

LIVING AND DYING IN
THE CONTEMPORARY
WORLD

A Compendium

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THE JURIDICAL HOSPITAL

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While the justiciability of socioeconomic rights is of increasing interest internationally, the volume of individual right-to-health lawsuits in Brazil stands out (Biehl, Petryna, et al. 2009; Collucci 2009; Gauri and Brinks 2008; Scheffer et al. 2005; Yamin and Gloppen 2011). Brazilian states are seeing the number of successful lawsuits brought in their courts reaching into the tens of thousands—a process that is, according to officials and some public-health scholars, altering administrative practices, encroaching upon health budgets, and ultimately producing inequality (Azevedo 2007; *An Injection of Reality* 2011; Ferraz 2009).

For the past four years, I have been coordinating a collaborative multisited ethnographic study of right-to-health litigation in the southern Brazilian state of Rio Grande do Sul, trying to understand this judicialization of health from a grassroots perspective (Biehl n.d.). With a population of eleven million, this state has the highest number of such health-related lawsuits in the country. 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 (figure 13.1). The majority of these judicial claims involved access to medicines, making up 70 percent of cases in 2008 and 2009. Our task was to find the people who judicialize and to illuminate their travails.

For me, what is extraordinary in right-to-health litigation—and why it is so important to study this phenomenon—is not simply its ever-growing numbers, but the fact that it allows the reentry of human voices into public debates about the object and scope of the right to health, the nature of care through and beyond technology, and the public-private

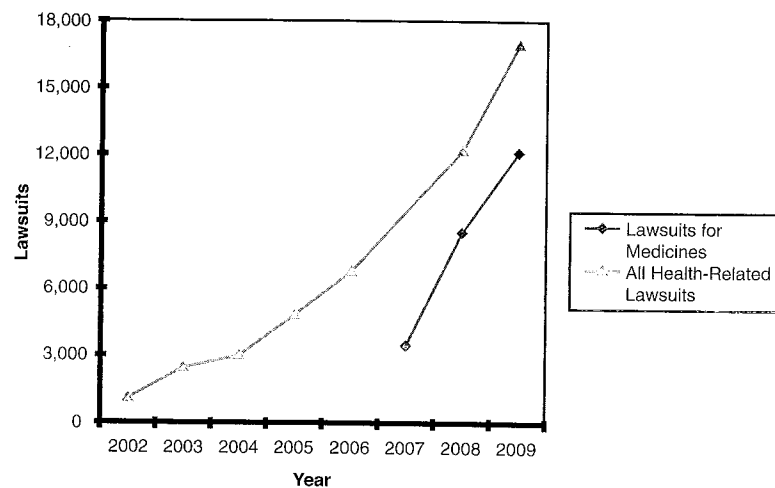


FIGURE 13.1
Health lawsuits, Rio Grande do Sul, 2002–9.

interface in contemporary governmental institutions. In order to address these issues in some depth, let me begin with an individual story.

"I ONLY JUDICIALIZE THIS MEDICINE BECAUSE I WENT INTO DEBT PAYING FOR IT"

Edgar Lemos, a retired bus driver, lives in a lower-middle-class neighborhood of Porto Alegre, the capital 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.

Coming from a destitute family, Edgar had worked since the age of eight. He was proud of the gated brick-and-mortar house he himself had built on the top of a hill. Edgar's ataxia affected not only his mobility but also his sense of dignity and worth, since it made him dependent on the care of his wife and two adult daughters. 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 antianxiolytics, 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 because I went into debt paying for it." A monthly supply of Somazina costs about two hundred dollars.

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 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.

Attorney Paula Pinto de Souza, who handled Edgar's case, says that the Public Defender's Office has become "a juridical hospital." As a legal advocate for the poor and chronically ill, she sees her job as being to ameliorate suffering and to restore the rights of her clients. "The person," she explains, "comes here sick and wronged by the failure of public policies. We are beyond preventive medicine here, and the concept of health as physical, mental, and social well-being is no more."

The Porto Alegre district judge issued a court injunction on his behalf, and Edgar received the medicine for several months, but then, Edgar said, "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. As for why he was not judicializing the other drugs he was taking, Edgar reasoned, "I know that the state cannot give everything to everyone. I have to do my part and pay for whatever I can."

The lawsuit is only one part of Edgar's labyrinthine treatment travail. Judicialization is not an attractive option to begin with. And although it saves him money, Edgar must periodically renew the lawsuit, with no guarantee that drug delivery will continue. One could say that Edgar even prefers the position of consumer instead of citizen since it gives him more control and confidence. The market, in this case, is more reliable than the welfare state. The medicine box is Edgar's arsenal. Yet what does not fit in this box is the psychosocial care, for example, that could help Edgar improve his quality of life as the disease progresses. And a lawsuit would not help him gain access to such services.

