PHARMACEUTICAL CARE, PUBLIC EXPERIMENTS, AND PATIENT KNOWLEDGE IN THE BRAZILIAN PUBLIC HEALTHCARE SYSTEM

by

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Thesis submitted to

the Department of Anthropology, Princeton University

in partial fulfillment of the requirements for the degree of

Bachelor of Arts

April 29, 2010

Declaration

I hereby declare that I am the sole author of this thesis.

Alex Kerbel Gertner

To Leo with love

Acknowledgments

This research is funded by the Adel Mahmoud Global Health Scholars Program of Princeton University's Center for Health and Wellbeing.

I must firstly acknowledge all my informants for giving their time and sharing their experiences. I consider myself very fortunate to have had an opportunity to explore the field of anthropology under the guidance of such a brilliant group of scholars. Therefore, I sincerely thank the Department of Anthropology faculty, in particular John Borneman, Carol Greenhouse, Rena Lederman, Alan Mann, and Janet Monge. Being part of this departmental community has been a source of joy, fulfillment, and growth. I must thank, then, the backbone and guiding light of this community, Mo Lin Yee. I would also like to acknowledge some particularly special graduate students I have had the pleasure to meet during my stay, namely Leo Coleman, Eva Harman, Peter Locke, Ari Samsky, Jamie Sherman, and Saul Schwartz.

This thesis would not have been possible without the support, encouragement, and understanding of my friends. I am especially grateful to Sonya Bishop, Dion Bubar-Hall, Josh Franklin, Suvi Gross, PJ Henley, Matthew Hooper, Miguel Sansalone, Mariana Socal, and Pamela Usukumah.

I would not be here today without my family. I must thank my parents for their hard work, my brother Leo, to whom this thesis is dedicated, for his continuous support and companionship, my grandparents for their care and generosity, and my many cousins for humoring the youngest of the bunch, who was so eager for their company and esteem.

There is no way to fully acknowledge the generous, invaluable, and multi-faceted support of João Biehl and Adriana Petryna in this and other endeavors. Professor Biehl has taught me the force and limitless possibilities of anthropology, and I am forever grateful. When it comes to this particular project, Professor Biehl acted as my adviser, providing patient support, faithful encouragement, and challenging criticisms that not only improved this thesis immeasurably but expanded my thought and understanding within the field. I am certain that Professor Biehl's lessons and example will continue to be guiding principles for me in future endeavors, regardless of what they may be.

Finally, I thank God, the most stable, precious, and forgiving force in my life.

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Introduction:

The Demand for High-Cost Treatments

Blinded by Technology: The Disconnect Between Evidence, Care and Health

Emerson Alencar, now in his 50s, worked from age 12 as a ticket taker on public buses. At age 18, he was promoted to bus driver and worked as one until 2004, when his treatment for hepatitis C made him woozy behind the wheel and he took medical leave. The treatment ultimately proved ineffective, as it does for about half of patients, and had the added effect of leaving Alencar partially blind in one eye. As a result, Alencar was unable to renew his bus-driving license and lost his job.

Alencar lives in a poor suburb of Porto Alegre, the capital of Rio Grande do Sul, Brazil's southernmost state. The streets in that area have no signs to aid the occasional anthropologist. On the way to Alencar's residence, the taxi driver and I asked several times for directions. People stopped, looked far into the distance, one way and then the other. Then, perhaps realizing it was a piece of information they neither had nor needed, turned back around and shrugged happily at us.

Alencar is one of over 300 patients who receive treatment for hepatitis C infection at CAMMI (*Centro de Aplicação e Monitorização de Medicamentos Injetáveis*), a novel evidence-based treatment center for hepatitis C in Porto Alegre. At the moment, hepatitis C is treated with ribavirin, an anti-viral, and one of two possible forms of interferon, a type of naturally occurring immunological protein. The older type of interferon is termed conventional interferon and is publicly produced by the Brazilian Ministry of Health and is, thus, cheaply available. The newer form is pegylated interferon.[1] Two forms of patented pegylated interferon are produced, one by the F. Hoffman-La Roche under the

brand name Pegasys and the other by Schering-Plough, now a subsidiary of Merck & Co., under the brand name Pegintron.

The World Health Organization (WHO) estimates that 3% of the global population is infected with the hepatitis C virus, representing 170 million chronic carriers (EASL 1999), over five times the estimated global HIV prevalence of 33 million (UNAIDS 2007). In Rio Grande do Sul, a state with roughly 11 million inhabitants, the number of people infected with hepatitis C virus may be as high as 539,000.[2] These estimates are highly uncertain, however, as surveillance of the epidemic is far from robust (Shepard et al. 2005). In addition, hepatitis C treatment is expensive, and outcomes of treatment vary greatly, with as few as 42% of patients in some circumstances undergoing a sustained virological response at the end of treatment (Digestive and Liver Disease 2010). A sustained virological response means viral levels remain below detectable levels and is frequently referred to as a cure, though viral levels may rise again in the future.

Treating all infected individuals is beyond reach of the state of Rio Grande do Sul's infrastructure and budget. At the same time, hepatitis C, as the head of one of the largest hepatitis C non-governmental organizations (NGOs) in Brazil puts it, is "a disease in extinction." Since blood screening has been put into place, the rate of new infections has been decreasing in many countries around the world, though complications relating to hepatitis C are likely to increase as the infected population ages (Shepard et al. 2005). "In 30 years, there will be few people left to treat,"[3] the head of the NGO told me. This thesis explores the political, medical and experimental economies of care that are formed as a state with limited resources and knowledge is activated to implement a complex and

high-cost treatment. Which public health practices, conceptions of health, forms of experimentation and approaches to care emerge through the treatment of this "disease in extinction" and what do these reveal about the state of global health science, the goals of public health policy, and the effects of treatment on patients inside and outside of the clinic?

Alencar believes he became infected when he had surgery in his 20s and needed a blood transfusion. He discovered the infection in 2003 through an unrelated medical procedure. Alencar began treatment with pegylated interferon in 2004. The treatment in CAMMI lasts 48 weeks and costs the state about 15,000 dollars per patient (Amaral et al. 2006). After the failed treatment, Alencar's doctor prescribed him a longer treatment regimen, 72 weeks, hoping it would be effective. Treatment at CAMMI is dictated according to an evidence-based protocol prepared by the Ministry of Health. The 72-week regimen broke with the state's evidence-based protocol, according to which Alencar was no longer eligible for treatment. Though Alencar has private insurance, hepatitis C treatment is only available through the public health system, and the state denied his request for re-treatment.

The Brazilian public healthcare system came into being with the 1988 democratic constitution and was in part the result of a movement for sanitary reform originating in the 1970s (Campos 2007). In part as a result of physicians' demands to continue operating with autonomy from the government, the public healthcare system came to operate largely through reimbursement of private healthcare providers. The paradoxical confluence of social service expansion and a neo-liberal approach to governance meant that the state's involvement in public health increased as health care providers saw an

increase in business (Campos 2007). In 1999, 66% of Brazil's 7,806 hospitals, 70% of its 485,000 hospital beds, 87% of its 723 specialized hospitals, and 95% of its 7,318 diagnostic support and therapy establishments belonged to the private sector (PAHO 2010). Rather than facilitating efficiency, evidence suggests Brazil's approach to healthcare provision has resulted in chaos and corruption within the system while benefitting transnational corporations and consultant firms (Homedes and Ugalde 2005). In addition, the country's institutions are ill equipped to regulate the complex health system (Campos 2007; Homedes and Ugalde 2005).

When it comes to incorporating new technologies into public healthcare systems, high-income countries, such as the United Kingdom and Australia, have lengthy and detailed guidelines on the use and application of economic analyses in technology appraisal (NICE 2007, PBS 2008). In contrast, the Brazilian Ministry of Health's guidelines offer little more than general suggestions on what kinds of studies should accompany proposals, saying nothing about how these studies should be conducted, according to what standards or best set of practices (Ministério de Saúde 2006). Thus, even as several developed countries with public healthcare systems are strengthening public institutions, Brazil exhibits weak and inconsistent regulatory practices.

The person largely responsible for CAMMI's creation and its "evidence-based" approach is Dr. Paulo Picon, the technical director for pharmaceutical policy in the state of Rio Grande do Sul. In 2000, Picon began developing evidence-based protocols for high-cost treatments, such as the one for hepatitis C. In her book *When Experiments Travel: Clinical Trials and the Global Search for Human Subjects*, anthropologist Andriana Petryna skillfully explores Picon's effort in light of a growing global clinical

trial industry and search for research subjects (Petryna 2009). As she notes, the protocols were created for high-cost treatments and were intended to "provide guidelines aimed at ensuring widespread consistency in their administration and optimally effective uses" (Petryna 2009:149).

Picon, who is also a professor of medicine and directs clinical effectiveness research at Hospital das Clínicas, the federal hospital in Porto Alegre, proposed the creation of "Centers of Clinical Effectiveness" for particular diseases. "The centers implement the evidence-based protocols towards the end of improving treatment outcomes while aiming to reduce public costs," Picon told me during an interview in his office at the federal public hospital in July of 2010. In a scientific paper about CAMMI's creation and operation, the center is credited with saving approximately 750,000 dollars a year in medication purchases (Amaral et al. 2006). In addition, the centers provide places in which to conduct studies on clinical effectiveness of treatments. CAMMI, one of the first of such centers has become the site for important research on clinical effectiveness of treatments. In light of weak regulatory practices and a decentralization of public healthcare services beginning in the 1990s (Campos 2007), the use of medical technologies can be fiercely and meaningfully contested in local spheres of health provision.

Though Alencar was one of the unfortunate patients who did not respond to treatment, he praised the form of care he received at CAMMI. "The staff is 100%. They cared for me." Karina Amaral has been CAMMI's director since its inception and has contributed more than anyone else to defining the form of care provided in CAMMI. Amaral, who is trained as a pharmacist, recognizes the importance of "rational-use" of

medications that justified CAMMI's creation. However, she ranks cost saving as the least significant of CAMMI's accomplishments. "We are not here to save money but to care for patients," she told me. Amaral's own motivations for involvement in CAMMI had more to do with putting in practice a pharmaceutical form of care, that is, involving pharmacists directly in treatment. Amaral emphasizes the role of "humanization" of treatment in care. "The humanization of treatment is a new movement within the public healthcare system and is fundamental to treatment. Pharmacists can play a greater role with patients since doctors are already overburdened. I am proud to be a pharmacist and do what I do."

Thus, CAMMI arises out of a dual push. "In developing clinical protocols the Ministry of Health joined the international movement of evidence-based medicine and showed a commitment to the most recent understandings of pharmaceutical care," Amaral and Picon wrote in the scientific paper concerning CAMMI (Amaral et al. 2006:20). One the one hand, CAMMI represents an attempt to implement evidence-based medicine in order to improve treatment outcomes and reduce public costs, while generating evidence concerning treatment effectiveness. On the other hand, CAMMI is the site for implementation of a pharmaceutical form of care that is sensitive to patients "humanity" and that shifts roles of health care providers in treatment and care. At the same time that Alencar did not benefit from treatment, and was denied re-treatment, he was pleased with the care he received at CAMMI.

