The Right of Recovery

by Adriana Petryna

The responsibility for medicinal access and care has progressively shifted from the biomedical clinic and doctor-patient relations to precarious social institutions and legal and experimental settings. These settings afford proxy public health care, triaging services, and care delivery often on the basis of emergency or strict criteria of eligibility, urgency, or need. In this essay I trace out a conceptual shift in biomedicine and global health from a focus on a right to health (often equated with the right to medicines) to the institutional dynamics that facilitate—or, more usually, obstruct—a right to recovery. The essay addresses this latter right as an unmet therapeutic potential and explores practical and conceptual challenges for what is known as the "sick role" from its original framing as social deviance to be biomedically controlled to a neglected but powerfully informative people-based social science of survival.

"Do you know," I hear, said into my ear, "my faith in you is very limited. You have been shaken off from somewhere, you have not come here on your own two feet. Instead of helping me, you make my deathbed more narrow." (Kafka 1997 [1919])

Recovery's Perils

Whether it is in the American privatized and extremely fragmented health system or in emergent economies such as Brazil, where a right to health is constitutionally mandated, sick individuals worldwide continue to struggle desperately to access medical care. All too aware of the prohibitive cost of such access, they may postpone it or never receive it. Insurance companies in the United States have discriminated against patients with preexisting conditions and courts in Brazil routinely hear cases of patients litigating for treatment access. In the United States, for example, mortality rates for all cancers are 12% lower among the privately insured than they are for the uninsured. Even the most advanced cancer treatments science has to offer cannot reduce the risk of death from cancer by this much.[1] That a "cure" for cancer is not merely hypothetical, but a reality out of reach for so many, raises questions not only about who has a right to access medical goods and a right to health, but also about who has a right to *heal* from disease. What social and political arrangements optimize recovery? And what arrangements make this path so perilous, even fatal?

These questions are pertinent to the United States, where President Obama's Patient Protection and Affordable Care Act was signed into law in 2010. This act focuses on the quality of patient outcomes rather than on the quantity of care. Yet the meaning of "quality outcome" has been hard to gauge. Understood as the affordance of the best chance for recovery (as well as a right not to be tormented by technological excess), what remains unthought with respect to quality, as I suggest in this essay, is a meaningful narrative of the "morality" of medical recovery. While cost-effectiveness research, mandated by the new legislation, gains a more prominent role, such research largely focuses on a collective optimality, not on an individual one.

In this essay I argue that quality is more than a research matter, a metric of savings, or a question of coverage or even patients' access to medical goods. I suggest that the focus on quality should prompt a reimagination of the ways we see and think about recovery, the missing coordinate in current health-reform debates that is also an urgent moral and scientific domain. The "true north" of my argument is not health or rescue at all costs but a conversation about what the new constellation of quality might look like and how patients can engage this constellation as a less costly and more obvious set of rights of recovery.

The "measure of health," wrote medical philosopher Georges Canguilhem (2008), "is a certain capacity to overcome crises and to establish a new physiological order, different from the old. Health is the luxury of being able *to fall ill and recover*" (132; italics mine). This essay juxtaposes this

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1. See "Ezekiel Emanuel on the Ethics of American Healthcare," accessible at http://www.chicagohumanities.org/Genres/Science-And-Technology/2012f-Ezekiel-Emanuel-Ethics-Health-Care.aspx.

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idea of health as luxury with the unbearable cost of survival in a variety of industrialized medical settings. It asks, What insures not only the right to health but also a right to heal, or a right of exit from one's disease? What is a right of recovery? In invoking such a right, I do not mean to attribute omnipotence to the medical profession (which it does not possess). Rather, I highlight the moral challenges associated with recent mandated shifts from volume-based to quality-based conceptions of health care, of harnessing therapeutic potential in a wide range of patients and circumstances.

This harnessing of therapeutic potential becomes even more complicated in global health, where responses to epidemics such as AIDS have been considerable but where a citizen's right to health (mandated by over 100 constitutions worldwide) often equates with a citizen's right to pharmaceuticals. Varieties of therapeutic agents and medical authorities proliferate, from physicians working in clinics to judges ruling on medicinal claims in courts and physician-researchers providing temporary care, albeit through an experimental compound, in global clinical trial settings that are nested in local public health facilities.[2] State public health obligations move from clinics and patient-doctor relations to "outsourced" institutions—transnational and nongovernmental organizations to be sure, but also to state judicial and local experimental public/private domains. As the trajectories of patient-subjects and patient-litigants considered in this essay suggest, these "paramedical" health-care settings are, for better or worse, acting as surrogates for treatment access in Brazil and Eastern Europe, two regions about which I have the most ethnographic knowledge and familiarity.[3]

This essay captures some of the therapeutic dynamics of these "proxy" terrains of health access, where patients experience medical attention episodically (registered in terms of medicinal legal cases won or clinical trials accessed) and where powerful therapeutic misconceptions are often at play. Clinical trials in Poland and right-to-health courts in Brazil are all about innovation, be it technical or social. The globalization of clinical trials, for example, transferred critical biomedical resources as well as practical and commercial know-how to medical experts and authorities working in Eastern European public health systems. And in the wake of a progressive 1988 democratic constitution affirming health as a right of the people and a duty of the state, courts in Brazil have been inundated with citizens' legal challenges for access to a variety of medicines including ones that are on government lists but out of stock.

