Experimental Futures

Technological lives, scientific arts, anthropological voices

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Pharmocracy

Value, Politics & Knowledge in Global Biomedicine

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grassroots nongovernmental organizations that had earlier mobilized around issues such as genetically modified organisms articulated a more antagonistic stance toward the state. A number of feminists in the consultation were also wary of the state, but it was a wariness borne out of the particular historical experience of the state's coercive family planning programs of the 1970s—a concern with a biopolitical state in which care of the population was articulated as a means of control over reproductive bodies.[19] The question of whether to demand state accountability from the outside or whether to engage in institutional endeavors from the inside was a vexed one that was itself subject to the historical trajectories of politics that individuals and groups brought to the table along with their concerns about unethical clinical trials. Seizing the state is all very well, but what that might tangibly mean is itself a deeply political issue.

Further, a critical question of representation is at stake in the imagining of a people-centered health through elite, globally articulated, largely metropolitan and cosmopolitan civil society movements. Who gets to decide what constitutes people-centered research? What relations with expert biomedical communities would need to be forged to facilitate such a conversation, and on what and whose terms? Often, concerns were voiced that only clinical research in the public interest or in the national interest should be allowed. Who would decide? While a relationship between public and national interest was aggressively posited and pursued by the Indian pharmaceutical industry in relation to the 1970 Patent Act (see chapter 5), what might such a relationship look like in relation to clinical research and clinical trials? Particularly vexed were questions about whether and on what terms clinical research should be allowed on vulnerable populations. How one might consider the articulation of the need to protect the vulnerable from clinical research (even as a component of people-centered research would necessarily involve ensuring that research was conducted on diseases and conditions afflicting the most vulnerable) provides particularly difficult and poignant considerations for a representative politics.[20]

All of this constitutes a fraught, tenuous, and contradictory space for the articulation of a democratic politics driven by civil society and in concert with the judiciary. But the state can also be seized by corporate capital to become an investor-state, which is what is imagined as a corporate horizon of the politics in TRIPS-plus arrangements such as the Trans-Pacific Partnership Agreement (see chapter 5). A contradictory democratic politics to seize the state seems infinitely preferable to one that cedes ground to its appropriation by corporate capital.

A FINAL POSTSCRIPT ABOUT HEALTH

As a book about pharmaceutical politics, this was meant to be about health and its reconfigurations as it gets appropriated by logics of capital. Yet it has ended up in equal measure being about the political as it gets constituted in contemporary India, its explanations resting, if provisionally, upon questions of the democratic. Indeed, my linkage of the political to the democratic is a conscious conceptual move away from a lineage of social theory about the contemporary life sciences that, following Michel Foucault, articulates the political to "life itself."[21] Even as pharmaceutical politics in India are repeatedly overdetermined by questions of health and illness, life and death, life itself suggests a sacralization of such politics that does not do empirical justice to the stakes of the political as they emerge in the domains that I am concerned with.[22] Yet of course health matters, not just as a structural abstraction but in deeply embodied, subjective, and experience-proximal ways.

My father passed away from stomach cancer as this book was under review. He was virtually asymptomatic; only a stomachache that did not respond to treatment for gastritis led to the sequence of tests that diagnosed the cancer. He was immediately hospitalized for a total gastrectomy, in a private hospital in Chennai. He was operated upon by the city's most renowned gastric surgeon. He was recovering well from his surgery and due to be discharged in a couple of days, though the biopsy of his stomach suggested a cancer far more advanced than we had expected, with poor prognosis. One evening, his oxygen levels suddenly started dropping precipitously. In spite of desperate attempts to revive him, he had a sequence of cardiac arrests. Within an hour, he had passed away. I had spent nearly a decade researching and writing about the politics surrounding an anticancer drug, but nothing prepared me for the visceral proximity of the disease, even though this encounter with it was all too fleeting. I miss him.