Alencar's story, while unique, is patterned within macro political, economic, medical, and legal terrains. How, then, did I come to be involved with CAMMI and eventually become Alencar's anthropologist? From mid-June to August of 2008, I

investigated the way by which the Brazilian Ministry of Health incorporates new medical technologies into its public healthcare system (Gertner 2010). With increased pressure to justify decisions and maximize resources in public health, the practice of basing decisions on evidence, rather than relying directly on other bases for policy, such as societal input or commercial interests, has been gaining popularity (Niessen 2000:859). In 2006, the Ministry of Health had overhauled the institutions responsible for the incorporation of new health technologies and began utilizing health technology assessment (HTA) in order make incorporation decisions (Decit 2006).[4]

I conducted participant observation and interviews in a company that prepared health technology assessments for the Ministry of Health. In performing economic analyses, company employees sought to locate/construct from known/measured parameters, a need/demand for the drug within the public system, thus creating a market. The strategic use of uncertainty in health technology assessment allows for the displacement of public health priorities by commercial interests and the supplanting of what is sensibly sound by what is methodologically permissible (Gertner 2010). Having examined how private entities deploy evidence to make cases for technology use, I thought it necessary to follow the technology into the public healthcare system, in order to investigate how the technology continues to be contested even after incorporation, what kind of knowledge it requires and produces, and how it affects patients' health and lived experience as well as the structures of public institutions of treatment and care.

I first came to learn of CAMMI and the challenges of treating hepatitis C when later in the summer of 2008 I went to Porto Alegre to assist with a research project coordinated by Professor João Biehl concerning access to medical treatment through

lawsuits (Biehl et al. 2009). In Brazil, health is a constitutional right, and an increasing number of patients are bringing lawsuits against municipal, state and the federal government in order to obtain the medications prescribed to them (Biehl et al. 2009). We learned that many lawsuits in Porto Alegre were for access into CAMMI. I visited the center one day and spoke with a handful of patients. The patients praised CAMMI and its staff without exception. “It is like a second family here,” one patient told me. I returned to Porto Alegre in the summer of 2009, which is when I met Alencar, in order to conduct an in-depth study of CAMMI.

Alencar’s doctor, Hugo Cheinquer, is the head of the viral hepatitis division at Hospital das Clínicas. He advised Alencar to sue the government in order to obtain the 72-week regimen. The research project into judicial access to medications showed that an average of 1,200 new cases for access to medications was being opened in the state of Rio Grande do Sul every month in 2009 (Biehl et al. 2009). Despite the fact that the 72-week regimen broke with Ministry of Health’s treatment protocol implemented in CAMMI, Cheinquer claims the protocol is outdated and his own prescriptive habits are evidence-based. Virtually all lawsuits for medical treatments include a request for an emergency injunction granting the treatment until the suits, which can take years to reach a final verdict, are concluded. The judge in Alencar’s case granted the temporary injunction, and, at the time we spoke in July of 2009, Alencar was 3 months into the new regimen.

Like many patients in CAMMI, Alencar had not been experiencing any symptoms as a result of his hepatitis C infection before beginning treatment. Though some individuals never require treatment for the infection, the precise long-term effects of

hepatitis C are uncertain, though increased risk of liver disease has been documented (Shepard et al. 2005). Treatment with interferon comes with a variety of serious side effects, however, including severe skin rashes, tooth and hair loss, anemia, fatigue, abdominal pain and depression. Alencar lost partial sight in one eye, could not renew his bus-driving license and, as a result, lost his job.

Brazil's social security agency sent Alencar to be re-trained as a mechanic. Alencar, who has a fourth grade education, said he struggled through the course. "The instructor accused me of not trying." Even so, Alencar completed the course and was certified. He returned to his company but, again, they refused to hire him without a bus-driving license. Mechanics must at times drive buses in need of repair back to the station, he told me. Alencar is proud of his decades of service. He looked for a new job for two years, but found none. Eventually, he tried to retire. "They denied my request but did not help me find a new job. What was I to do?" Alencar again sued the government, this time in order to retire. Once again, a judge allowed him to start receiving retirement benefits through a temporary injunction, pending a final review of his case. In listening to Alencar's story, I was intrigued by the role of the courts as a potent last resort in the provision of treatment and livelihood. Despite the power of courts in deciding these matters and the supposed irrefutability of Alencar's rights, the lawsuits exposed him to uncertain circumstances, in which he was guaranteed treatment and benefits through temporary injunctions that might be terminated at any time.

Alencar lives with his wife, two children and his mother-in-law. He spoke with pride of his son, now 22 years old, who is on his way to being a bus-driver as well. Alencar's wife is a nurse technician, a low-level healthcare provider in the Brazilian

healthcare system. Last year, she won a competitive public contest to receive continuing education, but they couldn't afford for her to stop working. “We have saved some money and she is trying again this year.” They live in a relatively large, flat and open house on one of those sign-less streets. Alencar is again experiencing the full range of pegylated interferon’s side effects. As the photo on his now-defunct bus-driving license reveals, Alencar has lost about 80 pounds since beginning his first treatment with pegylated interferon. He also takes anti-depressants.

Alencar’s disease and his disability, as well his present-day symptomatic existence, were both the result of medical treatments. We are likely to read these as accidental, unintended and impossible to predict effects of medical technology. Through this lens, the medical technology functions in neatly relating evidence, care and health. Evidence informs the use of the technology. Care, which is the implementation of technology, in turn produces health. There is, however, a presumption involved in this reading: that medical treatment produces positive effects and any negative consequences are always accidental. The alternative to this presumption is that medical treatments do produce harms in a systematic, even if not always predictable, way. In this view, the application of medical treatments and the use of medical technologies must be conservatively managed and their complex effects on patients and their lived experience carefully considered, in part, by analyzing these seemingly simple relationships between evidence, care and health.

Public health researchers, healthcare practitioners and social scientists may be “blinded” by the technology as a unifying factor in knowledge-production and treatment practices. Medical anthropology has increasingly moved away from re-theorizations of

the doctor-patient dichotomy, to complex considerations of how people relate to, utilize and make sense of medical technologies "outside the clinic" (Biehl and Moran-Thomas 2009). Through these considerations social scientists and healthcare practitioners can learn what patients already know about disease, treatment and health. As anthropologist Annemarie Mol (2006) writes in the context of diabetic care, "When we no longer foreground effectiveness but shift to the varied effects of treatment, hypoglycemia loses its status as an unfortunate 'side effect' of tight regulation and comes to be recognized as something on an equal plane and thus as something equally important" (412). Care, Mol argues, must not only involve the implementation of technology but also a management of its effects outside relations with healthcare professionals. For Alencar, who did not experience symptoms from his disease, the "side" effects of treatment were central to his physical disease experience and caused devastating disruptions to his economic activities and social life.

Alencar's doctor gave him a copy of a medical paper, published in English, which he said attested to the 72-week regimen's efficacy. Alencar made no attempt to read it, filing it with the other documents relating to his illness. I asked Alencar whether he was certain he wished to continue this longer regimen, given the damage the medication had already caused. "I am not worried. I think the best is to be cured." Even as Alencar aggressively addressed the consequences of hepatitis C treatment, challenging his employer and the social security agency, he accepted his doctor's orders to take the 72-week regimen. Treatment was a decision already made, but dealing with the side effects was a continuous struggle. Without seeming to subjugate himself to any authority, Alencar acknowledged limits to his knowledge. This unknowing was, in a certain sense, a

form of freedom. He could trust the doctor to act in his best interest. At the same time, Alencar continued to seek to provide for himself and his family. If that provision took the form of a lawsuit, when in the past it had taken the form of employment, this was the result of circumstance rather than some form of mobilization or political consciousness. Given Alencar's inability to find employment, his lawsuit for early retirement would likely do more for his health and that of his family than his case for interferon. "Good interventions might well bring substantial improvements, and they might be for the better," Mol (2006) writes, "but they do not bring health" (406). What conception of health, we may ask, is put into practice through technology-centered interventions and lawsuits under the right to health?

Alencar's lawsuits for the 72-week regimen would seem to result out of a conflict between the inalienable right to health and an attempt to restrict treatment in the interest of optimizing cost-effectiveness through evidence-based practices. To complicate matters, however, Alencar's doctor, and others who prescribed regimens that break with the government protocol, also claim their prescriptive habits are evidence-based. As anthropologists Helen Lambert and Stefan Ecks note, evidence-based medicine (EBM) has been one of the most powerful trends within medicine since the 1990s (Lamber 2006; Ecks 2008). In order to "question EBM epistemology," Ecks (2008) writes, we must first "have ethnographic accounts of what EBM does" (S88).

In this instance, the seemingly simple relationships between knowledge and technology, and care and health come under question. "For however well clinical trials might be able to prove or disprove therapeutic claims, and however strong their credentials when it comes to seeking evidence, they have their limits when it comes to

assuring good care" (Mol 2006:406). Mol proposes a form of research that addresses the challenges and nuances of care. "The point of such research would not be *proving* practice right—or wrong. The more interesting and appropriate thing to do is to try to contribute to *improving* them" (Mol 2006:411). What knowledge and practices does EBM ask of and offer to staff and patients? How does it respond to treatment failures and negative effects of medical technologies? What sort of experimentation does it engender? There is no one account of EBM does. Its significance is precisely to be found in how it stands to alter health systems, treatment goals, care practices and patients' possibilities. CAMMI is not only a site of implementation of EBM, but also a meeting place for EBM, the right to health, more humane forms of care and knowledge-producing practices. What kind of knowledge is produced concerning patients and the technology, and how does this knowledge inform care? What conception of health do lawsuits for treatment access put into practice? How do patients understand and experience disease in relation to the effects of the treatment? And what do these practices, experiences and forms of knowledge say about the state of global medicine and the future of public health in Brazil?

Global Health Imperatives

In order to address these questions, I spent early June to the end of August of 2009 conducting participant-observation in CAMMI. I interviewed the staff, patients, public health officials, scientists, and health care providers. In order to critically understand the nature of lawsuits for the right to health, I conducted participant-observation in the Public Defender's Office, where many lawsuits originate, interviewed

state lawyers and patient-litigants. I reviewed CAMMI's data and accessed case documents from patients' lawsuits. Even so, something escaped these efforts. Nowhere did patients have an opportunity speak on their own terms. In the treatment center, there were already hints that patients were pursuing health and wellbeing beyond the hospital doors when they would bring family members to accompany them, when they spoke about the importance of religion or volunteer work, or when they discussed the devastating repercussions of side effects for social relationships and income-generating activities. Disease, treatment, technology and health did not only exist in the treatment center and, so, could not be understood merely within it. I left the treatment center to conduct home visits with patients, to speak with their families, and accompany them to their activities. In all, I interviewed 20 CAMMI patients and conducted home visits with 5 families.

There is in Porto Alegre an opportunity to examine the relationship between knowledge and care, to provide an account of evidence-based medicine through CAMMI's treatment protocol and everyday practices, as well as an opportunity to elucidate evidence-based epistemology through the dispute of two groups of physicians who, while at odds with each other, both claim their positions are evidence-based.
In this thesis, I draw from the understandings of multiple actors in their own words and from scientific and legal materials from several institutions to produce a more complete picture of how evidence, treatment, care, experimentation and health operate. In Chapter 1, I explore the nature of care delivered in CAMMI. In Chapter 2, I move on to the role of evidence in delivering health and how lawsuits for access to treatment alter or counter the model of evidence-based medicine implemented in CAMMI. Side effects, while

peripheral to treatments' provision, are central to patients' experience. In the last chapter, then, I step outside of CAMMI to understand how patients suffer treatment, tame disease, use technology, multiply care and produce health far beyond the treatment center's wall and the medications' biomedical mandate.