Humanitarian, legal, and experimental settings make up new infrastructures of survival and global patient life.[4] Yet one key feature of these proxy health infrastructures is the impermanence of obligation. Patients must overcome this impermanence with specific kinds of appeals. As patients' roles are redefined—from patients to clients or patient-subjects and patient-litigants in the pursuit of biomedical care or goods—their experiences belie traditional (or idealized) notions of doctor-patient interactions. I illustrate these dynamics with three ethnographic case studies.

In the first case, I show how patients experience an untethering from their "sick roles" to fit new criteria of biomedical access. The sick role, a concept introduced into the sociology of medicine lexicon last century (Parsons 1951), describes the social dimensions of falling sick and the attendant rights and duties of doctors and patients and their families toward a patient's recovery.[5] The sick role was a deviance-controlling script meant to "guarantee" reintegration of the sick into a functioning social world. To be sure, the work of health-service agencies involved distributing medicines, but the goal of therapeutics was predominantly a reintegrative process (Parsons 1975:260). The sick role ascribed moral efficacy to a social world in which the sick are not only managed in terms of disease but also have a chance to recover through good faith, unmotivated by secondary gains.

Today, when judges become pharmacists or state health agents are emergency care providers, there are often few explicit norms informing decisions about whom to care for, when to care for them, and for how long. Where disease may lead to capitalizable data (as in for-profit clinical trials), the focus of health is not on recovery from disease per se but on the political and economic exploitation of diseased states. In the United States, health systems do not even calculate outcomes or profits by how well people get but by the volume of services and technologies delivered (Porter and Teisberg 2006). Volumetric conceptions and risks of disease eclipse therapeutic potentials.[6] The loss of recovery as a moral (and even economic) domain of potential reflects the motives and professional ethics of medicine that are at present too narrowly conceived in terms of delivery of services and management of disease. Left unchecked, the impermanence of

2. On the concept of pharmaceuticalization, see Biehl (2007*a*, 2007*b*). On the judicialization of the right to health, or the widespread adjudication of medicinal claims in courts, in Brazil, see Biehl and Petryna (2011) and Biehl et al. (2012). On global clinical trial settings as a crossroads for the twin phenomena of pharmaceuticalization and judicialization, see Biehl and Petryna (2013) and Petryna (2009). On the different roles patients take on, such as that of client, see Whyte et al. (2013). For an analysis of pharmacists as key therapeutic agents and the consequences for health, see Das and Das (2006), Ecks and Harper (2013), and Kamat and Nichter (1998).

3. For other theoretical and empirical explorations of clinical trials in broad contexts, see Abadie (2010), Dumit (2012), Fisher (2009), Geissler and Molyneux (2011), Nguyen (2011), and Sunder Rajan (2007), among others.

4. See the work of Fassin (2011), Feldman and Ticktin (2010), Redfield (2013), and Samsky (2011), among others.

5. Parsons understood this not as a dyadic doctor-patient relationship but as a triad that also included the family.

6. For a critique of the volume-based mind-set, see J. Y. Kim and M. E. Porter, "Redefining Global Health Care Delivery" (unpublished manuscript). On a discussion of the sick role and its "death" in US medicine, see Burnham (2012). Social scientists have poignantly moved caregiving out of the neglected corners of biomedicine. See the work of Kleinman (2010), Livingston (2012), Mol (2008), and Taylor (2008).

obligation (toward recovery) generates intensely complex—and largely unseen—sociomedical realities that may adversely affect more people. This diminishment of therapeutic potential is not only structural; it takes concrete ethnographic form.

In this essay's second case, such diminishment inevitably becomes part of a physician's professional skill set as external, commercial pressures come to define the value of a doctor-patient interaction.[7] I am interested in how patients fare in situations where health professionals can exhibit wide latitudes of action or inaction or indifference and how patients and families instantiate, through one-on-one confrontation, senses of obligation: a right to recovery that they perceive to be encompassed within their rights and duties as patients. How do the sick themselves bargain for the sick role and medical obligation within nonoptimal medical settings where strategic misrecognition or dangerous nonneutrality can prevail? How do they recreate some form of therapeutic complicity between all interested parties that the concept of the sick role generally aspires to?

Few cases are successful, but strung together I hope they tell a story about potential, not only of the inherently social nature of medical technologies or access to them but also—more centrally—of the inherently social indeterminacy of recovery in contexts where medical technologies are largely available but where the sick role is missing. Most of the medical and paramedical experts encountered here form the core of a tragic plot structure—nonrecovery—involving a misrecognition of their patients' desire for care or a devaluation of the "expected value of their patients' futures," among other things.[8] I make a distinction between a right to medical goods or a right to health and a right to heal. This is because what constitutes a medical good can be vague.[9] As such, a medical agent can provide medical goods (such as clinical trials) but "comfortably" not commit to a patient's recovery.

