biomedical market.

Surprisingly, the decentralization of state authority has created the space for a return of the juridical subject but in an altered form. Neither entirely controlled by nor fully accountable to the state or the market, those who inhabit this new political subject position negotiate the constraints and possibilities of a technological society using jurisprudence. They work through available legal mechanisms and instantiate new sociopolitical domains to engage and adjudicate their demands, making abstract human rights concrete. These various developments, in turn, end up consolidating the judiciary as a critical site of politics—and of political economy.

The Diseased Citizen and Justice in the Absence of Adequate Public Policy

"Welcome to the juridical hospital," said Paula Pinto de Souza, the lawyer in charge of right-to-health litigation at the Public Defender's office in Porto Alegre, during our first encounter in August 2009. Her office is where the poor get free legal assistance and where the majority of the lawsuits requesting medicines from the state originate. Souza did not mince words in describing what she thought the state's biopolitics had become: "When there are no defined public policies, or when they exist but are not executed, or when policies are not in touch with new maladies and medical advancements ... what do we have? We have a diseased citizen."

When people finally access public institutions, all their vulnerabilities are exposed and they have become quite sick. Souza continued, "We are beyond preventive

medicine here and the concept of health as physical, mental, and social well-being is no more. When this infirm person comes to me, the cure is most likely no longer possible. Her right to health has been profoundly injured by public power."

Souza speaks of her work in the office as an attempt to ameliorate human suffering and to restore rights to the sufferer. For the public defender, this means indicting local politics: "The person comes here sick and wronged by the failure of public policies. This is the medicine that I practice here: to help people survive with dignity. Even if the medication might not bring them life, the claim is also for their dignity."

The judiciary, in her view, can acknowledge the person's medical emergency and call on "the state writ large (federal, regional, municipal) to take on its responsibility to provide the prescribed treatment." Souza is adamant that "it is not the role of the judiciary to make public policies." Yet without judicialization, she reasons, state politics would remain populist and only electorally focused, failing to uphold constitutionally mandated responsibilities: "The government lacks political will to make public policies work. There is no concern with the human being, but a lot of concern with publicity. Forget about infrastructure. When it is election time, then medicines get disbursed, drug formularies updated."

In the past five years, right-to-health litigation, particularly over access to medicines, has become a subject of contentious debate throughout Brazil and has attracted international attention (Azevedo 2007; Economist 2011). At a conference a few years ago on "Accessing Medicines via Courts," a senior official in the health secretariat of Rio Grande do Sul affirmed the state's commitment to addressing the issue of pharmaceutical dispensation by SUS "in a manner that is more comprehensive, more just, and that benefits a growing number of people." But instead of speaking of specific policies the government might champion, the public administrator highlighted the secretariat's "partnership" with the General Attorney's office in addressing "frontier issues in knowledge and technology" that are increasingly "at the center of public services."

In his comments, the public administrator reduced the complex reality of right-to-health litigation to instances of demand for select and largely ineffective medical technologies recently brought to the market: "We try to guarantee the availability of medicines. But it is extraordinarily perverse that we have to guarantee the most expensive medicines, which have no effect whatsoever. The laboratories use patients to increase profits."

The public administrator mentioned the lack of convincing data on the efficacy and safety of drugs and asked whether "a medical professional has the right to prescribe whatever he wants, independent of protocols and scientific proof." Several times, he emphasized "public disinformation," "the draining of public health funds," and the "inequality" that the demand for new medical technologies by a selective population has inaugurated. "We are talking about public money here."

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This official's rendering reflects what has crystallized as the myth of judicialization: an apparently clear line between good and bad science, between need and interest, between unconscionable for-profit medicine and responsible public health officials. In the context of a process of protocol writing and resource allocation that is assumed to be perfect and fully certain, right-to-health litigation represents the unwelcome intrusion of special interests into the sphere of biomedical rationality and economic certainty. As the public administrator proudly announced, the state's Attorney General's office created its own taskforce of medical consultants to verify or disqualify claims for treatment access and efficacy.