THE JUDICIALIZATION OF BIOPOLITICS

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 (Biehl 2013). And while examining the tense negotiations of the Brazilian constitutional right to health in daily life, I often had a sense of social roles and political positions out of place: of the judiciary as a sort of pharmacy, the public defender as a physician, the physician as an activist, the patient association as legal counsel, and the patient-citizen becoming the 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, since they underscored the importance of the juridical subject to late-liberal political economies.

In his 1978–79 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 logics. 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 somewhere between the clinic, the court, and the marketplace. What do these processes of judicialization mean for how anthropologists approach the study of politics and engage with ongoing debates, inside and outside the academy, about the relationship of health to human rights and social justice? 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?

While much recent anthropology has stayed attuned to politics (Comaroff and Comaroff 2011; Das 2007; Ferguson 2006; Petryna 2013; Spencer 2007)—even as the substance of what is considered "political" has varied—and anthropologists have indeed productively applied Foucault's concept of "biopower" to a variety of contexts (Fassin 2007; Fassin and Pandolfi 2010; 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 (Biehl 2005, 2007; Biehl and Petryna 2011; Edmonds 2010; Han 2012). Most compellingly, anthropologists have begun to examine the politics involved in the formation of para-infrastructure such as humanitarian interventions and therapeutic policies (Biehl and McKay 2012).

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 or facing off over and disputing responsibility, evidence, and costs–benefits, these various parties bide their time and become at once empirically present and permeable.

Although precarious, para-infrastructure 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 2007, 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.

In what follows, I try to describe the entanglements of the judicialization of health without claiming that it is seamless. Instead, I urge us 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. As ethnographic descriptions and people's stories move in and out of this larger narrative of the pharmaceuticalization and judicialization of health, I mean to leave us with a sense of how present-day institutions and social fields dance, and how ethnographic writing situated at their intersections must also keep in step.

Ethnographic realities can help us to refine, complicate, and even dislodge totalizing assumptions about neoliberal structural adjustments and market-driven societies. In the Brazilian judicialization of health, we do not see a top-down biopolitical model of governance in which population well-being is the object of knowledge and control, but rather 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 the 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.

FROM THE RIGHT TO HEALTH TO THE RIGHT TO PHARMACEUTICALS

Even if only cursorily, let me first place these realities and claims in historical context. Two concurrent and paradoxical trends informed the structure of Brazil's Unified Health System (SUS), which extended health coverage to all citizens in the late 1980s: on the

one hand, the trend toward greater recognition of the role of government in the fulfillment of social rights through the democratic constitution of 1988; and, on the other hand, the neoliberal theory of government in which state functions were decentralized and outsourced to the private sector. While the federal government assumed a central role in public-health funding (also managing some programs of prioritized diseases requiring high-cost treatments), state and municipal health secretariats had to develop new structures to assess health needs and to manage funds for care delivery. This arrangement delegated responsibility but did not ensure funding compliance and technical capacity for implementation. Thus, although Brazil today has one of the world's most advanced AIDS programs, many people go to public pharmacies only to find that basic medicines are out of stock and that the newer medicines they seek—as in Edgar's case—are not included on official formularies. Governments at all levels have not been able to manage a complex health-care system under the increasing technological, infrastructural, and economic demands of the public and private sectors, which are becoming less distinguishable from one another.

With a population of about two hundred 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 twenty-five billion dollars in 2012, according to SINDUS-FARMA). Public and private doctors increasingly prescribe, and patients demand, new medicines, some of uncertain benefit (Petryna 2009; Gertner 2010). Newer medicines, however, are often available only through private purchase. Unable to pay out of pocket or to find low-cost generics at public pharmacies, patients are increasingly suing the government to obtain what they need.

As I documented in the book *Will to Live: AIDS Therapies and the Politics of Survival* (2007), AIDS activists were among the first to successfully equate the constitutional right to health with access to pharmaceuticals. In the context of the fight against HIV before the availability of antiretroviral drugs (ARVs), there was an incredible emphasis on knowledge, empowerment, and the recognition of how stigma, discrimination, and social marginalization led to infection. But these are hard issues to address, and with the availability of ARVs, the emphasis of the response shifted to a more biomedical and less comprehensive approach. What we are seeing now in Brazil is both how the success of this shift has affected how other health issues are addressed, and the limitations of the emphasis on pharmaceuticalization. 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. In this process, the country is becoming a profitable platform of global medicine. It is estimated that almost 50 percent of the adult population (about sixty million people) uses pharmaceuticals on a daily basis.