In his *Poetics*, Aristotle (2005) suggests a way of thinking about potential vis-à-vis tragedy. Potential is a plot or narrative arc that heightens the power of "structure and incidents" rather than "spectacle" to achieve a desired effect. The incidents he refers to are not self-contained dramas but more like increments of recognition that accumulate along "a spectrum between seeing and blindness."[10] Those increments include "half-unfolded" disclosures to false inferencing and "blind seeing"—all of which can block critical discoveries. I track potential here in terms of how the expected value of patients' futures is formulated, rises, or is lost within various medical encounters, and I track the potential for injury that can go largely unchecked in the absence of a mitigating force. I also track how patients lose and reclaim their identities as careworthy subjects in the global and experimental contexts in which I worked. I am interested in what Sharon Kaufman (2013) calls the "cultural work of potentiality": to carve out a conceptual space for a form of recognition that can address—and hedge against—evolving spaces of medical neglect or unintended tyrannies.

In this essay's last case, I explore the case of a man whose severe genetic disorder is not "recoverable" within the public health system because the medicines are far too expensive. His participation in a clinical trial for a high-cost genetic therapy is followed by a traumatic postclinical trial experience in which he reluctantly litigates for his "right to health." I explore the insurgencies of this patient who demanded care as well as those of his clinicians, whose power to heal they perceived to be literally taken away from them by chaotic commercial and institutional forces they were just learning to recognize.

To be sure, potentiality operates as a moral category that can fail patients; it is the failure of recognition that moves the tragic script of nonrecovery along. Potentiality is also a moment when telling increments combine, when idiosyncratic social knowledge of very real and desperate experiences accumulates and can push medical actors beyond the constraints of predetermined ethics or laws. Potentiality is thus about how this knowledge becomes coincident with a new structure of recognition in medicine, even virtue. This "becoming coincident" is what I take an anthropology of potentiality to be looking toward: a horizon in which a different kind of truth, objectivity, and outcome can become actual and operational. Turning to the first case, I show how other kinds of horizons can quickly appear in the absence of mitigating conceptual or institutional investments.

"I Don't See Patients, I See Data"

In the early 1990s, an unprecedented space of opportunity opened up in Poland and for Poland's health-care workers such that up until the mid-2000s, Poland and Eastern Europe would occupy a major share of what is known as the global clinical trial market (Petryna 2009). Available technical expertise, English proficiency, and high rates of certain untreated disease as well as centralized public health systems that could more easily become functional clinical trial platforms meant that drug companies would annually invest almost half a billion dollars each in clinical research in Poland (a country with one of the lowest shares of public expenditure on health in the Organisation for Economic Co-operation and Development countries). Trials for everything from hypertension treatments to high-risk surgical techniques moved to Poland and other Eastern European countries, providing data for drug approvals from the US Food and Drug Administration

7. On such latitudes, see Petryna (2007, 2009, chap. 3). For an exploration of the moral perils of doctor-patient relations in a context of commercialized health care, see Kleinman and Hanna (2008). For other explorations of the moral perils of doctor-patient relations in a postdisaster context, see Petryna (2002).

8. I adapted the phrase "the expected value of their patients' futures" from the brilliant essay "Obstacles to the Perception of Change" by development economist Albert Hirschman (1971:341).

9. I found this in my work on global clinical trials in which access to trials was often conflated with access to medicine (Petryna 2009).

10. On the nature of tragedy in Aristotle's concept of recognition, see Merback (2012).

or the European Medicines Agency while transforming public health care in these countries into an ever-greater mosaic of private-sector involvement and mounting patient demand for new drugs.

Dr. Jiri Stanek, a Czech public health specialist I interviewed in 2006, was a clinical trial market insider and an expert on how such markets rise and fall. He got his start in the early 1990s by turning ailing but centralized public health systems into nominally functional clinical trial platforms.[11]

> For companies it was cheap. They got good data quick. There was a need for services, and all of a sudden Western companies realized the huge potential here. Our population was not treated by remedies that were available in the West. So it was all quite attractive. We had many untreated populations. There were treatment-naive, steroid-naive, statin-naive people—people you could hardly find in the US or Western Europe. We had extremely high recruitment rates.

Trials had become so pervasive, particularly in cardiology- and oncology-related services, that by the end of the 1990s roughly 30% of expenditures on oncological treatment in Polish hospitals were covered as part of a clinical trial program.[12] Yet Stanek also hinted that each stage of developing clinical trial markets involved an unscripting of patients from their roles. He pointed out that clinical trial subjects as a general rule are only "temporarily loyal," and after a while "they no longer see the immediate benefit in participating in trials." For example, he mentioned that pools of "steroid-free asthmatic children are starting to get exhausted a little" in the Czech Republic. At a point of increased competitiveness for the right kind of patients and investigators, and when state regulators show signs of less flexibility, he said, "It simply becomes too expensive for us, just like in the United States, Western Europe, and Canada."

Moving between corporate and scientific offices in the United States and research and public health sites in Poland and Brazil, I documented the organizational cultures of industry-sponsored clinical research, probing scientific, ethical, and regulatory practices from the perspective of national regulators, corporate sponsors, trial workers, and monitors as well as public health physicians and scientists who were being recruited to do clinical trial work. As I tracked how clinical trial markets rose and ultimately fell, I observed the complex ways that commercial medical science, with all its benefits and risks, was being integrated into local health systems and emerging drug markets. Neither the language of coercion nor that of rational choice could fully capture the range of value systems at work in medical experiments today. Questions of posttrial treatment access and long-term care were often left unaddressed in an ever-expanding global market of health.