Governments all over the world, in the developing and developed world, are struggling with questions of treatment access, medical costs and paradigms of care. This thesis engages the politics of evidence, the dynamics of care, questions of access and rights weighed against resource scarcity and knowledge limitations, as well as the experience of patients inside and outside of treatment. The United States, currently embroiled in a large-scale healthcare reform effort, can learn much from the innovative practices in southern Brazil that attempt to take into account difficult-to-measure factors in care such as compassion, that bring into view complex social circumstances that affect treatment success such as family support, and that consider the effects of real-world circumstance on treatment possibilities through alternative research methodologies.

President Barack Obama has already begun funding comparative effectiveness studies of medical interventions (Conway and Clancy 2009), similar to the types of studies conducted in CAMMI, and has allocated resources to build and expand federally-funded community health centers in 30 states, as well as to develop computerized medical information systems in these centers (The White House 2009). The United States' public health efforts must be particular to its unique circumstances as a large country with a mixed market economy, and a federal system of government. As the United States continues its experimentations with increased government presence in public health, it can learn from Brazil, another large country with a federal government system, a

complex public-private health system and a growing commitment to improve public health through evidence-production and assessment. Using an anthropological approach, this thesis provides an on-the-ground view and critical assessment of how national policies and local efforts interact with larger social realities in an attempt to produce health. The ultimate goal is to allow patients, as guardians and subjects of their own needs and experiences, to speak back to these increasingly global assemblages of knowledge, interests, technology, treatment, and health.

1

Care Beyond Measures

Introduction: Technologies of Care

Sanatório Partenon, the hospital where CAMMI is located, was built in 1951 and was the state's first hospital devoted exclusively to the care of patients with tuberculosis. The tuberculosis treatment policy at the time called for the isolation of patients in sanatoriums, where they could spend years undergoing treatment (Kritski and Rufinno-Netto 2000). Historical accounts of sanatorium life in Brazil describe the patient experience as one of "unhappiness, disappointment and despair" (Antunes et al. 2000: 371).[5]

The main gate of Sanatório Partenon leads to a large open area where I imagine patients once wrestled with their sentences, chatting with fellow patients, perhaps doing minor chores or otherwise sulking without even the desire to think of something else to do. The introduction of better tuberculosis medications in Brazil in the 1970s dramatically reduced the time patients needed to spend in the hospital. Patients are still treated for tuberculosis in Sanatório Partenon. However, these days patients go to the hospital once a week, receive treatment, and are free to leave. The wide-open spaces of the facility are mostly used for parking. A few benches sit empty in unobserved gardens surrounded by parked cars.

Besides altering the patient experience, the advent of better tuberculosis treatment also meant that parts of the hospital could be devoted to other forms of care. In 1983, the state's first case of AIDS was diagnosed in Sanatório Partenon. By 2000, the southern region of Brazil, where the state of Rio Grande do Sul is located, had the highest proportion of pregnant women infected with HIV out of Brazil's five macro-regions

(Brito et al. 2000). In 2006, the state of Rio Grande do Sul documented an absolute prevalence of 16,798 cases of AIDS, of which 7,682, 46% of the total, were located in the capital (SES-RS 2007). Today, Sanatorio Partenon houses comprehensive AIDS and tuberculosis treatment services, supplemental AIDS and TB co-infection services, a vaccination center that provides 16 different vaccines, and a diagnostic laboratory that serves several other facilities.

The provision of HIV/AIDS treatment in Sanatório Partenon is made possible through Brazil's famous universal antiretroviral treatment policy. In 1997, Brazil became the first developing country to adopt a universal antiretroviral treatment policy. As anthropologist João Biehl writes, this policy arose out of a convergence of neo-liberal government reform, novel market practices and potent social mobilization (Biehl 2007b). As Biehl also demonstrates, the mass rollout of these medications was part of a *pharmaceuticalization* of public health, through which public health measures are increasingly conceived of in terms of access and delivery of pharmaceutical products (Biehl 2007a). Through partnerships with NGOs, the Brazilian government was able to extend treatment to some extremely poor individuals, fundamentally altering their understandings of personhood and expanding their life possibilities (Biehl 2007b).

Sanatório Partenon made history once again in 2002, by being the site for the implementation of CAMMI, an evidence-based reference center for the treatment of hepatitis C. Hepatitis C treatment is expensive and its effects uncertain. While tuberculosis medications have greatly reduced in price over the years, and while the government has made a commitment to treat all people with HIV infections, the Brazilian government, just as other governments worldwide, must deal with an increasing demand

for high-cost treatment to treat a plurality of pathologies. CAMMI represents a novel and experimental approach to dealing with this demand by creating a bounded and specialized treatment center within the larger public health system. CAMMI is, in part, a product of new public health strategies on the part of the Ministry of Health that explicitly utilize and produce scientific evidence to inform practices in order to "rationalize" policy and treatment (Decit 2006; Guimarães 2004).

Having passed the empty courtyard at Sanatório Partenon's center on the way to CAMMI, one enters the furthest building on the lot. CAMMI is nothing more than a handful of rooms down at the end of a hospital corridor. On my first day of fieldwork at CAMMI in June 2009, I had arrived just on time for the weekly staff meeting. As we waited for the meeting to start, staff members told me about a *Festa Junina*, a Brazilian celebration for Saint John that occurs at the start of winter, they had organized and held jointly with patients two weeks before. "The celebration gave the patients a much-needed opportunity to let loose," a pharmacist on the staff told me.

The meeting began. Rafaela Alma, the head nurse, brought up what she thought was a very serious matter. Quite upset, she said that some of the new employees had not been treating patients with an adequate amount of compassion and sensitivity. "When the patients come in, they just lift their shirts to get the injection. They don't want to talk." Alma's comment was taken as a serious accusation and led to a contentious discussion. Afterwards, Beatriz Luz, a nurse technician, presented a PowerPoint presentation on the importance of touch in medical care, providing suggestions for how and when to touch patients, a warm handshake or maybe a touch on the shoulder. "Some patients need that hug," she told us.

Over the next couple of months, I came to learn that, despite the prominence of evidence-based medicine in discourse concerning CAMMI's creation and the centrality of the Ministry of Health's clinical protocol to the provision of treatment, the staff was more concerned with instances of care than the politics of evidence. The staff attributed the center's success in large part to their concern and sensitivity and to patients' strength and resilience. In line with the histories of AIDS and tuberculosis, the story of the center, its staff and patients, is one of how a technology can affect and alter disease experience, life possibilities, health system organization, political concerns and public policy through both administrative and judicial means. In this chapter, I am principally concerned, however, with what form of institutional organization and care practices result from the introduction of a novel and highly disputed medical technology in light of the *pharmaceuticalization* of public health, the "rationalization" of policy and local actors' efforts to "humanize" treatment.

A Rational Place to Treat

CAMMI's staff treats patients according to a clinical protocol written by the Ministry of Health and last updated in 2007. In Brazil, private insurance plans do not pay for medications that must be administered in hospital settings. Pegylated interferon is registered as such a medication in the country, so it is provided through the public healthcare system and not by private healthcare facilities. If Brazilian states wish to provide interferon through the largely decentralized public healthcare system, they must implement it using the Ministry of Health's treatment protocol. Thus, hepatitis C

treatment is only available in Brazil through the public health system and according to the Ministry of Health's treatment protocol. Thus, in order to receive treatment, patients must enter the public health system.

The treatment protocol explicitly states its role in "rationalizing the dispensation of medications intended for treatment of the disease" (Ministério da Saúde 2007). The protocol specifies inclusion and exclusion criteria for treatment. In order to qualify for treatment, then, patients must undergo a battery of exams to determine their eligibility, including for many a liver biopsy. The exams culminate in an administrative request to the state health secretariat for treatment. A single physician is responsible for reviewing hundreds of requests. If approved, a patient then enters a waiting list and typically waits a few months for treatment.

What we learn here is that in order to reach CAMMI, in order to access a treatment that is in theory universally available for those who require it, patients must employ a great deal of personal initiative. It is presumed that patients already have access to the resources necessary to access these exams (such as transportation) and already have engagement with medical services that provide them. As we shall also see, patients must enjoy a degree of luck, as nearly all the patients I spoke with reported discovering their infections by chance, through blood donations or unrelated medical treatments.

"They looked for me several times to begin treatment and didn't find me," João Teixeira, a patient at CAMMI, told me. Teixeira, who is now 49 years old, says he used intravenous drugs when he was in his 20s and later became alcoholic. He is sober now, he says, but homeless. "I spend 15 days in one shelter then 30 days in another and so on. I have no way, you see, to take the medication home with me." Teixeira is receiving

conventional interferon, which is administered three times weekly, so patients typically take it home to self-administer. Because of Teixeira's circumstance, the staff made an exception for him so he can receive the conventional interferon in CAMMI. His presence in CAMMI is a testament to the staff's dedications but also to the center's limitations. He better demonstrates the difficulty, rather than the possibility, of treating unstably housed patients in this setting.

A doctor in the federal hospital in Porto Alegre that treats intravenous drug users told me they are never sent for hepatitis C treatment, though they typically have staggeringly high prevalence rates, since it is presumed they will not adhere to treatment. Teixeira says doctors at this hospital initially told him he did not need treatment. He consulted again at a health post where they directed him to CAMMI. Teixeira said he was also in line for five years to receive a leg prosthesis and was recently told the hospital did not have the prosthesis he needed. "It's not just that they are attentive here," Teixeira says of CAMMI, "They try in their way to overcome the deficiencies."

Dr. Paulo Picon, who idealized and coordinated CAMMI's creation, is proud that the center has seemed to improve care and reduce the state's costs with treatment. He also told me, however, that social inequalities are quite difficult to remedy, and he had not devised or implemented an approach to address them. An analysis of the socio-economic status of patients conducted in CAMMI showed that patients are mostly lower middle-class or higher. In Picon's words: "The centers merely reproduce inequalities that exist in society. The most privileged have the most ease of access."

Delivering Value to Patients

Today, Picon frequently explains his efforts through the reference centers in light of work by Michael Porter, a Harvard Business School professor who authored a book with Elizabeth Teisberg entitled *Redefining Healthcare: Creating Value-Based Competition on Results* in 2006. In their book, Porter and Teisberg argue that the American health system suffers from the wrong kind of competition. Rather than simply attempting to cut costs, health providers should focus on delivering value to patients by improving the quality of care. Value is understood as health outcomes per cost. "*Mandatory measurement and reporting of results is perhaps the single most important step in reforming the health care system*" (Porter and Teisberg 2006:7). The measurement and reporting of results allows for the rational revision of practices in order to improve value delivered to patients. Also crucial to their proposal is to measure value over the "full cycle of care," and not merely within a single intervention. A single intervention may be expensive, but over time it may prove its worth. "We converge with Porter," Picon says, "insofar as he departs from the principle that cost-saving comes only after the delivery of value to patients. The way to deliver value is to improve the quality of care through evidence-based practices."