With the judicialization of the right to health, courts have become battlefields of veridication-falsification and a politics of one-case-at-a-time medical rescues. But cases like Edgar's show that at a deeper level, right-to-health litigation also makes the judiciary a site for the emergence of a new kind of citizenship, and in which the state's complicity with the commodification of care—in collusion with the market—is exposed for public critique. The judicialization of health, while never fully free of market forces, represents a rare opportunity to make the state care, to respond to the need for palliation, and to attend to citizens' social suffering.

The Pharmaceuticalization and Judicialization of Health Care

While the justiciability of the right to health is of increasing interest internationally (Gauri and Brinks 2008; Yamin and Gloppen 2011), the volume of individual right-to-health lawsuits in Brazil stands out. In 2009, 5,536 cases appealing high court rulings related to the right to health reached the Superior Court of Justice, and about half of these cases were for access to medicines. In 2009, the federal health ministry spent US \$47.8 million on court-attained drugs, a significant increase from the \$20.4 million spent in 2008 and \$4.2 million spent in 2007 and dwarfing the 2003 federal expenditure of \$58,800 (Collucci 2009). There are currently more than 240,000 health-related lawsuits under review in state and federal courts in Brazil. Almost half of all lawsuits (about 113,000) have been filed in the state of Rio Grande do Sul (Zero Hora 2012).

HIV/AIDS activists were among the first to successfully equate the constitutional right to health with access to medicines, and the rights-based demand for treatment has now "migrated" to other diseases and groups. As I documented in the book Will to Live: AIDS Therapies and the Politics of Survival (Biehl 2007b), an incremental change in the concept of public health has also been taking place. In terms of both delivery and demand, public health is now understood less as prevention and primary care and more as access to medicines and community-outsourced care; that is, public health has become increasingly pharmaceuticalized and privatized.

Today, a variety of actors—industry advocates, public health and private-practice physicians, medical researchers, and patient associations—have vested interests in making high-technology medicine accessible to all. In the process, the country is becoming a profitable platform of global medicine. It is estimated that almost 50 percent of the adult population (about 60 million people) uses pharmaceuticals on a daily basis.

Government-purchased medicines make up a formidable market in Brazil (Gertner 2010). The health ministry spent more than US \$2.5 billion on the acquisition of drugs in 2007, accounting for 10.7 percent of its total expenditures that year, twice the 2002 percentage (Vieira 2009). However, new drugs are often available only for private purchase. Furthermore, we know that drug prices in Brazil are, overall, 1.9 times higher than in Sweden and 13.1 times greater than the mean bulk-unit prices listed in the International Drug Price Indicator Guide.

Let me pause to unpack what I mean by describing the judicialization of the right to health as part of a broader pharmaceuticalization of care and of public health. First, the concept of "pharmaceuticalization" builds on and revises the related notion of "medicalization," understood as a modern form of social control that obscures the political, economic, and social determinants of health by approaching disease and treatment in exclusively biomedical terms (Conrad 2007). Scholars have traced the public health, policy, and treatment consequences of the medicalization of a range of complicated social problems, from hunger and malnutrition to substance abuse and depression. In particular, critics note that the phenomenon has led to an overemphasis on access to health care (especially medicines) in health policy at the expense of equally needed improvements in financial and food security, education, housing, and environmental conditions (Lantz, Lichtenstein, and Pollack 2007). Medicalization, it is argued, strains health care systems, national economies, and household finances alike. Sociologist Peter Conrad and colleagues (2010) have gone as far as to estimate that in 2005 the pervasive medicalization of social conditions cost the United States \$77 billion—3.9 percent of total domestic spending on health care.