As markets for research moved eastward and southward, the ethics of placebo research were being hotly debated. I observed as industry actors scrambled to learn from US regulators about the legal enforceability of guideline documents (such as the Helsinki Declaration) and found ways to continue using the placebo (Petryna 2005).[13] A placebo is an inactive treatment made to appear like real treatment; it amounts to no treatment. During the time of my research, I observed how debates over its appropriate use, particularly in resource-poor settings, began to focus narrowly on the "ethics of research" and the role of the researcher as opposed to, for example, challenges to the therapeutic role of the physician in these settings. In spite of these ambiguities, a US regulatory requirement to test new drugs using a placebo control remained a key factor driving clinical trial globalization, and US Food and Drug Administration regulators remain committed to the placebo for scientific reasons (although they would be increasingly marginalized by their regulatory partners in Europe). As justifications for placebo use butted up against reality (most Americans who are sick generally do not want to be on the placebo arm of the study), many placebo-controlled study protocols originating in the United States "floated" to other countries, where there were people, according to industry and US regulatory reasoning, who were willing to enter a placebo-controlled study.

The industry expansion of placebo research proceeded as if there were a world of willing subjects, as if there were something completely obvious about how patients, no matter how poor or untreated, "consented" to trials, let alone placebo-controlled trials in which patients faced the possibility of not receiving treatment but just a sugar pill. Working in the field with clinical trial experts, I learned that such consent did not come spontaneously; it had to be engineered. Therapeutic expectation was manipulated; therapeutic obligation became negotiable; sick roles were untethered and at times sacrificed.

Dr. Henryk Król, an experienced human subjects recruiter in Eastern Europe, was one such expert "shredder" of therapeutic expectation and obligation. Like Jiri Stanek, he was a public health physician in a former life and led his firm's expansion across Eastern Europe. Joining him on a trip to Moscow, where he would carry out surprise inspections on his company's trial monitors that were supplied by a local company,[14] he recounted to me an enterprising way in which to enlist untreated patients for a placebo-controlled study but in an ethical way: "We all know that it is unethical to withdraw treatment from patients during a trial. If a patient can get

11. I employ pseudonyms throughout this essay.

12. With the rush of clinical trial programs and financial capital, governments eventually caught up with the new practices. With different degrees of success, they fostered a culture of regulation, compliance, monitoring, and auditing—all the capability that was necessary in hosting transnational commercial research.

13. They had a strong incentive: placebos lower costs, and many argue that placebo trials produce better evidence.

14. Monitors ensure proper documentation of informed consent and trial procedures and create an audit trail. They are critical to insuring the inflow of finance capital and the outflow of products (data) from new or untested research areas.

the required treatment where they live, then we certainly cannot withhold treatment or use the placebo. But for a patient with a newly diagnosed condition, say, hypertension, withholding treatment is ethically justified. That is because you cannot put the second patient immediately on the medication anyway. It is totally acceptable to wait and see if, say, the patient's hypertension can be controlled by nonpharmaceutical means." A patient can be treated "through diet, less salt, exercise," he added.

This lifestyle-treatment approach—which could be positive in its own right—was a mere stepping stone to remake a hypothetical hypertension patient into a placebo subject. The recruiter's task here is to identify people who are in a "window" of nontreatment. But that window, as Król suggests, must be engineered. In this window, patients will be diagnosed and told about their condition. They will learn about a new treatment that is available elsewhere but is unaffordable for them. Finally, they will be told that they would have a 50% chance of getting the treatment if they sign up for the trial. Here consent is culturally reoriented toward the pharmaceutical and toward a patienthood that is yet to be realized. A therapeutic potential is manipulated to facilitate consent and for the project to conform to ethics standards with respect to "autonomy." Yet for Król, the moment of informed consent is also the moment when patients are fully informed and fully exposed to the realities of a high-cost pharmaceutical market that excludes them. The intriguing process through which a person comes to "voluntarily" consent to participate in a trial is not easily observed here. In this "ethical" recruitment, populations, either by intention or by default, can be reconfigured as "fair game" in global research structurally different and dislocated from normal, anticipated, or nonutilitarian paths of expected care.

As this case shows, while ethics may be suited to protect subjects in trials, they may not be suited to protect patients in trials. It also shows that a proplacebo regulatory push for creating "exceptions" to the best care standard overinvests physicians (turned researchers) with powers to define that standard and to redirect the therapeutic desires of patients toward settling for a second-best option, understood as the trial, and thus propagating therapeutic misconception and thwarting patient roles toward some other, utilitarian market end. These incremental steps toward exposure are implied in Król's ethics of what "we all [presumably] know." In other words, and to invoke Aristotle's sense, we are "seeing blind." The words of one of Król's colleagues—"I don't see patients, I see data"—are echoed in the blind recasting of the patient role as data to be captured, transferred, or manipulated. In what follows I turn to Brazil, a country that has seen considerable growth in its clinical trial markets and where I explore how patients attempt to reinstate "sick roles" (often via the judiciary, as we will see) following their exposure to trials, all the while challenging an impermanence of obligation in medicine and its legal, market, and ethical justifications.