The judicialization of the right to health does not resist these trends. But it can, I believe, point to what is missing in the health systems and provide a critical supplement to fragile social support networks as patients face the increasing privatization of health

care. People often use the expression *entrar na justiça*, “to enter the judiciary” or, literally, “to enter justice,” to refer to their lawsuits. There is a poetic force to this expression: the recognition of a generalized desire to want to belong to the body politic and to no longer live out of justice—the vision of a country with less inequality and discrimination. Recognizing the fact that the judicialization of health raises questions not only philosophical but also practical, the judiciary has by and large chosen as its main guide the concrete circumstances of patients litigants instead of abstract legal arguments. In questioning the place of the people in the design and implementation of public policy, the judiciary is also exposing the realpolitik of the executive and the legislative branches of government, and this, in turn, is opening a new chapter in the history of democracy in Brazil. In this panorama in flux, the social is up for grabs. As Chief Justice Joaquim Barbosa told me in an interview in June 2013, “It is the judiciary that represents society.”

THE MYTHS OF JUDICIALIZATION

There is an emerging body of scholarship on right-to-health litigation, but most studies tend to corroborate the views of many public-health administrators: that the judiciary is overstepping its role and that judicialization generates enormous administrative and fiscal burdens, distorts pharmaceutical policies, encourages irrational drug use within the public health-care system, and, ultimately, widens inequalities in health-care access (Borges and Ugá 2010; Da Silva and Terrazas 2011; Messeder et al. 2005; Pepe et al. 2010; Vieira and Zucchi 2007). Yet the evidence for these claims is too often obscured by ideological arguments and constrained by small samples and limited geographic coverage, with few variables examined. Many scholars have argued that the judiciary should be more concerned with the problem of limited resources and should abide by established clinical protocols. The constitutional right to health, they say, is a governmental mandate, not the right of any single individual. And throughout these works, people—their health-seeking struggles, hopes, and outcomes—are nowhere to be found.

In my view, this line of critique does not account for the on-the-ground realities of patient-citizens, nor does it acknowledge the political possibility that individual litigation represents. Ideologically committed to evidence-based public health, these critics fail to recognize that right-to-health litigation can be an urgently needed corrective measure when administrative mechanisms fail people. There are important differences in the field of evidence-based medicine itself, and critics don't seem to grasp that judicialization itself could serve to compel the creation of new sources of evidence to improve the management of public health.

Individual demands are not simply the antithesis of a collective need: individual experiences are often modeled by common phenomena within different communities. I am not saying that right-to-health litigation is a perfect process—it is rather costly administratively and humanly—but that it is instead an opportunity to ask how these citizens' demands could be politicized to attend to the diverse, urgent needs of all people.

Certainly, litigation is not a substitute for health policy, but it can be a crucial adjunct; individual claims highlight what is missing in health policy and make systems responsive to citizens, making the state *care*.

To respond to the need for a people-centered knowledge of the struggles to realize the right to health, we created a database of 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.

Edgar's case (presented earlier) was not among these lawsuits, but as I share some of our results you will see that his travails are not an exception. 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 three hundred dollars) 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 2008, 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 sought through litigation 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 alongside them. Off-formulary medicines requested by plaintiffs were also often low cost, and many had been available in the 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 where the initial ruling was in favor of the provision of medicines, the state's higher court most often upheld the decision.

This staggering number of lawsuits is generating significant legal and administrative costs. In 2008, the state, which has a population of about eleven million people, spent \$30.2 million on court-mandated drugs. This expense represents 22 percent of the total amount spent by the state on medicines that year (Biehl et al. 2009).

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 "solidarity" between levels of government to assert broad shared responsibility in guaranteeing the right to health. Lawsuits become the site 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.

THE JURIDICAL HOSPITAL

Patients in our sample of 1,080 lawsuits were, for the most part, chronically ill. Almost half of patients (48 percent) reported cardiovascular disease, diabetes, disorders of the lipid metabolism, 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 on 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 exceptional-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—one single case—for medicines for HIV/AIDS. Both pathologies have a similar prevalence in the south of Brazil, and both treatments 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. Whereas 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 exceptional-medicines program is decentralized: it is managed by states that are federally reimbursed. The latter program depends on administrative cooperation among federal and state governments 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 exceptional and special medicines must be accessed in the public health-care system. When patients fall outside of 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.