The concept of pharmaceuticalization, however, stands for something more complex than an increase in the quantity of medications that societies consume (Biehl 2007a). In the last decade, medical anthropologists have critiqued the medicalization paradigm for being overly deterministic (Lock 2003). While the culture of biomedicine is undeniably powerful, people do not simply become the diagnostic categories applied to them—they inhabit them to greater or lesser degrees, refuse them, or redefine and deploy them to unanticipated ends (Biehl 2005; Han 2012; Petryna, Lakoff, and Kleinman 2006). Likewise, both policy debates and patient struggles surrounding access to pharmaceuticals are part of broader transformations in public health (Biehl 2007b; Ecks 2008). Understanding pharmaceuticalization requires moving beyond the

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unidirectional construction of patient subjectivity by medical diagnostics and treatments to account for the entanglement of multiple social forces and markets, the chemical concreteness and circulation of pharmaceuticals and illnesses, and the role of patients' agency and desires.

I also want to highlight that contemporary processes of pharmaceuticalization have historical antecedents in international health policies and interventions. While health development programs once focused primarily on large-scale public health measures (e.g., sanitation, availability of clean water, hygiene), in recent decades, global health organizations have increasingly focused on access to pharmaceuticals as an indicator of health care development.

This trend is crystallized in the "Essential Medicines" list of the World Health Organization (WHO), first proposed in 1975 and then codified in a published list revised every two years (Greene 2010). According to historian Jeremy Greene, while the idea that public health should be rooted in essential medicines "has taken on somewhat of a moral universality ... and commonsensical status" (2011, 28), creating such a taxonomy of fundamental drugs has revealed ambiguities and raised difficult questions. Access to new medical technologies and treatment strategies is increasingly thought of as a human right, like shelter, education, and clean water—but how are "essential" medications selected? Can effective but new and experimental treatments be considered "essential"?

As the HIV/AIDS epidemic increased in severity in the early 1990s, the WHO did not identify any ARVs as essential medicines because they were very expensive and had only recently been developed. The disease, however, claimed a larger and larger portion of total deaths in developing countries, and activists forcefully challenged the absence of ARVs on the Essential Medicines list (Greene 2011, 23). While the WHO now considers some ARVs essential, the HIV/AIDS epidemic continues to provoke the difficult question of whether access to treatments that extend lives—but ultimately do not save them—should be considered a human right. These questions of which things are "truly indispensable" to health and living and who is legally and financially responsible for making these things available are central to how the people described in this essay both invoke and critique biopolitics: from Edgar's comment in the beginning of the chapter—"I know that the state cannot give everything to everyone"—to the state official's deployment of evidence-based medicine to both rationalize care delivery and authenticate misrecognition and disregard.

In Brazil, pharmaceuticals clearly have become key elements in the state's public health arsenal. As AIDS activism migrated into state institutions and the state played an increasingly activist role in the international politics of drug pricing, AIDS became, in many ways, the "country's disease." Yet, while new pharmaceutical markets have opened and ARVs have been made universally available (in the case of AIDS, the state is actually present through the dispensation of certain medicines that carry high

political stakes), it is up to individuals and makeshift communities to locally take on the roles of medical and political institutions as they learn to interact with and navigate in expert domains. These individuals and groups use survival strategies that require extraordinary effort and self-transformation and, increasingly, undergo juridical initiation as they become formal subjects of rights and engage the ritual travails of the courts amid the growing privatization of health care (Biehl and Petryna 2011). In the process, the question of what is frugal and essential to health and well-being—what one can do without and what one must have to survive—is ever more tangled and contested.

The Return of the Juridical Subject

Despite the growing number of lawsuits for access to medicines in Brazil, and amid polarized debate about the phenomenon and its costs, there has been scant information concerning the content of lawsuits, the characteristics of patient litigants, and the legal strategies and rationales deployed by the various stakeholders. Research into right-to-health litigation has also been constrained by small samples, limited geographic coverage, and the few variables examined (Borges and Ugá 2010; Da Silva and Terrazas 2011; Messeder, Osorio-de-Castro, and Luiza 2005; Pepe et al. 2010; Vieira and Zucchi 2007). Most studies tend to corroborate the arguments of public health administrators that the judiciary is overstepping its role and that judicialization generates enormous administrative and fiscal burdens, distorts pharmaceutical policies, widens inequalities in health care access, and encourages irrational drug use within the public health care system.