"Take Care of Me"

Inês kept saying to me, "I am a number, I am just a number there." She is a 55-year-old Brazilian mother of four daughters who for the last decade has suffered from an untreatable and often fatal lung disorder (a type of pulmonary hypertension) that is resistant to current treatments. Once she learned that her breathing difficulties were linked to this particularly rare disorder, she was able to find a specialist through a network of family and friends. Inês tried the standard plan of medical care, but it did not work for her. To help with her symptoms, she took five other medications. In 2008, her pulmonologist invited Inês to participate in a clinical trial for a new medicine for someone with her exact medical condition. Knowing that Inês was a "good" patient (she was reliable and compliant), the doctor pressed Inês hard to join the trial, which he told her would be of benefit to her medically. The trial had a placebo arm. And, after much discussion in her family, Inês decided to join the trial because she "trusted the doctor," she told me.

For the first 3 months, the study was double-blind, meaning that no one, including the patient-subject and the physician-researcher, would know who was on the placebo and who was on the active arm. After 3 months, patients would learn who was getting what. Complications began to arise. Inês, the once trusted patient, stopped taking the experimental pills that she had been given. "The doctor chastised me. He told me that I couldn't come back to the clinic with all these leftover pills." Every pill Inês took or didn't take was counted. "I told my doctor that I am taking too many pills already, a diuretic, a heart pill, a high blood pressure pill, I can't take any more pills!" Her doctor responded, "If you are going to skip any medicines, *skip the ones you are taking now*, not the experimental one!"

I realized in the course of our discussion over unconsumed pills that she was staging a "noncompliance" as a way of leveraging the doctor's care and commitment to her well-being—to reinstate a doctor-patient relation. Inês continued to be a "deviant" subject in exchange for having "given up" her sick role. But when she discovered (given her palpable improvements) that she was probably not on the placebo arm, she understood that she may not have a sick role to return to in part because of the overwhelming cost of the medicine she was being tested with. As she told me, "I asked the doctor, 'What happens to me afterwards? Who is going to take care of me? I'll take your pill only if you guarantee that I will get it after the trial ends.'"

Faced with disappearing avenues of care, her question rises to a level of quiet revolt. In his short story "A Country Doctor," Franz Kafka (1997 [1919]) describes a hapless doctor whose values are controlled by other, unknown, and unnamed forces. He is called one evening to attend to a boy in the countryside who is suffering from a fatal stab wound. The physician reluctantly arrives at the boy's home and without much of an examination tells the boy halfheartedly that he

will be fine. Sensing betrayal, family members shove the doctor into the same bed as the patient. Next, the sick boy whispers searingly, "'Do you know,' I hear, said into my ear, 'my faith in you is very limited. You have been shaken off from somewhere, you have not come here on your own two feet. Instead of helping me, you make my deathbed more narrow.'" Stories of narrowing deathbeds and withholdings of obligation suggest the pressing need for a less morally costly and more obvious set of rights of recovery to be born. In the first (Polish) case, sick roles are thwarted while therapeutic hopes are manipulated; in the second, these same events occur but with possibly more dire outcomes. And finally, here in Kafka's story, one reaches a point at which the patient ceases to be medicine's reason for being and becomes its very reason for nonbeing.

Importantly, Inês did not want to use legal options afforded to Brazilian citizens (of suing the state to provide medicine) as a hedge against such dire Kafkaesque prospects. Many physicians in Brazil are encouraging patients who lack access to newly tested technologies to "judicialize" their case. Inês used the expression *entrar na justiça*—"to enter the judiciary" (or literally, "to enter justice")—to refer to this process. However, cases can take years to resolve. Most defendants ask for temporary court injunctions, and if granted, they can receive treatment immediately. They can also be trapped in an endless cycle of requesting new court injunctions, depending on the judge. Already in the third stage of her pulmonary disease, Inês felt that "judicializing would surely take me into stage four."[15] She held a narrative of the "morality" of her own recovery—of what would be lost (time, energy, hope, health) in the maelstrom of "judicialized disease" and the increasingly smaller increments of what was to be gained (dignity, a future, family and political belonging)—in the struggle for her right to stay in the sick role along recovery's perilous path.

Medical obligation is a "thought-style" (Fleck 1981) with active legal and ethical norms. Today its parameters are shaped by a host of differently invested political agents entering the field of medical provisioning with a certain readiness to provide "life-and-death" rulings. Left unthought are the terrifyingly vague institutional assignments of ultimate responsibility for the sustained recovery of patients such as Inês. The hypothetical lawsuit that she did not file most likely would have ended up at her local public defender's office (where the majority of the lawsuits requesting medicines from the state travel) and in the able hands of one very fiercely committed public defender, "Dr. Paula." According to Dr. Paula, "By the time an ill person gets to me, all [her] vulnerabilities are exposed; the cure is most likely no longer possible. . . . This is the 'medicine' that I practice here." As Dr. Paula's comment suggests, healing becomes a moral act for patients who have been overly exposed to the impermanences of medical obligation. But why did we have to wait so long for healing to be moral? What can act as a mitigating force to such overexposure?

Even where there is universal health care, as in Brazil, seemingly rational processes of prescription butt up against—and fall apart in the face of—serious obstacles to the harnessing of a medical system's therapeutic potential. The long struggle for universal health care worldwide, particularly in the United States (Starr 2011), is a case in point. After the Second World War, President Harry S. Truman advocated for a single-payer universal health-care system. Yet vehement opposition by the American Medical Association scuttled the plan, and the United States ended up with a tiered system of private health insurance, welfare services for other qualified groups, and vast pools of the uninsured. As the above public defender's words suggest, even universal health care will not solve all problems of disease. Quality medicine inheres in relations and is itself subject to moral and literal deterioration (Kleinman 2009).