Amidst the talk of evidence-based medicine, rational use of medications and improving the quality of care, the exact source of the cost saving in CAMMI is often lost. Before CAMMI's creation and the implementation of the treatment protocol, patients received interferon from pharmacies and administered it themselves at home. Because interferon is unstable, once a vial is opened, it cannot be re-used, so medication is wasted.

In CAMMI, the staff is able to safely use the same vial for multiple patients, saving medication and costs. This sharing is only possible with Pegintron (produced by Schering-Plough), since Pegasys (produced by Hoffman-La Roche) is packaged in individual syringes. Though the individually packaged syringes may make application more convenient, they do not allow the use of medication that is not immediately applied. Dosages vary greatly with patient weight. This cost saving is more directly and specifically, then, a result of collectivizing treatment. The cost saving that Porter and Teisberg discuss in relation to improved service quality is of a different nature. It has more to do with avoided costs of unnecessary complications that come with low-quality medical service. This type of cost-saving may also be occurring in CAMMI. However, the immediate source of the significant savings that are discursively attributed to improved quality have more to do with the collectivization of treatment.[6]

The treatment protocol also determines which medications and dosages patients receive. There are six hepatitis C genotypes, though only three are common in Brazil. The hepatitis C treatment protocol specifies who is eligible for treatment, what dosages patients receive and how frequently different exams must be conducted. Under the current treatment protocol, those infected with genotype 1, the hardest to treat, received pegylated interferon while those with genotypes 2 and 3 receive conventional. If a patient with genotype 2 or 3 fails to undergo a sustained viral response to the conventional interferon treatment, he may be re-treated with pegylated interferon according to the protocol. A sustained viral response means the virus remains under a certain threshold. Tests are administered at certain intervals during and after treatment to confirm response according to the protocol.

There is no physician seeing patients at CAMMI. The staff is entirely composed of nurses, pharmacists and technicians who carry out the protocol in the everyday of workings of CAMMI. It soon became evident to me that the treatment protocol largely played the role of the doctor. As medical anthropologist Helen Lambert (2006) states, "The encounter between the doctor and the patient in a clinical setting was seen as the dramatic moment when two sets of knowledge confronted each other. This notion might have been plausible at a time when the practicing doctor seemed to be the highest authority to decide on the available evidence. Yet in times of EBM, it is impossible to uphold this" (S87). As the doctor's authority diminishes, three new characters have taken greater importance—the scientist, the public health official and the low or mid-level healthcare provider. Within CAMMI, one can say, the doctor disappears, as scientific evidence becomes the source of authority and the treatment protocol the vehicle for its implementation.

Atul Gawande discusses how there is at once always too much evidence for physicians to keep up with and always too little evidence to know precisely what course of action to take (Gawande 2009). I will discuss in greater depth the nature of evidence in CAMMI in the next chapter. For now, let us appreciate how the protocol is part of a strategy that stabilizes treatment practices given existing evidence, which can open an opportunity for healthcare providers to focus on the provision of care. As we do this, let us not draw too strong a distinction between treatment and care, as they are always part of the same thing. When I speak of care in CAMMI, I am trying to get at *how* the technology is implemented and its effects managed.

Pharmaceutical Care

The narrow hallway that leads to CAMMI with its small windows and the occasional old-looking stretcher reveals the hospital's aged materials and structure. Nevertheless, the place is immaculate and well preserved. Sunlight presses through the slanted openings in the textured glass illuminating the hospital-gown green walls, and, if one arrives early enough, he can witness the cleaning staff working in silent focus, without hurry or hesitation. Halfway down the hallways are eight chairs where patients wait their turn to receive an interferon injection. Some know each other from previous visits and chat and joke, but frequently they sit with their hands in their laps or with a magazine, occasionally looking up and around but not at each other.

I spoke with pharmacist Karine Amaral, CAMMI's director, in the small room that serves as staff break-room, the medication storage area, and the data analysis center. The dynamics of care that take place within CAMMI were not part of its administratively planned creation but a result of Amaral's initiative. "The pharmacists in CAMMI were able to rediscover their profession," Picon told me. "Pharmaceutical care has been talked about since the 70s but rarely implemented, much less in Brazil and much less in the public system. So we have created an environment where pharmacists can engage in the full plenitude of their practice," Picon asserted.

Pharmacist Karine Amaral became teary as she spoke of the importance of caring for patients. To Amaral, the improvement of quality in CAMMI comes from the organization of services, as Picon says, but also the "humanization" of treatment. The effort to care for patients is related to their outcomes through adherence, Amaral says.

"Whichever member of the staff is dealing with the patient tries to welcome and shelter him. It's especially important for this type of prolonged treatment. Many patients are with us for almost a year and if they don't feel cared for, they won't adhere to treatment." Adherence is not merely the patient's individual responsibility to be reached through a rational consideration of his circumstance. In Amaral's conception, adherence is a form of accountability, a check on how effectively the staff addresses the patient's needs. In this construction, the staff and the patient share responsibility for adherence. As a result of interferon's debilitating side effects, dosage reductions and treatment discontinuation are common (Manns et al. 2001; McHutchinson et al. 2002). According to Picon, the adherence rate for treatment with pegylated interferon has risen from around 60% before CAMMI to above 87% within CAMMI.

Patients in CAMMI often complain that the staff is frequently running late with appointments. The straight and sterile look of the hallway and the patients' tense repose is intermittently thwarted by a small figure in a white coat who steps out of the injection room as she calls another a patient. Alma, CAMMI's head nurse, is a small woman in her fifties, with blonde hair and blue eyes. She is always either smiling or seems to be searching for a reason to. Even when she is serious, as in the staff meeting, her severity pivots on a sort of coaxing compassion. As patients came in to receive their injections, she greeted them warmly, hugging many, and immediately asking them about recent events or how they had been feeling. Though the injection itself can be done in a couple of minutes, most patients stayed for ten to fifteen.

CAMMI does not boast of any advanced technology, no electronic reminder of health provider's responsibilities or computerized system for tracking patients or keeping

their information. The injection and interview rooms are actually part of a single hospital room subdivided using movable walls. In these rooms, the effects of treatment, both reported side effects and the results of laboratory exams, are recorded by hand on paper records and filed. On the first day I accompanied interviews with the pharmacist, she was unable to take the patients' weight as her scale had broken. Despite the fact that a single flask of pegylated interferon costs about 300 dollars, the hospital always provides Alma with large gloves that wrinkle around her little hands and catch on corners because small gloves are not in supply. Alma told me that a few weeks before she had accidentally pricked herself after injecting a patient on account of them. She got a hepatitis C exam that showed she thankfully did not infect herself. The staff spends little time nagging or fretting over these annoyances. "Each day is a day," Alma tells me.

I sat in on Alma's appointments injecting patients. The first patient is a fast-talking man in his 50s with streaked blond hair and a sudden and joyful laugh. He brings his latest exams to Alma who files them in his folder. He complains of pains and dry skin. Alma writes these down, to check if they have improved next time she tells me, and suggests an over-the-counter lotion. He lifts his shirt and together they search for a spot near his navel that has not been hardened by previous administrations. Next comes another man, younger and in a stylish T-shirt, nearing the end of his treatment. He holds Alma's small hands as he is leaving and seems at a loss for words. "It was very good to know you and to have support from someone."

Alma takes a few more notes before the next patient. "Some start shy but everyone becomes very affectionate by the end," she says, "This is time they don't have with a doctor." The patients are many and their faces and names start to blend together.

As I am trying to make sense of my notes, Alma escorts in another woman while she explains who I am. The lady promptly agrees to my presence and, as Alma prepares her injection, the woman turns to me, “This isn’t just a problem in the body; it’s a problem in the mind. They talk to us here.”

At one point a former patient stops in to drop off her latest exam, attesting to her positive response to treatment. She compliments Alma who congratulates her; the two beam at each other. One of the last patients looks to be in his early 30s and is having his first injection. He is quiet and suspicious, sitting with his knees together on the injection chair. Alma’s questions into his personal life startle him, and he seems unsure of how to respond. As he leaves, he stops to thank her, still a bit uneasy. In addition to their injections, once a month, patients undergo an interview with a pharmacist where they speak about their side effects and discuss their treatment experience in greater depth.

Patient Perspectives

After observing injections for a few days, I began conducting interviews with patients either before or directly after their injections. Two and a half years ago, Rodrigo Peixoto, a graphic design artist who lives in a working-class suburb of Porto Alegre, was diagnosed with gastritis. At the time of the diagnosis, Peixoto had a lesion on his liver. “My doctors did not take interest,” he said. Another doctor informed him the lesion was not a normal part of gastritis and investigated further, which resulted in discovering the hepatitis C infection. The episode highlights the difficulty in discovering the infection,

which necessitates access to medical care and “interest” on the part of health care providers.

I spoke to Peixoto in a small room the staff lent me to talk to patients before their injections. Now 37 years old, Peixoto believes he was infected through a blood transfusion when he was 17 or 18. All of the patients I spoke with had come across their hepatitis C infection accidentally, through another treatment, a check-up or when trying to donate blood. All patients had guesses as to how they were infected, but none knew with certainty.

Peixoto first underwent treatment with conventional interferon near his home. By the end of his treatment, exams showed Peixoto had undergone viral response to treatment, suggesting the treatment had been effective. Peixoto is one of the 24% of Brazilians who have private health insurance (Viacava et al. 2005). Though the protocol only calls for an exam six months after treatment, CAMMI’s staff recommends patients continue the exams. Peixoto continued submitting to exams through his insurance plan. “I did a new exam and it was as if I had not done anything, absolutely anything.” The new exam showed Peixoto’s viral levels had climbed again. After the failed treatment with conventional interferon, Peixoto was referred to CAMMI to receive pegylated interferon. Whereas conventional interferon must be administered three times weekly, pegylated interferon is only administered once weekly. As a result, patients at CAMMI receiving conventional interferon take supplies home for self-administration, while patients on pegylated interferon typically, but not always, come in once-weekly for their dose. Peixoto, like many others, found the side effects from pegylated interferon more severe than those of the conventional form. He remembers having a fever for three days after his

first injection. Peixoto wondered whether he could continue working and considered stopping the treatment. Subsequent doses have not been as bad, but he still has frequent fevers and says he is “useless” for two days a week.

Despite the side effects of treatment, Peixoto rates the care he receives at CAMMI very highly. “The treatment is VIP, really VIP. It’s as if you are paying for the treatment and in reality it’s free, which is hard to find nowadays.” Patients frequently compared CAMMI to private services in order to communicate its quality. “I’ve usually gone to private doctors through my health insurance. But you know, here through the public healthcare system, a government program, for free, they are better than the private ones,” Sandra Faust, another patient I spoke with, told me.

Faust, who is a homemaker, discovered her infection when she tried to donate blood. The initial tests that are submitted to the Health Secretariat in order to qualify for treatment must be done through the public healthcare system. Faust said the doctor she consulted in the public system did not know which exams to administer and how to prescribe interferon, so he had to call her private physician during the consultation for assistance. Faust was worried about what the service would be like in CAMMI and says she has been pleasantly surprised. Faust’s husband, a driver for the state Department of Justice, accompanies her to her injections. “They have a tenderness with people,” he said of CAMMI’s staff. “There isn’t a day when you arrived and find one of them in a bad mood. They are always treating you well, by your name, with care.” Peixoto echoed the Fausts’ sentiments, “The people who work here are always the same, whether it rains or shines, independent of their personal situations at home. It’s as if we’re dealing with family.”