To better understand the burgeoning number of right-to-health lawsuits in the state of Rio Grande do Sul, our research team first examined electronic registries of health-related lawsuits in the health secretariat (Biehl et al. 2012). We found that the number of new lawsuits grew more than 1,000 percent in just seven years, from 1,126 new cases in 2002 to 17,025 new cases in 2009. The majority of these judicial claims involved access to medicines, making up 70 percent of all health-related cases in 2008 and 2009.

As a second step, we created a database of medicinal lawsuits against the state of Rio Grande do Sul. Our data collection team worked in the Solicitor General's office, which is responsible for defending the state. From September 2008 to June 2009, we analyzed 1,080 lawsuits being reviewed by state prosecutors.²

Edgar's case was not among these lawsuits, but his travails are not exceptional. Among the plaintiffs who reported their employment status, more than half were retired, and about one-fifth were unemployed. Among those who reported income, over half earned less than the monthly national minimum wage (about US \$300) and relied on the free legal services of public defenders.

Past research has suggested that right-to-treatment litigation is, for the most part, a practice of the financially better off (Chieffi and Barata 2009; Vieira and Zucchi 2007) and that low-income patients tend to sue for low-cost medicines, while higher-income patients tend to sue for very expensive medicines (Da Silva and Terrazas 2011,12). In contrast, our results suggest that patients who procure medicines through the courts are mostly poor individuals who are not working and who depend on the public system for both health care and legal representation.

Roughly two-thirds of the medicines requested were already on governmental drug formularies. About a quarter of lawsuits were exclusively for access to specialized high-cost medicines, though low-cost essential medicines were frequently requested along-side them. Off-formulary medicines requested by plaintiffs were also often low cost, and many had been available in the Brazilian market for a long time. This suggests that government pharmaceutical programs are failing to fulfill their role of expanding access and rationalizing use.

Moreover, judges at district and higher court levels almost universally grant access to all medicines requested, recognizing that their provision is consistent with Brazil's constitutional right to health. For example, in almost all cases, district judges granted plaintiffs an immediate injunction for access to medicines. In cases in which the initial ruling was in favor of the provision of medicines, the state's higher court usually upheld the decision.

While decentralization tried to establish clear responsibility at specific administrative levels—municipal, state, federal—our analysis found that plaintiffs tend to hold the regional state responsible for medicines, regardless of the designated responsible party, and that judges rarely disagree. State attorneys frequently argue that the state is not responsible for the provision of certain services. Judges, however, cite the principle of "unity" between levels of government to assert broad shared responsibility in guaranteeing the right to health. Lawsuits become the sites of a reluctant and undisciplined cooperation. In this way, the judicialization of the right to health momentarily instantiates the state as the singular governmental entity responsible for the provision of social rights.

Chronically III

Patients in our sample of 1,080 lawsuits were, for the most part, chronically ill. About half of the patients (48 percent) reported conditions such as cardiovascular disease, diabetes, lipid metabolism disorders, and pulmonary diseases. Some 16 percent of the patients reported neurologic and psychiatric conditions. Patient plaintiffs in our sample had various comorbidities and procured multiple drugs for their treatments. On average, they reported 1.5 diagnoses and requested 2.8 drugs. Among the twenty-five most requested drugs, twenty-three were medicines to treat chronic diseases, and

only seven were not included in official drug formularies. However, we also found patients with a single disease who demanded one high-cost treatment.

Patients with chronic hepatitis C, for example, made up a significant number of cases. These patients typically demanded ribavirin and peginterferon alfa, both of which are on the federal government's specialized medicines formulary. The high frequency of requests for drugs to treat chronic hepatitis C in our sample stands in sharp juxtaposition to the rare request—a single case—for medicines for HIV/AIDS. Both pathologies have a similar prevalence in southern Brazil, and treatments for both are distributed by governmental programs at no cost.

What are some of the possible reasons for this sharp contrast?