Curiously, it was in the fraught moments of aborted universalization in the United States that Parsons conjured the "total interaction of being sick." The sick role, one could argue, became a conceptual prescription of sorts for "deviance control" in modern medicine as well as a reminder of medicine's sociocurative obligations.[16] Even Parsons's contemporary, American economist Kenneth Arrow (1963), gestures to the sick role as a normative ideal in a leading economic paper of the postwar era, "Uncertainty and the Welfare Economics of Medical Care." Acknowledging his indebtedness to Parsons, Arrow warned of the encroachment of market principles in health care—namely, in doctor-patient relations—and deploys aspects of the Parsonian ideal as a kind of moral corrective to "asymmetric" biomedical power. With "informational asymmetry," as he called it, Arrow (1963) warned of physicians becoming merchants of a growing stock of biomedical information, using information to "please customers" (950) rather than socially reintegrating the sick in the Parsonian sense. Arrow referred to the ills bound up in this informational asymmetry as "moral hazard."[17] In such a sys-

15. Indeed, treatment disbursements may be stalled through the state pharmacies. As a result, treatments are interrupted, compromising adherence and health outcomes. Some people die before a final decision is reached. See Biehl et al. (2012).

16. Social scientists for many years have critiqued the sick role as facilitating unchecked biomedical authority; its inherent focus on deviance control places too much blame on patients when they do not recover. Lost in the notion of "secondary gain" in which a patient "chooses" sickness over health for a variety of reasons, e.g., is a broader sense of the sociopolitical fields and actors that limit health. We could not have so vast a literature as exists today on "noncompliance" if it were not for Parsons's analysis.

17. Indeed, in the debate over US health reform, progressive economists drew on Arrow's work on information asymmetry and moral hazard to critique the workings of a purely profit-driven health market. They saw that informational asymmetry was at the root of moral hazard, allowing for a nonoptimal and even predatory "social interaction of being sick" (in which the insured use health care even when they are not sick) to evolve. Another facet of moral hazard is revealed when insurance companies take advantage of this situation by increasing the cost of insurance (high premiums) to insured groups, thus driving up the cost of health insurance for everyone else. Such "predatory" processes linked

tem, he argued, "the risks of gaps in medical knowledge and skill are borne primarily by the *patient*, not the physician" (Arrow 1963:967; italics mine).

In analyzing some of the clinical trial environments in which a similar information asymmetry rules, ethical standards have not been enough to eliminate such moral hazard but have only provoked it. In the cases I have shown, physicians, like Kafka's country doctor, may have knowledge of the proper deed but "leave it undone." Arrow (1963) hoped that new social institutions "in which the usual assumptions of the market are to some extent contradicted" could "create guarantees of behavior which would otherwise be afflicted with excessive uncertainty" (967). Here the problem of the sick role was not that it was too fixed or inflexible, as some of its sociological critics would hold.[18] Rather, it was not scripted enough to eliminate the moral hazard stemming from asymmetric biomedical power.

To be sure, an unbearability of "excessive uncertainty" plagues Inês and is buried in her passionate plea, "Take care of me." Her plea poses a series of other empirical questions linked to such excess and how to insure against it. How do patients—be they in a clinical trial, a struggling household, or a litigant and activist group—gain a sense of value of their own participation in the broad political economy of health? How do they resist sacrifice (of themselves or of others) as a predominant political strategy of health-care access? How do they engage chances of recovery as both medical and political realities? Like Inês, the following case involves a patient who sets the terms for what defines the sick role, medical compliance, and rights of access and recovery. It also shows how practices that legitimate disease as a manipulable potential can change as a group of physician-researchers confront the hazards of impermanent obligation and reassert their healing role.

Attempted Exit

Inacio Santos is a 56-year-old former bank employee and public servant residing in a small town in Brazil's interior. I met him in 2008 in a center for clinical genetic excellence at a large hospital in the capital of the southern state of Rio Grande do Sul, where he traveled bimonthly to be medically monitored and to receive clinical care and support from a group of talented clinical geneticists. Since adolescence, Inacio suffered from a rare genetic disorder that had for years gone undiagnosed. The disease is merciless. According to one clinician, "Patients complain of extreme pain and numbness in hands and feet. They usually survive into adulthood but they are at an increased risk for strokes, heart attacks, and kidney failure." Moreover, symptoms of the disease are not age dependent: "A 25-year-old might suffer from end-stage renal failure; a 45-year-old may just be starting on hemodialysis." Often patients have gone undiagnosed because the "disease is unknown to many physicians. Many times, their complaint of pain is brushed off as psychosomatic."

That was fortunately not the case for Inacio. Before coming to this center of genetic excellence, Inacio was under the care of a private endocrinologist in his hometown who took an active interest in his case and provided him with symptom relief and palliative care. Inacio spoke admiringly of him: "When I had the money, I paid, and when I didn't have it, he saw me anyway." Once Inacio landed a steady job as a public servant, half of his medical expenses were paid. Not knowing what disease Inacio had, the doctor "taught me how to live with the disease" nonetheless. The day he figured out that Inacio's affliction had a genetic root and no known cure, he referred him to the center for clinical genetic excellence, a key referral center, which biotechnology companies coveted as a site for multinational studies in the area of enzyme replacement therapy.