Alma, the head nurse, tells me one of the principal challenges of providing care is that side effects are usually experienced at home and not in the treatment center. The staff is challenged, she says, to extend the care they provide to other domains patients inhabit. They frequently attempt this by encouraging patients to come with family members. In particular, when patients complain that family members do not understand the side effects, the staff asks patients to bring a family member to the center. "The family member must see that this is real, that it is a profound and intimately devastating experience for the patient. Suddenly, the patient feels impotent. You were something yesterday and today you are not anymore."

"A Protocol of Compassion"

Whereas in psychiatry there has been a fast movement towards community and home-care in Brazil (Biehl 2005), when it comes to hepatitis C, patients are forced into the public healthcare system for treatment. The evidence-based protocol involves a restructuring of authorities of care within the treatment center but another transformation is taking place also. When CAMMI staff attempt "extend care" to patients' home they are, in effect, co-opting family members as participants in health care provision. This co-opting is not, however, a hijacking of social relationships, but an engagement with them that is born out of recognition of their importance for treatment success and, also, out of what must be a sincere concern for patients.

"It's not as if I think to myself, 'I must smile,' and once the patient is gone I say, 'Ah! This patient is such a pain!' It's not like this. It has to be sincere, it has to be true, to

come from the heart," Alma told me in the staff break room. The way Alma interacts with patients is conscious but not calculated. The effort is not only for the patient's benefit. "It is really a kind of therapy for me, an exchange of wellbeing." In this configuration, wellbeing is not something to be had by the patient and worked on within him, but to be exchanged, to be created in that space between him and the healthcare provider. Alma says working in CAMMI involves a transformation. "Sometimes you arrive with things in your head, more tired, more stressed, emotionally shaken. You start seeing patients and you begin to forget. You're no longer that Rafaela from outside, you're the here-Rafaela, and you have nothing else except what's in front of you."

"Sometimes people go into public service because they think it is stable. They do a mediocre job and go home," Amaral, CAMMI's director, told me. Amaral handpicked CAMMI's original staff, looking for providers whose "personality" suited the form of care she intended to deliver. Even as Amaral emphasizes the particularity of personality, which would seem to thwart efforts to reproduce or scale-up CAMMI's efforts, she is actively engaged in setting up new CAMMIs throughout the state. Amaral has already trained the staff of four other institutions in the state who are starting their own CAMMIs. CAMMI's compassionate work ethic is the principal lesson she tries to convey when training other institutions, she says. Alma seems more skeptical about the possibility of sustaining this form of care. I asked her if CAMMI continues to expand, whether they will be able to sustain the same form of care. "I don't think so… Who knows, maybe you can help us with this? Perhaps you can help us write a protocol of care, of compassion. Perhaps a manual of some kind, a book of memories, I don't know…" The reproducibility of the treatment protocol is contrasted with the transient and contingent form of care the

staff works to sustain. There seems to be no clear way to institutionalize care in the same way the Ministry of Health's clinical protocol institutionalizes treatment.

Despite the contingency of this care, CAMMI's patients value it greatly. Peixoto, Faust and other patients particularly appreciate the opportunity to ask questions of the staff during their visits. Peixoto says he has been very irritable on treatment, a common experience, and it has affected his family life. "It's also important to come here and speak with the nurse. She is able to clarify things that I am not able to." Faust says consulting with the staff puts her at ease. "Alma even tells me beforehand what will happen, so that when I'm home and feel something I'm already at ease. I know it's a normal part of the drug. If I didn't have this kind of accompaniment I would be running to the doctor for the smallest things." Discussing the side effects of treatment with the staff helps to normalize these, creating a coherent treatment experience. Side effects are not inexplicable, unnamable or unmanageable experiences, but can become firstly legitimized and then made comprehensible as part of the treatment experience.

"The value here comes from the human resources," Cesar Verício, another patient at CAMMI, told me. Verício is 55 years old, though his burly figure and hearty dark hair speak of a man in the mature vigor on his early 40s. Verício seemed insecure about his position as a patient. "I never got sick. I tried to be an athlete; I never smoked, never drank, never used drugs." Rather than become a professional soccer player as he had hoped, Verício has been a prison guard for 25 years. Verício greatly values being able to receive his injections at CAMMI, as he told me he is embarrassed to do them himself at home or work. "It's hard to find people with good will, who will speak with the ill. It's hard. They have this ease here, they compliment everyone, treat everyone."

Verício struggled to contrast CAMMI with the prison where he works. “What can we control?” Verício asks as he ponders his work in the prison. He then turns his thoughts again to CAMMI, “The discipline here is different. What can we control here? The disease. It’s very different.” Controlling the diseases means distinguishing it from the person, identifying it as a distinct set of experiences. Peixoto, and other patients, compared the staff to “family,” a move that communicates the staff’s dedication, affection, intimacy and understanding, but also breaks open their positions as healthcare providers. In order to control the disease, the patients and staff must move outside of it. Verício notes the staff “speaks with the ill.” Just as the women in the injection room told me, “They talk to us here,” or as Faust’s husband noted, the staff call patients by their names. Whether the disease is something of “the body” or “the mind,” as the woman in the injection room put it, is less important. If we choose to conceive of these as separate, the disease is surely both. The salient point is the recognition of a person outside the disease.

Care at CAMMI, then, is the result of sustained work to engage with patients within as well as outside of their disease/treatment experience. A crucial component of care is the education of patients with regard to the side effects to treatment, which helps create a distinct treatment experience. The involvement of family members helps legitimize this experience and acknowledges the importance of social relationships in sustaining treatment. As I will discuss further in chapter 3, both staff members and patients regarded the form of care they received as crucial to treatment adherence. The care practices are concerted but not calculated; they are always being worked. As anthropologist Annemarie Mol (2006) writes, “Professional care is not a matter of

separating out elements, fixing them, and putting them to use in a linear manner. It is a matter of tinkering, of doctoring, if I dare to reclaim that word from the negative connotations it has acquired and give a positive appreciation to the creative calibrating of elements that make up a situation, until they somehow fit—and work" (411).

CAMMI staff is always counseling patients on how to better adjust to their side effects, through changing diets, light exercise or speaking with family members, for instance. This pliable provision of care exists in contrast to the steadiness of the treatment protocol. While the treatment protocol is informed with scientific evidence from clinical studies, patients are more interested in questioning staff members concerning in the experience of side effects and their consequences for social relationships. Even as the staff members implement the "evidence-based" protocol, they must educate patients with a more people-centered form of knowledge concerning treatment.

Fragility

The form of care provided in CAMMI is highly contingent. Indeed, the reference centers Picon has created are fragile entities. CAMMI is exceptional among the over a dozen reference centers now in existence, from centers for treating Gaucher's disease managing mucopolysaccharidosis to applying botulinum toxin, because it has been formally institutionalized. Most, but not all, of the other centers are created and managed on an ad-hoc basis. The reference centers ease the burden on the public health system, since the responsibility for delivering the high-cost treatments, which are typically complex, is shifted to specialized staff in centralized locations. Operating the reference

centers involves carefully implementing locally drafted protocols and fastidiously collecting patient information. Because the reference centers are not formal institutions, the staff that participates in them volunteers their time to the additional responsibilities the reference centers entail. The reference centers are precious but frail entities.

Though formally institutionalized, CAMMI is not without its own fragilities. Here, the fact that there are no doctors officially working in CAMMI can be read less as advancement and more as a deleterious lacuna. Most treatment decisions are predicted in the protocol, the staff is able to treat minor complications, and major complications are sent to patients' primary physicians. The absence of doctors is frequently communicated as an accomplishment. Nevertheless, questions still arise. Patients may be on the border of qualifying to continue treatment or they may have other pathologies that complicate treatment and so forth. The reality is that a doctor from the Health Secretariat does go to CAMMI every Friday morning to review cases. He does not see patients, merely reviews their information, acting as an arbiter of evidence. He is the same doctor who reviews the administrative requests to enter CAMMI. Neither of these functions is part of the official responsibilities in his position, but if he did not carry them out, it does not seem anyone else would.

When CAMMI began, Amaral and a nurse were its only two members. From 2004 to 2009, CAMMI had been able to expand in part because it had come to serve as the site of clinical trials for the efficacy of a form of conventional interferon developed by Cuba and produced in Brazil. The funding for the government-financed studies allowed for an expansion to around 12 employees, who treated approximately 350 patients at a time. Once funding ran out for the clinical studies of the Cuban interferon in

early 2009, CAMMI underwent a crisis. Without the research funding, CAMMI could not sustain this level of operation. Many of CAMMI's staff stopped receiving salaries and the center no longer accepted new patients from its long waiting list. Employees continued to work so that patients' treatment would not be interrupted while Amaral and Picon appealed to state authorities for funding to sustain CAMMI.

Tarsila Crusius, the daughter of Rio Grande do Sul's first female governor Crusius, has adopted hepatitis C as a personal political project. When funding for the trials in CAMMI ended, Crucius, who worked for the Ministry of Health before her mother's election, negotiated with state authorities to continue funding the center. Under the compromise, however, CAMMI's staff, which had been handpicked by Amaral, would be replaced with employees who had passed public examinations used to allocate government jobs. Only Amaral, Alma (the head nurse), and an additional pharmacist from the original staff remained.

Though the transition preserved CAMMI's structure, it threatened the form of care Amaral had worked to provide at CAMMI. Amaral had specifically chosen staff who she thought could be affectionate towards patients and engaged in CAMMI's mission. The new staff had to be educated in CAMMI's "philosophy," as she called it. Though Amaral complemented the new staff for "really becoming team members," she remained frustrated with the state's decision and tense moments, such as the one during the Friday meeting, occasionally took place. Now that CAMMI has twelve staff-members, Amaral fulfills only administrative duties. "You cannot be listening to the patient while thinking about administrative tasks that have to be done. I miss the caring for patients, but today I can no longer do both things."

Despite the challenges, CAMMI continues to be seen as a success. “We improved the quality of care. We have a 100% patient satisfaction rating, we never again ran out of medication, and the adherence rate has improved,” Picon says, summarizing CAMMI’s accomplishments. However, to say medication never runs out is a bit disingenuous given that number of patients in CAMMI is controlled. The public costs saved with CAMMI’s creation have allowed more patients to be treated, but funding for hepatitis C medications has not risen. Since CAMMI is perennially working at full patient capacity, new patients must go to a waiting list before they enter the center. The consistency of treatment within the center is the other side of the coin from the scarcity of resources to fund treatment for all those outside the reference center who need it. The medico-administrative difficulties in identifying a hepatitis C infection and accessing treatment I discussed earlier, prevent the demand for hepatitis C treatment from rising beyond CAMMI’s treatment capacity. While CAMMI’s accomplishments are not trivial, their presentation is constructed to elide its dire limitations.

Island of Excellence

The reference centers have a complex relationship with the main public healthcare system, at once drawing resources and easing burdens. Fernando Levi, a doctor who has worked both in the public and private systems and who is currently a patient at CAMMI, characterized the reference centers are “islands of excellence” within a health system that is frequently characterized by inefficiency and lack of dedication. I spoke to Levi, who no longer works in the public system, in the glass-covered private hospital where he has an

office on one of the top floors “Anywhere you go in the public system the service is sloppy. In CAMMI the professionals, from the technicians to the pharmacists, are truly engaged.” I asked Levi, who is the former director of a public health institute, if he thought CAMMI’s work ethic could be replicated elsewhere in the public system. He took a long pause. “We have to rethink the service, to value our professionals,” he said and then paused again. “I think it’s possible, but I wouldn't know what more to say about it.”