It may reflect variations in the efficiency of governmental pharmaceutical distribution programs. While the strategic medicines program that distributes HIV/AIDS drugs is centrally managed and funded by the federal health ministry, with a single acquisition process for the entire country, the specialized medicines program is decentralized: it is managed by states, which are federally reimbursed. The latter program depends on administrative cooperation between federal and state government and is vulnerable to the vagaries of regional health policy and management.

The contrast may also result from the specific eligibility criteria and, in some cases, from the detailed treatment protocols through which specialized and special medicines must be accessed in the public health care system. When patients fall outside eligibility requirements and protocols, they may use lawsuits to access treatment. In addition, patients who were granted requests may use lawsuits to expedite treatment delivery or to guarantee provision of medicines when the government fails to provide them. As the case of a patient named Nelson Silva illustrates, the judiciary seems to offer citizens who are both diseased and politically injured the possibility of articulating a time-sensitive legal effort to make the state act biopolitically to guarantee the possibility of survival.

Head down, Nelson Silva walked into the Public Defender's office in August 2010 accompanied by his wife Sandra, who did most of the talking. "We cannot interrupt the treatment one more time," said Sandra. Her husband was a retired steel factory worker, and she still worked as a kindergarten teacher. Sandra begged the public defender to "treat us," for "we know that people who come here get the medicine they need."

Nelson had chronic hepatitis C, and he was greatly benefiting from a forty-eight-week treatment regimen of ribavirin and peginterferon alfa. His doctor said that he needed twenty-four extra weeks of treatment, but the state's medical expert denied the request for the medication, and "my doctor told me to come here," Nelson said. "It's just a matter of the judge releasing the treatment."

"Our first treatment," Sandra continued, "was in 2001 with regular interferon." Nelson added, "But after a while the state pharmacy did not have interferon, so I had

to interrupt the treatment." In 2005, he fell ill and a doctor at Hospital Conceição prescribed ribavirin and peginterferon alfa. The health secretariat denied Nelson's treatment request, alleging that it would constitute "retreatment," which was not allowed by the medical protocol in place. "Then we had to file a lawsuit for him to get it," Sandra stated. In 2009, he was declared eligible for retreatment and now needed medicines for the twenty-four additional weeks.

"The doctor gave me the meds for two weeks," Nelson continued, "but I am afraid that the legal procedure will take too long and that by the time I get the meds, if I get them, I will have to stop treatment for it failed once again. I need it fast." Nelson was desperate to adhere to the treatment. For him and so many other patient plaintiffs facing a fatal condition, judicialization is a temporal lever. "We don't want to stop everything we started," lamented Sandra.

In line with the philosophy of "I will not let the citizen die," Souza gave the couple a road map of all they had to do and the documents they had to produce so that she could open the lawsuit the following day. Here, the court system—so often thought of as a place where claims go to die a quiet, bureaucratic slow-motion death—winds up being a surprising milieu of catalysis for the uncertainty and time-sensitivity of the body and its possibilities of repair and, ultimately, of survival. "Afterward," Souza told Nelson, "you open a lawsuit against the state for medical injury."

Open-Source Anarchy

According to legal scholar David Fidler, developments in health jurisprudence "have produced open-source anarchy and a more elastic relationship between power and ideas in global politics." In such an elastic relationship, "changes in material capabilities of state and non-state actors, and changes in the world of ideas, have more impact on each other than in the closed, state-centric system that prevailed during the Cold War" (Fidler 2008, 410). Fidler recognizes a "deeper importance for law in public health endeavors within and between countries" (2008, 394; see also Fidler 2007).

Anthropologists John Comaroff and Jean Comaroff have been attending to such a "judicialization of politics" in postapartheid South Africa and how it has affected social mobilization, particularly in the field of HIV/AIDS. Class struggles, they argue, "seem to have metamorphosed into class actions. Citizens, subjects, governments, and corporations litigate against one another, often at the intersection of tort law, human rights law, and the criminal law, in an ever mutating kaleidoscope of coalitions and cleavages" (Comaroff and Comaroff 2006, 26).