Lawsuits may be a mechanism with which to challenge treatment protocols that

limit access based on cost-effectiveness and epidemiologically derived risk-benefit considerations. Rather than accepting these protocols, our results show that judges give broad deference to individual circumstances and physicians' prescriptions—deference that may undercut efforts to rationalize pharmaceutical use. As in the case of one patient named Nelson Silveira, the judiciary seems to offer citizens who are diseased and politically injured the possibility of articulating a time-sensitive legal effort to make the state act biopolitically so as 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. At first, attorney Paula Pinto de Souza and I mistook Sandra for the patient, but it soon became evident that the "we" she referred to in our conversation was a kind of domestic advocacy group. "We cannot interrupt the treatment one more time," said Sandra. Nelson had retired as a steel-factory worker, and she was still a kindergarten teacher. They resided in the nearby city of Esteio and had two adult children. 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 the 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, 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 then 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 this would be "re-treatment," 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 eligible for re-treatment and now needed the medicines for 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 them a road map of all they had to do and the documents they had to bring 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."

TEMPORARY COLLECTIVES

The next story I want to tell suggests new social forms emerging on the interface of right-to-health litigation, medical technology, and the state. Where institutions fail, communities articulate fragile and short-range solutions that nevertheless demonstrate that social ties are often the last and best resource in the face of disregard and death.

Sixteen-year-old Leticia and nine-year-old Katiele are the daughters of a migrant family that lives on the outskirts of Porto Alegre. Both suffer from Phenylketonuria, or PKU, a metabolic genetic disorder. The difference is that the younger sister, Katiele, was immediately diagnosed and treated with a combination of diet and medication, whereas Leticia, who now suffers from severe mental retardation, was not. Leticia was diagnosed only because when her sister was born screening had become mandatory, and the special baby formula needed to prevent the development of the disease had become universally available via SUS.

In the state of Rio Grande do Sul, about 120 patients need this formula. But given distribution problems, twenty-five families had to file lawsuits to ensure access. We interviewed all these litigant families, who, for the most part, live in the interior and are in fact poor. Like Marizete and Neri (Leticia and Katiele's parents), they all have had low levels of formal education. But this does not stop them from judicializing.

Leticia and Katiele's family receives the formula through administrative procedures, but they decided to file lawsuits to obtain special food (such as pasta and flour), which is vastly more expensive than the common food that the sisters are not allowed to eat, and which took up much of the family's budget.

Because the state failed to make the formula available, the parents also thought about judicializing it. At the very last moment, however, the family decided not to do so because Dr. Paula Vargas, the girls' beloved physician, and other families lent them formulas till distribution resumed. As Marizete puts it, "Mothers help each other. When one gets something she teaches the others. So one keeps helping the other, until we get it."

In this example, the family of Leticia and Katiele found something that they identified as more useful than or preferable to judicialization: a caring health professional and a social network.

Rather than turning to the courts, Dr. Vargas helped to create and sustain solidarity networks among her patients, facilitating the sharing of the formula when it was missing, and mutual support among families living with PKU: "When the formula is lacking, families can call me anytime and I'm sure I can do something even when the state is not doing its job. These patients simply cannot go without the treatment. It would be a crime." Right-to-health lawsuits give us only a partial view of the therapeutic trajectories of patients and their families: new sociomedical forms also become a kind of para-infrastructure for access to treatment and care. Without this, Dr. Vargas says, "many more would judicialize."

As the cases of Edgar and of Leticia and Katiele show, the booming number of right-to-health lawsuits not only points out the weakness of public-health administration and



FIGURE 13.2
From left, Marizete, Leticia, Neri, and
Katiele. Photograph by Torben Eskerod.

policy in Brazil and that the judiciary has indeed become a powerful purveyor of medical technology access, but also puts into focus a widespread reductionist approach to health care. The needs of patients are not addressed holistically, and in spite of the universality of health care, its delivery is stuck in an access and volume mind-set, rather than focusing on the value of interventions to patients and families over time (Kim, Farmer, and Porter 2013).

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” (2008, 410). 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” (410). Fidler recognizes a “deeper importance for law in public health endeavors within and between countries” (394).

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; see also Vianna 1999).

The judicialization of right-to-health litigation thus speaks to productive open-source anarchy at both macro- and microlevels in Brazil today. As I mentioned earlier, policy makers contend that the judiciary is overstepping its role and that judicialization skews

budgets and increases inequalities in health-care access. Yet 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 new urban spaces. Rather, the judges 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.