Levi believes CAMMI’s knowledge-producing practices, which I will discuss in greater depth in the next chapter, are crucial to the staff’s involvement. Indeed, knowledge-producing practices do not merely extract information from CAMMI, but inform the everyday care that takes place in the center. The staff must carefully attend to patient concerns, complaints and clinical progress, even if for the purpose of recording these. Several informants noted that following patient outcomes for knowledge-production purposes encourages staff to be more engaged in their work. Staff members must ask patients about their side effects because these effects must be documented. At the same time, however, as Alma notes, care must involve a sincere concern for patients. The documentation practices offer an entry-point for engagement and an opportunity to cultivate concern. Evidence collection is meant to create the possibility of altering administrative and medical practices to improve treatment, and, as I shall show in chapter 2, evidence production may elide important factors that inform and affect patient’s treatment. However, knowledge-production practices also affect the form of care practiced in the everyday.

Picon struggled when presented with the question of how to extend CAMMI's achievements to the main public healthcare system. "I suppose you would have to have a reference center for every disease," he said quietly as he thought. In their book, Porter and Teisberg propose the integration of multiple forms of care, an approach that runs counter to the possibility of a reference center for every disease. "Rather than building practice units that integrate the talent and facilities required to deliver outstanding care over the care cycle, hospitals and physician groups remain organized along the lines of traditional academic specialties—radiology, anesthesiology, surgery. This not only ensure a disjointed experience for the patient, but makes excellent coordination and communication among the provider team next to impossible" (Porter and Teisberg 2006: 49).

Ultimately, though Picon argues for quality over cost saving, the reality is that reference centers have only been created for high-cost treatments and cost saving is a frequent talking point in his lectures, discussions and presentations. One need not go far to appreciate how poorly integrated CAMMI is with regard to the main healthcare system. One physician responsible for tuberculosis treatment down the hall from CAMMI said the prevalence among tuberculosis patients of hepatitis C was extremely high. "These patients cannot undergo both treatments at the same time, but there is also no effort to have them return for hepatitis C treatment," he told me.

"Today, I'm seeing the question of scaling-up in a more tranquil light," Picon says. Still acting as technical director for the state's pharmaceutical policy, Picon has been working unsuccessfully to have the treatment protocols he developed with his team of doctors and pharmacists adopted at a federal level. "It's not that I am disappointed, I

don’t think so… CAMMI is going to be reproduced in other municipalities and several have already. This is an initiative from the Governor’s Office, which has decided to adopt CAMMI within the hepatitis C strategy. So, today, this is the Governor’s project.” There was a mix of frustration and uneasy excitement in Picon’s tone.

Even as staff members and patients are deeply engaged in a rewarding form of care, the institutions responsible for their provision are fragile. The form of care provided at CAMMI is partly made possible by its separation from the main public healthcare system, as it allows healthcare providers with an opportunity to engage more with patients. At the same time, this separation thwarts the integration of care Porter and Teisberg argue are necessary for delivering value to patients. Institutional restructurings aimed at preserving the center (and its successes) also threatened the form of care practiced there. Institutional forms and care practices are inextricably interlinked. As Levi and others note, so are evidence-producing practices and care. Staff members are uncertain about the possibility of reproducing the form of care they provide, and Picon struggles to scale-up the form of “evidence-based” treatment he is pioneering in southern Brazil given existing regulatory policies and the potent influence of commercial interests in medical practice. Crucial to our understanding of this approach is the evidence produced in CAMMI and other reference centers, as well as the relationship between reference centers and judicial demands concerning the right to health.

2

The Politics of Experimentation

Introduction: Experimentation and Health Policy

The evidence-based reference centers for high-cost treatment in southern Brazil are intended to operate both as treatment centers and sites of knowledge-production. CAMMI, the reference center for treating hepatitis C, was one of the first of these centers. CAMMI's creation, its expansion and even the form of care it provides are all intimately linked to knowledge-production practices and initiatives. Anthropologist Adriana Petryna discusses the role of the reference centers is conducting post-marketing research, that is, evaluating the effects of technologies after they have been introduced into markets (Petryna 2009). Interestingly, one of the main purposes of CAMMI soon after its creation became to serve as the site of clinical trials for the efficacy of a form of conventional interferon developed by Cuba and produced in Brazil. In this capacity, CAMMI is not merely monitoring treatment effects, but utilizing patients as experimental subjects with the end of reducing public costs and strengthening national scientific capacity. While public health officials criticize private medical research as geared towards commercial interests, public science is also highly interested and patients are just as powerless to assert their needs within it. Patients in CAMMI are not only being care for, but also experimented on. In this chapter, I am concerned with the role of evidence and experimentation in CAMMI as an approach to public health.

Cuba has a large external debt with Brazil. In 2003, the federal government sent scientific missions to Cuba in order to explore technology transfer possibilities as a way of repaying debt. From 2002 to 2005, spending on medication in Brazil increased as a percentage of total health spending from 6.35% to 7.86% for state governments, and from

5.39% to 9.11% for the federal government (Vieira and Mendes 2007). Nádia Batoreu was on the first mission. She is the manager for the development of bio-pharmaceuticals at the FioCruz (*Fundação Oswaldo Cruz*), a public biomedical research and development institute. I interviewed Batoreu and other members of FioCruz at its campus, located in Rio de Janeiro and surrounded on three sides by one of the city' most dangerous shantytowns. At the time of the scientific mission in 2003, interferon accounted for a larger percentage of state government budgets than any other exceptional medication and was the medication patients most frequently requested medication via judicial means (CONASS 2004).[7] Batoreu came to discover that Cuba produced its own conventional interferon, and had been for some twenty years.

"Despite stigma, Cuba has extensive experience with cutting-edge technology in the area of bio-pharmaceuticals," Batoreu told me. "Given the challenges Cuba faces, its researchers have accomplished this through nothing less than gymnastics." Batoreu recommended a technology transfer program to allow Brazil to produce interferon and erythropoietin, a protein that controls red-blood cell development and is used to treat the severe anemia that sometimes accompanies treatment with interferon. The technology transfer program began in 2004, and Brazil now produces its own conventional interferon and erythropoietin. The international intellectual property rights regime put in place by the Trade-Related Aspects of Intellectual Property Rights (TRIPS) agreement creates barriers that hamper research in developing countries and limit possibilities for north-south technology transfer (Forero-Pineda 2006). The Brazil-Cuba partnership is a striking and unprecedented instance of south-south cooperation that would seem to thwart this restrictive international regime. The publicly produced interferon is provided to CAMMI

at production cost and, as a result, is significantly cheaper than the commercially available forms. Batoreu reports that since the project's completion, talks have begun with several other developing countries for technology cooperation projects.

Before the publicly produced conventional interferon could be used, however, it had to be licensed by ANVISA (*Agência Nacional de Vigilância Sanitária*), the autonomous government agency responsible for licensing and monitoring health products. In order to be licensed, public health researchers and officials needed to prove the new conventional interferon efficacious in clinical studies. CAMMI became the site for testing this interferon. The funding from FioCruz for the studies allowed CAMMI to undergo an institutional expansion, hiring more staff and treating more patients as experimental subjects. Petryna discusses how the reference center in Porto Alegre for treating Gaucher's disease allowed public health officials to monitor the effects of treatment, ultimately making a case for a lower dosage of medication that reduced public costs without seeming to reduce clinical benefits, thus minimizing side effects and avoiding medication shortages (Petryna 2009). The clinical studies in CAMMI, in contrast, involved testing a bio-pharmaceutical product of unknown safety and efficacy. While ANVISA approved the publicly produced conventional interferon, some, such as Hugo Cheinquer, the chief of viral hepatitis at the federal hospital, and Carlos Varaldo, the head of one of Brazil's largest hepatitis C NGOs, argue it is still inferior to commercially available forms and more studies are needed.

With the conventional interferon technology transfer program complete, Brazil and Cuba initiated a joint project to develop a public form of pegylated interferon. This project represents a new strategic role for public science in pharmaceutical policy. As

anthropologist João Biehl (2007b) shows in his book Will to Live: AIDS Therapies and the Politics of Survival, the Brazilian AIDS program has been able to secure reduced drug prices through reverse engineering of chemical compounds in order to produce generic versions of patented medications. In negotiating drug prices, Brazil acted within TRIPS, the international agreement governing patent rights. Biehl (2007b) discusses how Brazil adopted, as part of broader neo-liberal reforms, the most market-friendly form of the TRIPS agreement into its legislation, allowing pharmaceutical companies to take advantage of extended patent protections. Under the legislation, pharmaceutical companies are frequently able to renew patents by altering some small components of a drug (Petryna 2009). AIDS activists are now contesting this practice in court on the basis that it is not innovation. “This is a new chapter of legal activism. We are working with notions of innovation, intellectual property and monopoly,” AIDS activists I spoke with in Rio de Janeiro told me, “The judiciary is still getting used to these kinds of cases.” These activists, who have been at the forefront of AIDS social mobilization, do not work with individual lawsuits for access to drugs. “We are concerned with access but also sustainability.”

Unlike antiretrovirals, interferons are bio-pharmaceuticals, complex proteins molecules rather than simple chemical compounds. Bio-pharmaceuticals have revolutionized the treatment of several disorders (Covic and Khulmann 2007). The flexible nature of innovation utilized to extend patents for chemical compounds works in favor of the team attempting to develop a public form of pegylated interferon. A generic drug is the same compound as the name-brand drug. Because bio-pharmaceuticals are

large, complex molecules rather than simple chemical compounds, producing a generic version of a bio-pharmaceutical molecule is impossible (Covic and Khulmann 2007).

Rather than attempt to produce a "generic" form of the bio-pharmaceutical, Brazilian and Cuban public scientists are seeking to produce a "similar" molecule, avoiding patent infringement. The different nature of the medicinal compounds allows these public scientists to take opportunity of the flexible conception of innovation pioneered by pharmaceutical companies based on their commercial interests. Clinical trials for the Cuban-Brazilian pegylated interferon are in planning stages and will likely be carried out in CAMMI. If they show positive results, the price of pegylated interferon is likely to fall, allowing for increased access to treatment. In the meantime, Varaldo, the head of one of the largest hepatitis C NGOs, is now on FioCruz's research ethics board. When we spoke in his home in Rio de Janeiro, he vowed that if the clinical trials for the publicly produced pegylated interferon did not meet the highest standards of research methodology, he would sue the government if it attempted to use the drug in treatment.

The pegylated interferon project signals the Brazilian government's entry into the development of bio-pharmaceuticals.[8] "The knowledge and experience gained through this project will be utilized in future bio-pharmaceutical development," Barotreu told me. A new building to house bio-pharmaceutical research, development and manufacture is being constructed on the FioCruz campus. The structure is covered in cobalt-colored bulletproof glass, to protect it from occasional stray bullets from the surrounding shantytown. The conventional interferon technology transfer project allowed for an expansion of treatment through the need for evidence it involved, which meant more patients were treated in CAMMI, and also through the cost-reduction it resulted in. The

pegylated interferon project promises to have a similar effect, but also necessitates engagement with the definition and determination of innovation. The nature of bio-pharmaceuticals and the flexible understanding of innovation pioneered by pharmaceutical companies in AIDS therapies are facilitating the development of a public form of pegylated interferon. While the state reduces its costs and builds its technological capacity, what is the role and value of the patients who are experimented on in order to make these accomplishments possible?