The judicialization of right-to-health litigation speaks to a productive "open-source anarchy" at both macro and micro levels in Brazil as well. Political scientist Luis Werneck Vianna (1999) would say that this is only one part of a broader pattern of the judicialization of politics in the country. For him, judicialization does not

necessarily reflect judicial activism. Rather, it can be understood as a lever for multiple minority actors (from political parties to public defenders to civil society groups) to constitutionally challenge the political majority's efforts to determine the fundamental norms and objectives of government. In attending to these concrete and dynamic processes, the complex way in which the judiciary actively participates in everyday politicking in a large country with a young constitution comes to the foreground. The question is thus not who—the judiciary or the executive—is right in the debate over judicialization, but how to integrate their actions to best serve individuals and collectives while making democratic institutions more robust.

In this new chapter of the Brazilian history of citizenship and the right to health, then, the judiciary has become a powerful arbiter and purveyor of care and access to medical technology. Interviews we conducted with judges, attorneys, and health officials revealed divergent and conflicting views on the litigation pathway. Policy makers and administrators contend that the judiciary is overstepping its role and that judicialization skews budgets and increases inequalities in health care access. Some acknowledge, however, that legal pressure has improved the distribution of some medicines.

Many local judges working on right-to-health cases feel they are responding to state failures to provide needed medicines and that these waves of lawsuits are a milestone in the democratization of a culture of rights. For these judges, the poor Brazilians who are working through modes of legally arbitrated justice to access health care are not just fighting against legalized privileges and legitimated inequalities, as in James Holston's (2009) chronicle of "insurgent citizenship" practices in Brazil's urban spaces. Rather, they see widespread litigation as the expression of a distinct, equalizing legal system and of a novel rights-conscious society. Whether such a democratization of socioeconomic rights can be attained through individual claims and in courts, however, is contested. In fact, judges employ idiosyncratic rationales and create their own standards in adjudicating right-to-health cases. They tend to rule in terms of "risk of death" and "right to life" and base their rulings for the most part on constitutional interpretations and personal experiences—having specific tragic cases in mind.

The judiciary recognizes that the judicialization of health has the potential to attend to social inequality and to affirm citizens' rights. Like Souza at the Public Defender's office, Judge Eugenio Terra finds that lawsuits are largely filed by poor and desperate patients seeking treatments that should be available in the public system. He is in charge of all health-related cases in Porto Alegre.

"I am doing social justice, one by one," Terra told me in an interview in August 2011. "When I am issuing an injunction for cancer treatment provision, I am also indicting services that have not kept up with people's needs." It did not escape Terra that the high number of right-to-health lawsuits in southern Brazil might well speak of "a distinct political culture" fostered by numerous administrations of the Workers'

Party (Partido dos Trabalhadores) both in the capital and at the state level in the past two decades (the Workers' Party regained state power in 2011).

Patient-Citizen-Consumers

Even as judges recognize the constitutionality of individual lawsuits and grant requested medicines in the overwhelming majority of cases, the judiciary has repeatedly avoided directly mandating changes in policy or issuing decisions that would broadly affect the public health system. In April 2009, the Brazilian Supreme Court held a rare public hearing to examine the pressing challenges posed by right-to-health litigation (Supremo Tribunal Federal 2009). Public health officials, lawyers, physicians, activists, and academics testified before the court, providing varied viewpoints and recommendations on how to respond to the enormous judicial demand for medical goods. As an immediate outcome, there was a long overdue updating of governmental drug formularies. The Brazilian National Council of Justice also issued a set of recommendations for local judges, asking them to more systematically attend to scientific evidence and to strive for "more efficiency" when ruling on health-related cases (Conselho Nacional de Justiça n.d.).