There was no evident malpractice on the part of the hospital. A cardiac arrest can happen to anyone, and this one was possibly caused by a pulmonary embolism. My father had all three major risk factors—old age, postoperative, cancer—for developing such an embolism. Nonetheless, my family and I have felt a lack of closure, an inarticulate anger, toward the hospital. As a former government employee, my father's surgery had been approved for reimbursement by the Central Government Health Scheme. Yet the hospital decided that the amount approved was insufficient and refused to conduct any preoperative tests or even attend to him until we changed his status to a private, full-paying patient. They did not deign to inform us of this, however; so he spent his first day in the hospital wondering why no one was coming to see him, already

worrying that this was a bad omen. Since he had been a smoker for five decades, the doctors knew (and constantly reminded him) that their biggest concern was his poor pulmonary function. Yet not once did a pulmonologist deign to see him, either before or after his surgery. When we insisted upon the routine pulmonary tests that needed to be conducted before he could be considered fit for surgery, the pulmonologist responded, "If they want to see me so badly, let them come to my department and I'll see them." And so after a morning full of strenuous cardiac function tests, he tottered over to the pulmonologist, utterly exhausted; we had to obsequiously plead with the pulmonologist to conduct the tests. When he was transferred to his ward from the intensive care unit after his surgery, the surgeon asked the nurses to ensure that oxygen supply be constantly available to him; it took an entire day for it to be arranged. The day before he passed, the consulting doctor on morning rounds asked the nurse to have an X-ray taken; when he returned for evening rounds that day, the X-ray still had not been done in spite of our constantly badgering the nurse. At one point she helplessly proclaimed, "We are trying, but the radiologist is not coming." Once my father passed away, the hospital ensured that the money owed for his surgery and hospitalization was paid before his body was released. Not once did any of the doctors follow up—let alone to condole, but even to explain what had caused his death. It was only when members of our family reviewed the sequence of events that we concluded that it might have been because of an embolism.

All the while, relentlessly, closed-circuit TV screens around the hospital blared with public relations announcements, as the hospital owner's son bleated on about how the only thing that mattered at this hospital was the care of the patient. And indeed, this hospital was a major destination for medical tourists from around the world. A French couple in the room across from our father's stood with us in the corridor, in sympathy and horror, during those last moments when futile attempts were made to revive him. In those few days, my family and I experienced a personal tragedy, but also felt the limits and apathies of elite profit-driven private medical care in contemporary India.

The structural analysis that I have developed in this book seeks to highlight the differentiations of global biomedicine. From that perspective, the case of clinical research on marginalized populations, or denial of access to medicines to those who cannot afford it, represents one kind of limit. But I bring up the case of my father in the conclusion to this book as another kind of limit—the limits that the experiential dimensions of health pose to structural political considerations. When the first suspicions of cancer were voiced, I found myself wishing that if my father had to have cancer, that it might be gastrointestinal stromal

tumor, which could be treated by Gleevec. It was not. After the surgery, we asked for his resected sample to be tested for her-2, the marker that manifests in certain breast cancers but also in a subset of gastric adenocarcinomas, in the hope that a her-2-positive diagnosis would open up the possibility of treatment with Herceptin. Before the results could come in, he had passed. Nonetheless, the developments of targeted anticancer therapy beckoned to us as a genuine possibility, inscribing us if all too fleetingly into a political economy of hope (Good et al. 1990; Novas and Rose 2005). Needless to say, structural considerations are always present in such an inscription, which would not have been possible had we not had the capacity to pay—for his surgery, for the tests, and indeed for treatment in a private hospital in the first place. Indeed, knowing full well the likely apathies of private medical care in India, it still seemed like a preferable and more comfortable option than being treated in a more democratized public hospital.

One can think easily about the relationship between health and capital (in the argument of this book, in terms of the appropriation of the former by the latter). One can also think easily about the relationship between capital and democracy (in the argument of this book, the severe limits placed upon the latter by the former, especially in its corporatized, financialized form). But it is harder to think across the gap between health as deeply experiential and embodied, operating at the level of intimate relations of care, and the democratic as structural, differentiated, and operating across scales that extend up to the global. Experience proximity humanizes the stakes of a politics of health and illness, even as it blurs structural and situational distinctions. How does one think about health across this huge scale from experience proximity to distance, in ways that are sensitive both to the deeply individualized stories of suffering and loss that are felt across contexts, and to the longue durée and spatially differentiated structures that result in international and intranational divisions of health? A story that simply creates a hierarchy of suffering based on structural inequity is as insufficient as one that fails to take structural inequity into account in its attention to the individual narrative.