Experimental Citizens

In her book *When Experiment Travel: Clinical Trials and the Global Search for Human Subjects,* Petryna discusses how clinical trials sponsored by pharmaceutical companies become a way to access treatment for patients in desperate circumstances or otherwise unable to access healthcare (Petryna 2009). In the case of hepatitis C treatment in Brazil, a public initiative to cheaply produce a medication necessitated evidence concerning the medication's efficacy in order to authorize its entry into the market. The production of that evidence generated new immediate opportunities for treatment and care within the public healthcare system through the institutional expansion of CAMMI. Once the research funding was exhausted, local care providers struggled to sustain the expansion (see chapter 1). Patients in CAMMI are already embroiled in the experimental schemes that serve national policy initiatives, such as building bio-pharmaceutical technical capacities, and local policy priorities, such as cost saving.

The treatment protocol developed by Picon and later implemented by the Ministry of Health includes a consent form patients *must* sign in order to receive treatment. The form says the Ministry of Health may use information from the patient's treatment as long as anonymity is preserved. In order to receive treatment, patients must submit to becoming participants in research. In the everyday access and engagement with treatment, patients seem to be participating in an exchange: patients submit to becoming experimental subjects, allowing their biologies to become objects of evidence, in exchange for treatment. Within this exchange, the patients effectively give up the right to contribute to the form or function of the evidence. That is, patients never have an opportunity to insert their voices, interests or experiences into evidence. The everyday care in CAMMI is left to its dedicated staff. In the meantime, as part of the government's evidentiary, knowledge and financial interests, patients are made into a captive research population, always available for the next public experiment. Their citizenship, which guarantees them the right to health, also ties them to these policy projects and seals their positions as experimental subjects.

Anthropologist Kaushik Sunder Rajan (2005) has developed the concept of bio-capital, "not only the systems of exchange and circulation involved in the contemporary workings of the life sciences but also a regime of knowledge pertaining to the life sciences as they become increasingly foundational epistemologies for our times" (21). In Rajan's accounts, individuals, through their biologies, are taken up or used in markets that produce or utilize scientific evidence. "The worker's body becomes available to systems of capital—as well as to systems of science—as a source of value generation and as a source of knowledge production" (Rajan 2005:27). The operation of these systems of

knowledge and capital involves the management of future markets and income possibilities. He writes, “both genomic diagnostic tests and pharmacogenomic clinical trials indicate potential future markets: in the former case, by indicating the existence of illnesses that are arriving in the future and, thereby, indicating the existence of a potential market in the first place, and, in the latter case, by suggesting that drugs that have already been developed have safety and efficacy profiles that suggest their potential success on the market” (Rajan 2005:27).

In Rajan’s eager critique of the commercial science and in his construction of biocapital, in which research subjects appear as a powerless class that derives no benefits from participation in systems of knowledge-production, there seems always to be an implicit promise of a clearly identifiable and pursuable public interest. If only the state were to reinvent itself and wrestle knowledge-making apparatuses away from private interests, Rajan always seems to be suggesting, a more just and equitable science would be at hand. In CAMMI, the state is visible as an active participant in knowledge production, but also as an interest-laden entity. Patients access high-cost treatment through a constitutional right to health but are also captive participants in the state’s policy agenda. Rajan’s analysis is cast against an imaginary set of possibilities that facilitates an elision of the problematics of the public. Just as commercial science creates future markets, public science, through the capture of experimental populations, is positioned to produce evidence and conduct research according to its own interests that may go unexamined under the blanket of the “public good”.

Once funding to conduct clinical trials from FioCruz ran out, CAMMI struggled to maintain its institutional expansion. The confluence of research and care not only has

the potential to thwart the sustainability of treatment provision, through the temporary nature of research projects, but also has repercussions for medical ethics. As anthropologist Rena Lederman discusses, medical research ethics have historically arisen out of a perceived need to carefully differentiate research from treatment born from well-known abuses such as the Tuskegee experiment (Lederman 2006, 2007). Presumably, research carries more risks and fewer potential benefits for participants than treatment. As Petryna shows, however, this distinction between treatment and research is not so clear, as trials become a form of treatment access in resource-scarce environments and in the way people understand their research participation on the ground (2009). In CAMMI, research and treatment are already explicitly combined. While patients have no right to decline from participating in knowledge production or to inform evidence with their own concerns, the combination of research and treatment brings into view biases that pervade traditional forms of clinical research.

The studies conducted at CAMMI utilize relatively small study samples and do not abide by conventions concerning high evidence "quality," such as the use of double-blind treatment arms. Picon, who has limited resources available for research, is always in search for opportunities to produce a body of "counter-evidence" to existing literature, much of which is funded by pharmaceutical companies (Petryna 2009). Picon is highly suspicious of trials conducted by the pharmaceutical industry. Indeed, there has been much concern over the reliability of these in the medico-scientific community (Damdron 1986, Easterbrook 1991, Smith 2005, Heres et al. 2006). "We have learned to delineate the limits of the possible," Picon told me. When his studies are published, they are typically in minor journals. In practice, Picon conducts a kind of "guerrilla science,"

striking at weaknesses in what he perceives as the pharmaceutical industry's knowledge hegemony. Picon, who refuses to accept any assistance from pharmaceutical companies, even free pens, is frustrated as some of his colleagues who work with pharmaceutical companies are published in international journals. At the same time, CAMMI's knowledge-production potential has become a way for local professionals to capacitate themselves in research. In addition to being CAMMI's director, Amaral is utilizing CAMMI in order to complete her doctoral dissertation, as other researchers have done for doctoral and masters programs.

In CAMMI, knowledge-production is not an incidental endeavor that comes and goes with the occasional clinical trial; it is part and parcel of treatment. It is important to note that CAMMI is a center of clinical effectiveness and not of clinical efficacy. Randomized controlled trials (RCTs) frequently run by pharmaceutical companies in order to authorize a drug's entry into the market are concerned with measures of efficacy, the capacity of a treatment to produce an effect. Efficacy is different from effectiveness, the actual effects of a technology once it is used in care environments where mistakes take place, resource constrains may disrupt therapy, and older, sicker patients may not respond as well to treatment. The notion of efficacy relies on a biomedical understanding of treatment. Anthropologist Andrew Lakoff (2002) writes that in the biomedical understanding of treatment "the drug is understood to operate directly on a physical problem through its biochemical effects on the body of the patient" (73). This understanding leaves no room for the influence of contextual factors on treatment success.

The nature of efficacy trials requires them to be conducted in highly controlled circumstance with selective populations. As a result, RCTs may not even be rep-representative of the regional contexts in which they are conducted. The distinction between efficacy and effectiveness is a theoretical one. “Controlled conditions” used for efficacy trials should not be taken for granted, and, as Lakoff discusses in the case of anti-depressants, demonstrating favorable results can depend upon selecting the “right patients” for the trial (2002). These trials are in reality highly context-specific, because they occur in highly controlled conditions, but conceptually non-specific, because they supposedly produce a measure of a drug’s theoretical ability to work. According to Petryna (2009), pharmaceutical companies make the non-specificity of evidence produced through trials into an advantage. Clinical trials of products intended for developed-country markets are increasingly conducted in developing countries. Because results are not region-specific, they can be extended to virtually any locality. The non-specificity of clinical trial results follows from a biomedical understanding of treatment that favors measures of efficacy over effectiveness.

Typically, medico-scientific trials are judged according to their “quality.” Quality is judged according to study format, indicating a concern for studies’ internal validity (Rychetnik 2002:121). Dobrow and colleagues (2004) argue that it is insufficient to consider only the “quality” of the evidence as determined by study design in public health decision-making. The contexts in which evidence is produced must be considered. Contextual factors can be taken into account through evaluative categories such as “relevance, appropriateness, applicability, acceptability, and utility” (Dobrow et al. 2004:214). These health policy researchers from the London School of Hygiene and

Tropical Medicine and the University of Toronto remind us that technologies necessitate their own context-specific considerations and practices, requiring knowledge from caregivers and accommodations from patients in implementation. Implicated in the authors' arguments is a concern for the relevance of evidence collected in one epidemiological, institutional, and clinical setting to other dissimilar settings. Such "context-specific" forms of knowledge and assessment challenge the seeming universal applicability of "high-quality" evidence but are, nevertheless, excluded from evidence hierarchies that explicitly rank the value medico-scientific evidence according to study format. Recently, there have been calls for more "pragmatic" randomized clinical trials that enroll varied patient populations and may be carried out within existing healthcare infrastructures (Tunis et al. 2003, Treweek and Zwarenstein 2009). These proposals aim to introduce context as a factor in trials.

"The importance of these studies is to show that Brazilians' response to treatment are similar, or perhaps it is worse. It is probably worse since people here are poorer, sicker. This is what we are showing in CAMMI," Picon told me during an interview in the federal hospital in Porto Alegre. Anthropologists have judiciously criticized clinical trials on the basis that they fail to acknowledge the value of research participants, are unable to do justice to culturally specific forms of treatment, or manipulate the under-scrutinized nature of the placebo effect (Petryna 2009; Adams et al. 2005; Lakoff 2002). These criticisms, however, do not address the consequences of the specific form of evidence clinical trials produce when that evidence is then applied in treatment. By excluding populations of patients, clinical trials produce a form of evidence that is not faithful to biological needs of the patients who ultimately receive medical treatments.

While only "biology" is allowed to speak in clinical studies, not everyone's biology is permitted to speak. With a conception of medical technologies as bringing both benefits and harms, the need to include more vulnerable patient populations in research is crucial for a realistic evaluation of the appropriateness of treatment. Brazilian patients who typically receive treatment in CAMMI are not likely to respond as well to treatment as the "ideal" patients recruited in clinical trials, who are typically younger and healthier. Even as patients in CAMMI have no choice to participate in research and no say in what kind of evidence is produced, by participating in research they are, in a sense, *asserting their biologies* (or having their biologies asserted of them) against an *evidentiary exclusion* that typically elides their reactions to medical technologies.

By asking how drugs affect patients in Rio Grande do Sul in particular, researchers in CAMMI and other references centers more broadly introduces local context, or external validity, as an important factor in treatment outcome and knowledge-production. They also implement a conception of *medication as potentially bringing more harms than benefits*, present but weakly elaborated and easily over-looked in much public policy and physician's prescriptive habits. In order to introduce context into studies, however, the institutional context of treatment must be first be re-created so that evidence may be reliably produced. "There was never a way to study hepatitis C in Brazil, there was no information registry or an organized place where patient information could be aggregated," Picon noted when we spoke. Thus, the production of context-specific evidence is not a unilateral endeavor, but requires that context first be remolded in light of the requirements of biomedical evidence-production and in contrast to private research initiatives that the researchers in southern Brazil oppose.