If access to AIDS therapies was the litmus test of the right to health in the 1990s, access to genetic therapies now plays this role. Twelve-year-old Alexandre Lima de Moura suffers from mucopolysaccharidosis (MPS), an inherited metabolic disorder. Every week, the fourth grader travels with his mother, Cleonice, to Hospital de Clínicas in Porto Alegre, where he receives enzyme replacement therapy, a treatment that costs about US \$200,000 per year. Because of his age, Alexandre was not allowed to enroll in a clinical trial taking place at the hospital. Without "the right to be researched," as the mother of another MPS patient put it, Alexandre became a patient litigant.

With the legal support of a well-organized patient association in São Paulo (partially funded by the drug manufacturer), the family won a court injunction forcing the federal government to begin providing the therapy. Like all parents of MPS children we spoke to, Cleonice suggested that not obtaining this treatment would be unconscionable and tantamount to killing her child. She knew that the federal attorneys would appeal and was ready for the struggle: "Besides entering the judiciary, we also entered the media." Cleonice has taken Alexandre's cause to all possible media outlets and is also using his condition to educate neighbors, local medical personnel, and officials about the meaning of, in her words, "citizenship" and a "normal life." "Ela é uma mãe boa" [She is a good mother], says Alexandre, who is thriving in school and seems to be responding positively to treatment.

One of the latest right-to-health landmark cases involves a request for a high-cost medicine for a genetic disease. This treatment was not recommended by the Ministry of Health's therapeutic guidelines and was not publically available. In March 2010,

the court rejected the state's argument that it was not responsible for providing the medicine and decided in favor of the provision of the treatment. In his ruling, Justice Gilmar Mendes stated that once the disease was medically confirmed and treatment was indicated, "the Ministry of Health's guidelines can be questioned." Moreover, "the state has to provide resources, not only to support and fund the provision of universal care for its citizens, but also has to provide variable resources to attend to the needs of each individual citizen" (Supremo Tribunal Federal 2010).

The role of market forces in judicialization—a mix of clinical trials and marketing strategies that target physicians' prescriptions and fuel patient demand and of industry lobbying to have new treatments included in governmental drug formularies while facing limited regulatory oversight—must not be overlooked (Petryna 2009). Ample evidence shows that laboratories' monopoly on medico-scientific information and pharmaceutical marketing strongly inform physicians' prescriptive habits and patients' demands (Lakoff 2006). Additional qualitative studies are in order—they could help us chart how judicialization has become part of a pharmaceutical business plan in Brazil, with companies supporting patient associations and lawsuits for access to high-cost medicines specifically to open or enlarge markets (Diniz, Medeiros, and Schwartz 2012).

There is a heated debate in Brazilian courts on the positive duty the constitutional right to health imposes on the state and the extent to which the courts must enforce this right. But the country lacks a substantial public debate about the meaning of the right to health in light of medical advancements and financing, between what is possible and feasible and what is frugal and essential. As a "right to pharmaceuticals" is consolidated in Brazil, the various branches of government have yet to develop a systematic approach to tackling drug value and financing and the responsibilities of private health insurance plans to cover drug costs. Moreover, how can access to new medical technologies be reconciled with systems that foster the equitable inclusion of people in preventive as well as basic and sustained care initiatives? Is there a way to balance individuals' urgent demands for health care, often in the form of medicines, with the long-term, programmatic aspect of health care management and reform? Attention is also needed on the many other factors that play into the right to health, such as education, water quality, sanitation, vector control, air pollution, and violence prevention. These complementary concerns, which can be understood as social determinants of health, are critical to addressing the health needs of both the chronically ill and comorbid individuals in our database and the Brazilian population more generally.

Meanwhile, hard-to-pin-down *patient-citizen-consumers* draw from human rights language and jurisprudence and make governments work for them as they negotiate medical inclusion and the vagaries of the market and survival. The judicialization of health has, indeed, become a para-infrastructure in which various public and private

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health actors and sectors come into contact, face off, and enact limited "one by one" missions.