District judge Eugenio Terra, who is in charge of all health-related cases in Porto Alegre, does not agree that the judiciary is exceeding its role. In line with the experience of attorney Souza at the Public Defender’s Office, he, too, finds that lawsuits are filed largely by poor and desperate patients seeking treatments that should be available in the public system. “I am doing social justice, one by one,” he 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.”

Rather than accepting one-size-fits-all medical protocols, judges give broad deference to individual circumstances and physicians’ prescriptions—a practice that may appear to undercut state efforts to rationalize pharmaceutical use. State high-court judges like Denise Oliveira Cezar are also holding pharmaceutical companies accountable, particularly to patients participating in clinical trials. As she puts it, “We struggle for jurisprudence. We are challenged to create the right and to enable the person of rights.”

If access to AIDS therapies was the litmus test of the right to health in the 1990s, it is access to genetic therapies now. The last story I want to tell is that of twelve-year-old Alexandre Lima de Moura, who suffers from mucopolysaccharidosis (MPS), an inherited metabolic disorder. Every week, the fourth-grader travels with his mother, Cleonice, to Hospital de Clinicas in Porto Alegre, where he receives enzyme-replacement therapy—a treatment that costs about two hundred thousand dollars 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.

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. Ample evidence shows how laboratories' monopoly on medico-scientific information and pharmaceutical marketing strongly inform physicians' prescriptive habits and patients' demands (Diniz, Medeiros, and Schwartz 2012). Additional ethnographic studies are in order; they could help us chart how judicialization has also become part of a pharmaceutical business plan in Brazil, supporting patient associations and lawsuits for access to high-cost medicines specifically to open or enlarge markets.

THE RIGHT TO A NONPROJECTED FUTURE

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 costs and financing or to determine the responsibilities of private health-insurance plans in covering drug costs and medical services. Local governments should certainly track court cases and use them to inform efforts to remedy specific disease policies, administrative shortcomings, and poor public-health budgetary planning. Attention is also needed to broader aspects of the right to health, including interventions that tackle the social and political determinants of health such as education, water, sanitation, vector control, air pollution, and violence prevention, as well as access to justice.

As for our understanding of the ever-growing and complex judicialization of the right to health, I believe that field research has much to contribute and that ethnography can work as an early warning system. People on the ground recognize what's troubling them. And it is somewhere in the middle of their social lives that our critical work begins. Ethnographers are uniquely positioned to see what more categorically minded experts may overlook—namely, the empirical evidence that emerges when people express their most pressing and ordinary concerns, which then open up to complex human stories in time and space that should be the center of public debate and action.

The judicialization of the right to health has become a para-infrastructure in which various public- and private-health actors and sectors come into contact, face off, and enact limited "one by one" missions. There is no pre-given biopolitical population in Brazil today to which Edgar, Leticia, Katiele, Alexandre, and thousands of other atomized subjects of rights belong. Seen from the perspective of these medical subjects and their

fragile collectives—undesirable, according to actual care-delivery policies, budgets, and state public-relations 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 knowledges, 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 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 "state activism without statism" (Arbix and Martin 2010, 6) coupled with extraordinary market expansion and the vanishing of "civil society" as a viable transactional reality.

Yet people refuse to be stratified out of existence. The humanism and in-your-face politics of public defenders such as Paula Pinto de Souza (whom I briefly introduced you to) produces 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.

The hard-to-pin-down patient-citizen-consumers to whom I introduced you speak to novel forms of social becoming at the interface of law and medicine, and their medico-legal trajectories show that politics matters differently to a growing number of low- and middle-income sick Brazilians. People's life chances and health outcomes are overdetermined by the kinds of marketized juridical subjects they are able to become through appeals to the judiciary, government, and research and health industries driven by profit and the construction of new therapeutic market segments. As ethnographers, we must attend to the forms of statecraft (national and regional) and jurisprudence as well as to the kinds of medico-scientific literacies and political subjectivities that are built into the para-infrastructure of rights and interests that the judicialization of health has occasioned. We must consider both the possibilities opened up and the exclusionary dynamics at work at the judicialization front evident throughout Brazil and in other emergent economic powers. 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 over what is frugal and what is vital.

Taken together, these human accounts and numbers that I have shared with you also affirm the urgency of a crosscutting and holistic framework that integrates the right to health with comprehensive care and that links social justice to sustainable forms of development. At stake is the development of institutional capacities that go beyond the repetition of history and help to defend—in the luminous words of economist Albert Hirschman (1971, 37)—“the right to a nonprojected future as one of the truly inalienable rights of every person and nation.”

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