One solution to this conceptual and methodological challenge is to begin with the experience-proximal narrative and situate it across structural contexts. This is a strategy that has fruitfully been employed by medical anthropologists. But the relationship between the individual (or even collective biosocial) experience of suffering and its rendering in structural terms is not just a theoretical question; it can also be an intensely political one. Hence the gap I am referring to is something more complex than one between the personal and the political.

For instance, the battle to control the price of Gleevec in Korea saw an alliance between leukemia patient advocacy groups and HIV-AIDS groups in the country.[23] However, once Novartis offered a compromise that involved them subsidizing the cost of the drug for patients while maintaining the actual price of the drug, differences of opinion arose among these allies. Leukemia groups were happy with the compromise because it would ensure easier access and availability of the drug for suffering patients. Groups for HIV-AIDS were not, because what was at stake for them was a principle of drug pricing policy, a structural concern that would go beyond the availability of a single drug for a single suffering group of patients.

Capital literally operates within such cracks that emerge between experiential and structural politics of health and illness, prying them apart. Sometimes capitalist interests are adept at sprinkling a good dose of ethics into the mix while positioning their solutions as win-win, as Novartis managed to do in Korea, and as it tried and failed to do in India as it attempted to institute an ethical monopoly through GIPAP (see chapter 4). When it can, capital simply uses its power to coerce (as in the case of the TPP, where the interests of corporate capital are underwritten by the geopolitical power of the American state). At other times, it walks away (as in the case of PATH's refusal to engage Indian actors in the HPV vaccine controversy).

The empirical scales at which the capitalized politics of health operate are often simultaneously too close and too far to easily allow for a simultaneous conceptualization of the experiential and the structural, except occasionally in situational and contingent fashion. Across these scales, lives continue to be lived, loved ones continue to be lost, and health and democracy in all their contradictory complexity remain very much at stake. The problem space of pharmocracy is as immediate and proximal as it is global and dispersed.

NOTES

INTRODUCTION

1. Conversation with the author, Qazi Camp, Bhopal, November 23, 2011 (translated from Hindi).

2. Satinath Sarangi, conversation with the author, October 31, 2012. See also Hanna (2006).

3. Yusuf Hamied, interview with the author, August 28, 2008.

4. Interview with the author, November 2, 2012.

5. Current industry estimates put the cost of developing a new drug molecule in excess of $2 billion, with a failure rate of nearly 80 percent. While such figures have been disputed in some corners, they are widely accepted and form a basis for the justification of patent monopolies and high drug prices in the United States. I discuss this in greater detail in chapter 1, and unpack the ideology of innovation that underlies assumptions such as these through the course of this book.

6. Gramsci developed the notion of hegemony through a series of observations, many of which were recorded when he was imprisoned by the Italian Fascist government in the late 1920s and 1930s, and subsequently compiled into his famous *Prison Notebooks* (Hoare and Nowell-Smith 1971). Therefore this is not a term that he describes with a single definition, but is rather a problematic that he developed through fragmentary writings on a range of contemporary political issues over a number of years.

7. Even though I am uncomfortable with the term *harmonization*, I use it here as an actor's category that describes the processes I am interesting in unpacking.

8. I am referring here to pharmaceutical clinical trials, that is, the conduct of clinical trials to approve new drugs for market. There are many other forms of clinical research that may not be about drug approval: for example, epidemiological, outcomes-based public health research. While it is important to distinguish between the two, it is not always easy to make clean-cut distinctions (see chapter 2).

9. Important ethnographic work describing the rise of the CRO industry in the United States and globally includes Adriana Petryna's (2009) *When Experiments Travel* and Jill Fisher's (2008) *Medical Research for Hire*. Petryna is especially concerned with the globalization of clinical trials, a process that started in earnest in the mid-1990s, and the consequent "ethical variability" that has emerged in the conduct