Conclusion

There is no pregiven biopolitical population in Brazil today to which Edgar, Nelson, Alexandre, and thousands of other atomized subjects of rights belong. Yet, in their private efforts to become such subjects, individuals have to rely on social relations and temporary collectivities that crop up at the intersection of patient-family demand, state institutions, therapeutic markets, and law.

Seen from the perspective of these medical subjects—undesirable, according to actual care delivery policies, budgets, and state public relation efforts—biopolitics is an insecure enterprise indeed, more a symptom of the limits of government than a marker of its presence and control. The ethnographic realities presented throughout this chapter also suggest that the subject of rights and the economic subject may actually be included or excluded according to shared or similar logics, practices, technologies, and knowledge and that the pursuit and enforcement of rights may be a key means by which one becomes part of a market segment.

If, for Foucault, "the question of the frugality of government is indeed the question of liberalism" (2008, 29), then in Brazil's late-liberal moment, one could argue, the biopolitical question is not necessarily about the "futility" of the rehabilitation of diseased and underserved poor subjects (Biehl 2005) but about the expansion of frugal government in the form of pharmaceutical access in lieu of infrastructural reform. Thus, in this contemporary republic of interests, we see the consolidation of an "inclusionary state activism without statism" (Arbix and Martin 2010) coupled with extraordinary market expansion and the vanishing of "civil society" as a viable transactional reality.

I have written elsewhere about ambiguous political subjects in light of the country's pioneering policy of universal HIV/AIDS treatment access as it was actualized in the context of poor urban communities: "Their political subjectivity is articulated through pastoral means, disciplinary practices of self-care, and monitored pharmaceutical treatment" (Biehl 2007b, 324–325). For Souza and her patient-citizens at the Public Defender's office, politics is not a sphere but a lack, a technology, and a process all at once. In Brazil today, medical commodities work in tandem with other ways of claiming citizenship, and desperate and creative interactions occasion novel public sites in which rights and health are privatized alongside the emergence of novel political subjectivities.

In the face of this situation, the public defender puts up a fight. Souza's pragmatic critique of the state brings attention to the symbiotic relationship between a hybrid government of social protection and market expansion and the ways that public institutions, in their frugality or futility, acquiesce to the social and biological death

of those too ill or too poor to live in the new economy. Yet, as abandoned and injured as they are by various levels of actual government, some people still understand themselves to be the subjects of present rights and try to access care via the judiciary. People refuse to be stratified out of existence.

Souza's humanism and in-your-face politics produce a pathway to improving patients' situations. Against institutional realities that undermine health, control, and effectiveness, public defenders utilize medical and legal modes of veridiction and the framework of constitutional rights and human dignity to sustain their work and demand that the state act biopolitically.

Chronically ill and poor people find their way into the judiciary reluctantly, tinkering with available human and material resources. They are neither governable nor disruptive of the system. This minimum biopolitical belonging is part and parcel of the immanent field people invent to live in and by as they navigate the vagaries of market inclusion and survival in wounded cities. So, although right-to-health litigation is not by itself a solution for health problems or social injustice, it is an opening for citizens to engage creatively with public and private institutions and to reshape the social practice of care and demand that the state guard its citizens' human rights. It is not a substitute for health policies or health care systems, nor does it contribute to the privatization and fragmentation of those systems; on the contrary, right-to-health litigation allows for the reentry of human voices in these debates and institutions.

It is, paradoxically, by revealing the fragility of biopolitical interventions, showing how they are constantly entangled with and shaped by other (often economic) imperatives, that the stories of these patient litigants point to the temporal dimensions of medical technologies and to their own power to remake subjectivities and social worlds as they open up new spaces for claim making, contestation, and ethical problematization. It is at the intersection of the therapeutic imperative, the biotechnical embrace, and market reasoning that the intensity of survival becomes visible and the political battle over what is frugal and what is vital is played out.

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Notes

- 1. This chapter derives from a 2008–2012 multidisciplinary investigation of the judicialization of the right to health in southern Brazil (see Biehl n.d.).
- 2. See http://www.princeton.edu/grandchallenges/health/research-highlights/aids/Database_project.pdf.

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