When I met him, Inacio was in the midst of navigating a medical and legal quagmire. The clinical trial he had diligently participated in had been stopped abruptly by the sponsors. With the sudden withdrawal of the study drug, he ran the risk of quickly relapsing to a physical state that was even worse than when he began the trial. The clinician-geneticists who had initially enrolled him were desperate to figure out some institutional recourse so as to continue Inacio on the experimental therapy and to protect him from any damages that were sure to come in its absence.

In the past 2 decades, biotechnology companies have increasingly innovated in the field of orphan-disease treatments and breaking new ground (Petryna 2009). For these companies, Brazil was ground zero for testing and market making as companies incorporated the country's constitutional right to health and active judiciary as a path to getting the country to purchase these treatments for its universal health-care system. Indeed, state-purchased high-cost medicines now make up a formidable market in Brazil. Inacio's trial, sponsored by a US biotechnology company, tested the safety and efficacy

to information asymmetry insure that someone will be driven out of the insured pool. See A. Petryna, unpublished manuscript; and Brief Amici Curiae of Economic Scholars in Support of Defendants, 2010, State of Florida, by and through Bill McCollum, et al., Plaintiffs, v. United States Department of Health and Human Services, et al., Defendants, Case no. 3:10-cv-91-RV/EMT. For a different take on informational asymmetry in terms of power differentials and the importance of knowledge flows in global health, see Feierman et al. (2010).

18. Within midcentury medical sociology, Parsons's structural-functionalist approach to health-care systems and his theory of the sick role were the subjects of considerable debate. For example, he took multiple empirical questions—e.g., the decision to seek care or the obligation to comply—and made them normative. The work of several scholars shifted the field's gaze from the macrolevel "social system" to microlevel individual social interactions (Conrad 2007; Hafferty and Castellani 2006) and developed complex notions of patienthood that can partly account for the novel illness experiences above. In particular, Anselm Strauss, Erving Goffman, and Eliot Freidson—three prominent mid-twentieth-century sociologists trained at the University of Chicago in the school of symbolic interactionism—each took day-to-day interactions between individuals as a point of departure for their sociological work on patienthood.

of a new therapy for the disorder that he was now experiencing the advanced stages of. Inacio was an ideal candidate for the trial as defined by its protocol's strict enrollment criteria: his renal disease was advanced and never treated. In earlier-stage trials, the therapy had proven to be somewhat successful in stopping the progression of renal failure, and so from both a study protocol and patient perspective, it made good clinical sense for Inacio to be on the trial.

All who knew Inacio considered him to be a highly compliant patient and trial subject. He was motivated to live: "At my age, most people with the disease were already dead or had killed themselves," he told me. Yet while his seasoned clinicians were excited about the possibilities of finally offering their patients something more than just an accurate diagnosis of their genetic ailments, they were also extremely cautious about hyped claims of efficacy. "It is a new world," said Dr. Maria, who was an innovator in palliative and rehabilitative care. And if the drug worked, there would be other problems: "I think we are bringing new things from genetics to Brazil's universal health-care system. But to guarantee treatment access and to follow up on the effectiveness is very problematic."

Clinicians told me that the experimental drug worked well for Inacio—in fact his renal disease markedly improved, and the drug's clinical efficacy for this patient was absolutely clear. But its effectiveness—in the real world Inacio was living in—would be a whole other matter. The sponsor, who had agreed to provide medication for 2 years, withdrew the study drug midway through the trial. The clinicians who worked closely with Inacio learned about this "right to withdraw" too late. Much to their dismay and horror, they discovered that a clause stipulating the sponsor's right to withdraw the drug at any time was written into the consent forms that the patients signed or fingerprinted. This "right," they learned, apparently was a last-minute concession that the trial sponsor had extracted from the center's director, who thought that it was better to concede rather than risk losing important resources that the trial would bring. The reason for the withdrawal was market related—a company representative hinted to the clinicians that Brazil was too slow in registering the drug for countrywide sale. Company lawyers actually instructed patients about how to sue the state for treatment access and encouraged them to form a patient-activist group to pressure the government to buy the needed drug (its cost is roughly $200,000 per patient per year). Here therapeutic potential is engineered to mobilize vulnerable people as leverage for the pharmaceutical industry. This effort failed. Later, I learned that the company running the trial had been sold. Whatever had led to the withdrawal, clinicians knew that their advanced-stage patients' conditions would deteriorate owing to the lack of the drug.

One sad irony in this story so far is that although the drug had worked well for Inacio, he did not know himself how well it actually had worked. Owing to protocol, Inacio could not be told. In his self-assessment, he complained of raised stress levels: "I know that when I began treatment, I only had the problem with swelling. But now I have hypertension too." As he made sense of his new medical and legal challenges, he asked himself questions: Should he go home and live out his normal life span? Should he wait, in hopes of another company stepping in to run other trials? or Should he press his case in an attempt to make the government pay for an unaffordable drug? One of the five subjects who participated in the trial moved to another research unit in another state; two were starting to file legal suits against the state of Rio Grande do Sul; and one, according to their clinician, called weekly, "asking whether we have gotten the therapy." As the interests of clinical research, public health, and biomedical markets swallowed up Inacio's disease and body whole, he tried his best to not be overcome by the drive to have the drug at all costs.

In fact, Inacio was never drawn to the hype of a cure when he enrolled in the trial. He explained his reasoning as follows: "What is research? It is something that can turn out right or not. It is risk. All in life is risk. I understand that quite well. And I decided to enter the study. The dice was cast." I asked him whether the enzyme had improved the quality of his life. His answer was, "I have survived. I made a choice to enter the study. I could have chosen not to do anything, and maybe I would not be talking to you today. But there is no way I can know the actual impact of the study. . . . We exposed ourselves to the drug without knowing if it was or was not going to work. Some benefits the company had. We didn't die." He told me that the only document he remembered signing said "that I was not responsible for paying the bill for anything. For 2 years they even provided me with a full tank of gas." In case the treatment worked, "those patients who were willing to continue were told they were going to have continued treatment until they died." Inacio and other patients couldn't understand how a company had been allowed to begin a trial and could now be exempted from the legal responsibility to provide the treatment.

With his life precariously tethered to a new medical commodity, who was responsible for Inacio's treatment access? Who would pay? How was he actually doing medically? All were open questions. His disease was mapped and capitalized on in all kinds of ways except for the *recovery* way. Yes, I am using a very low bar here; by recovery I mean restoration to his pretrial state of disease. His case was being lost in the cracks of a clinical research enterprise whose ethical labor was divided and that shifted risks to those who were not necessarily in a position to flag them.

Like Inês, Inacio resisted becoming a patient-litigant at first. In fact, he said he was ashamed of taking on that role. Finally, by joining a class-action suit against the state, the question of Inacio's treatment was temporarily settled when the highest court in the state of Rio Grande do Sul, through majority opinion, required the drug maker to continue providing the treatment to those who did not have the means. The drug maker, sensing an impending media scandal around these

patients, finally conceded and provided treatment for some patients.

When I spoke to him recently, Inacio told me he was hard of hearing and had experienced five small strokes in the past 3 years. His physician was helping to organize his medical paperwork to obtain back taxes that were owed to him because of his disability status. His disease had progressed far more rapidly than those in his cohort of clinical trial subjects. Of the five patients on the trial, three were now obtaining their medicines directly from the manufacturer, and two were receiving it from the government.

Conclusion

In diverse settings the project of health has progressively been displaced from the clinic and the doctor-patient relationship to precarious paramedical settings that themselves enact distinct moralities that limit patients' access to the sick role only to privilege some other role (such as trial subject, activist, patient-subject, patient-litigant). As this essay shows, there is nothing certain in the doctor-patient relation as the legal and economic bases for dispensing or triaging care and ethical rationales for withholding treatment unleash their own kinds of hazards. At stake is how patients, the unreflected-on collective in these settings, make sense of these conflicting values and enact therapeutic potential and a politics of recovery not only in clinical but also in juridical and experimental settings.

The sick, perhaps like never before, are being confronted with the full cost of their survival. At the same time, recovery has become much more idiosyncratic and unpredictable or much less guaranteed or even calculable by design. In Brazil, for example, information about right-to-health rulings for individual patients is not traveling up the state administrative chain to effect systemic political change or create a sense of permanence of obligation. The same cases can be litigated and relitigated so that rights never get bureaucratically fixed. Recovery from disease, actual recovery—which involves continued access to proper medicines and unbroken care or access to state health guarantees—entails new problems that are beyond biomedicine, but that also pose challenges to its ethics, expertise, and scope. Inês's and Inacio's "expertise" suggest ways that the sick must summon the sick role within nonoptimal medical settings. The fine-grained social realities of patients on whom the burden of recovery lies and their subjacent sociopolitical worlds beg for analytic attention that would allow for such people-centered evidence to add up and matter publicly beyond the rhetoric of human rights or individual consumer choice.

If the mastery of the "social interaction of being sick" was staged largely within the confines of an ideal doctor-patient relationship, today the fields in which patients enact that social interaction in order to obtain care are far more complicated. It is striking that although Inacio's initial therapeutic agent from the interior did not have any medicines for him—he did not even have a diagnosis—he did not lose sight of the cure: "He taught me to live with the disease," Inacio told me. Such a "cure," however, was an impossibility in the clinical trial setting that gave him hope and even stopped the progression of his renal failure. But because of the impermanence of obligation written into the trial's very protocol, his injury became the scene of a litigious public health trial. And every professional around him, no matter how caring and capable or narrowly self-interested, became "complicit" in the mismanagement of his disease.

The 12% higher death rate experienced by cancer patients among the uninsured means that they will have encountered a multitude of discriminations, sporadic treatments, or denials on their private and perilous paths toward therapeutic potential. More stories can be told about how this all adds up to untold percentages of thwarted recoveries. In politicized fields of transnational medicine, as in the United States, recovery remains somewhat of a black box: a kind of afterthought, highly arbitrary, individual, and even idiosyncratic. This essay illuminates why this may be the case and shows that the burdens of impermanence and high medical costs are shifted to individuals who may or may not be successful in demanding or negotiating care. The real-life phenomenon of patient recovery entails much more than a right to access medical goods or a right to health; it entails a right to exit from disease. The social and political fabrics of Inês's and Inacio's attempted exits speak to the morally ambiguous uses of therapeutic potential that blocked their way.

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