Bruno Latour argues that the laboratory's ability to make knowledge arises from its potential to translate the field in the laboratory and the laboratory in the field. "The laboratory positions itself precisely so as to reproduce inside its walls an event that seems to be happening only outside—the first move—and then to extend outside to all farms what seem to be happening only inside laboratories" (Latour 1983:266). CAMMI would seem to signal a kind of inversion, in which the conditions of the laboratory are applied to the field. However, it is also an attempt to make this model accountable to itself, by ensuring that the conditions in the field (the effectiveness of technology) do indeed replicate the conditions of the laboratory (the efficacy of technology). Scientific evidence is produced in dialogue with existing evidence. In the context of the production of medico-scientific evidence, the evidence-producing practices within CAMMI are an attempt to make the laboratory accountable to the field, especially in light of commercial trials that elide context specificity. The relationship between the "laboratory" and the "field," to the extent that we choose to conceive of these as dichotomous entities, is thus more complex than Latour's construction suggests, as the two are in constant re-negotiation of their conditions and the forms of evidence they produce.

The introduction of contextual factors is largely implicit in the research conducted at CAMMI and other reference centers, however. An explicit consideration of what particular contextual factors may affect treatment, such as income or education, remain out of the discussion. Even CAMMI's philosophy of care, so central to CAMMI's founding and practice, is absent from the publication celebrating the center's accomplishments. Rather, as noted above, the study focuses on cost-savings. Amaral says she is certain that demonstrating cost-saving has been crucial to CAMMI's continued

existence, though she rates the accomplishment as CAMMI's least significant. The study's authors, which include Amaral and Picon, attempt to reference the form of care CAMMI implements through the measure of patient satisfaction. All surveyed patients expressed satisfaction with the care they received in CAMMI, 78.5% reporting it as excellent and 21.5% as good (Amaral et al. 2006). This construction presents cost-saving and clinical outcomes as severed from patient experience, however. Ways in which these may be related, and can be seen to be in CAMMI's everyday practices, are elided. The use of patient satisfaction also elides the particularity of patients' voices, the texture of care and the complexity of the treatment experience.

Evidence production is part and parcel of treatment within CAMMI. Local researchers, primarily Health Secretariat staff pursuing degrees, evaluate the effectiveness of treatment in order assess the medical technology's biomedical effects within the local context and also as a way of producing "counter-evidence" to the pharmaceutical-industry-dominated scientific literature (Petryna 2009). Patients are required to participate in research, becoming in effect a captive experimental population to meet state evidence needs and policy priorities. At the same time, in participating patients are, in a sense, making a "biomedical imprint" in a scientific body literature that would otherwise disregard them. Ultimately, the contextual factors that likely affect treatment outcome remain unexplored in the evidence produced.

The Science of Rights

Even as CAMMI pursues its mission of improving the quality of care while reducing public costs through evidence-based medicine, a large number of patients break the evidence-based treatment protocols through court orders. Patients sue the government on the basis on the constitutional right to health in order to access treatment despite the protocol's restrictions concerning who is eligible to receive the expensive medication, how much medication and for how long. Ana Márcia Messeder, a Ministry of Health researcher, showed that the number of court cases for access to medications began rising dramatically in the early 2000s in the state of Rio de Janeiro, around the time CAMMI was coming into existence in Rio Grande do Sul (Messeder et al. 2005). The number of cases for access to medications in Rio de Janeiro went from 85 in 1999 to 1,144 in 2002.

Before antiretroviral drugs were universally available in Brazil court cases against the government for access to the expensive drugs were an important form of social mobilization. While Messeder shows that court cases in the early 1990s were exclusively for antiretroviral medications for treating HIV/AIDS, as the number of cases increased their content diversified to cardiovascular illness, diabetes, cancer, psychiatric illnesses and other disorders. Recent research I have participated in shows a similar trend in Rio Grande do Sul. In 2008, an average of 1,200 new cases for access to medications was being opened in the state every month (Biehl et al. 2009). It seems the right-based and access-oriented approach to drug pioneered by the AIDS movement has migrated to other disease categories. In Rio Grande do Sul, interferon for hepatitis C treatment is the

seventh most frequently demanded treatment by judicial means behind drugs for asthma, cardiovascular disease and gastroesophageal reflux (unpublished data).

The protocol implemented at CAMMI has strict provisions concerning who is medically eligible for treatment, how much medication patients receive and for how long. Court cases are being successfully utilized to break the protocol, allowing some patients to receive more medications for longer periods. Frequently, the court cases demand that a patient, who did not respond to treatment, be retreated. When the protocol was first created, retreatment was not an option, but it was changed in 2007 to allow for retreatment in some cases. Doctors who prescribe these longer regimens defend their practices as evidence-based as well. While court cases promise to increase access to treatment and guarantee the constitutional right to health, they constitute a tremendous budgetary burden. In addition, public health officials claim the judicially obtained regimens are no more effective than the ones recommended in the state's protocol. Lawsuits are said to thwart efforts to further "rational, evidence-based" initiatives, but we have to explore futher the substance of the arguments concerning evidence, experimentation, and ethics that are carried out within these lawsuits.

Hugo Cheinquer is head of the viral hepatitis division at the federal hospital in Porto Alegre. Cheinquer does not dispute the significance of scientific evidence, but argues for more consideration of individual patient situations in prescribing regiments. "If you were a patient, would you rather be treated by a public health administrator who will see you as a statistic or a physician who will see you as an individual?" At the same time that he argues for most expansive treatment access, he acknowledges the difficulty of cementing a treatment protocol. Referring to the physicians who write the guidelines

compiled by the American Association for Study of Liver Diseases, Cheinquer says, “They discuss for hours which words to use in the guidelines, whether it is ‘should,’ ‘could,’ ‘may’ and so on.” Cheinquer’s comment addresses the difficulty of implementing treatment in context of, not only resource, but also of *knowledge scarcity*.

One of the patients Cheinquer encouraged to sue for treatment access was Ana Cruz. Cruz is a small and frail-looking woman in her sixties. Her frizzed grey hair sticks out to the sides of her head in the shape of a trapezoid. Far from seeming tired by her age, Cruz is good-humored and relentless. She would hardly stand still as she led me through her shack in one of Porto Alegre’s shantytowns, called *vilas*, making beds and putting away dishes as we went. She, her daughter and granddaughter live together in the shack Cruz is proud to say she owns. She hopes to someday add a second story to the bare-brick structure.

Cheinquer prescribed Cruz the 72-week regimen of pegylated interferon and encouraged her to sue the state in order to access the treatment. Cruz, who cannot afford a private attorney, was represented in her case by a public defender. In Brazil, public defenders, where they exist, may not only serve as criminal lawyers for those who cannot afford one, but as general lawyers for the poor. Indeed, it seems over half of patients who sue for medications in Rio Grande do Sul are represented by the Public Defender’s Office (unpublished data). I spent several weeks conducting interviews and participant observation in the Public Defender’s Office. Individuals go to the Public Defender’s Office seeking everything from hospital beds to high-cost drugs, from entry into multidisciplinary care centers for genetic disorders to geriatric diapers. The number of individuals seeking to open lawsuits for access to medication has been growing, and a

public defender has been exclusively assigned to opening these cases. These individuals arrive, most of them sent by their doctors, with different levels of knowledge concerning what the public defenders do and how they will access the desired medical products.

Court cases for access to drugs can take years to reach a final outcome. With her permission, I was able to obtain the documents pertaining to Cruz's lawsuit through contacts in the Public Defender's Office. In Cruz's case, which was opened in June of 2008, and which is still open, her public defender requested an emergency injunction allowing her to begin treatment immediately, alleging she risked irreparable harm if she were to wait to begin treatment until a final decision was reached. The strategy is employed in most cases for access to medications and is frequently successful. Cruz's public defender writes in her court case "the gravity of her condition puts her life at risk." Hugo Cheinquer's written statement, which accompanies the lawyer's petition, does not say as much, however. Rather, he noted, failure to receive treatment may necessitate a liver transplant in the future, which would come "at a higher cost to society." We see two rationales at work in the doctor's and the lawyer's statements. While Cheinquer employs an argument of cost-effectiveness, the public defender is eager to highlight the risk of death, implying not only the right to health but also the right to life. Such slippage is frequently appreciable in court cases, and highlights the uncertain position of the right to health in light of an understanding of medical technologies as bringing high costs and potential harms. The judge in the case granted the emergency injunction the same day it was requested, giving the state five days to provide the treatment. If the state failed to do so, the value of the treatment would be blocked in a state bank account, a strategy frequently used by judges to ensure compliance with the order.

In response to such lawsuits and the administrative burden they cause for the Health Secretariat, Picon worked with the Socilitor General's Office, which defends the state in these cases, to form of group of doctors who would provide expert statements on behalf of the state. In Cruz's court case, both Hugo Cheinquer and the doctor representing the state allege their positions are evidence-based, citing numerous scientific articles to back their respective positions. In arguing against the provision of the 72-week regimen, the state doctor notes the hepatitis C is a chronic condition, which rarely represents an imminent risk of death. In cases where there is an imminent risk of death, the treatment is not indicated. The state doctor implicitly questions the value of treatment, especially given its high cost and severe side effects. She also puts into practice a conception of disease as something to be managed rather than urgently eradicated. The frequent allusion to the "risk of death" in these lawsuits, even when not precisely true, is not only a rhetorical tactic to ensure treatment provision, but also a reflection of an understanding of disease as unambiguously menacing, requiring aggressive and immediate remedy. The dispute of the nature of disease reveals it as not a stable category, despite the biomedical truths it implies, but a highly contested one, especially as it comes into consideration by fields other than biomedicine, such as law. Anthropological constructions of disease as a stable biomedical construct distinct from illness (Kleinman 1988), elide such complex forms of disease contestation. Social scientists must be sensitive to how disease is differentially constructed, especially in relation to varying conceptions of health, treatment, citizenship, evidence and experimentation.

The state doctor also argues in her statement that the 72-week regimen is experimental and, as such, specific permission must be granted from research-ethics

institutions in order to provide the treatment. Cheinquer, who argues sufficient research has accumulated to justify the 72-week regimen and categorize it as non-experimental, also mobilizes ethics on his behalf. Cheinquer cites several articles of Brazil's Federal Medical Council's Code of Ethics. Article 16 states that no institution may limit the doctor's choice of which means to implement in diagnosis and treatment, except when it benefits the patient (CFM 1988). Article 57, which Cheinquer also cites, states that a doctor is prohibited from not exhausting all available diagnostic and treatment tools within his reach for the patient's benefit (CFM 1988). Through his ethics-based arguments, Cheinquer attempts to position himself as the dedicated doctor, exhausting all possibilities for his patient despite a state that attempts to limit treatment in order to control costs. Indeed, a new code of ethics was adopted the Brazilian Federal Medical Council on April 13, 2009. One of the explicit goals of the revision, according to the organization's newsletter, was to "strengthen the physician's freedom to make choices and exercise autonomy" as well as to "reaffirm that medicine as commerce and an understanding of patients as consumers will not be tolerated" (CFM 2009). Cheinquer contends the treatment protocol is more concerned with limiting state costs than providing safe and effective treatment for patients.

The most recent practice guidelines for the treatment of hepatitis C were published this year in Digestive and Liver Disease drafted by experts from three Italian scientific societies based on existing studies (Digestive and Liver Disease 2010). They note that a 72-week regimen has only been shown to be more efficacious in specific circumstances. The guidelines support the use of 72-week treatment for treatment-naïve patients with a type 1 hepatitis C infection who are "partial early responders," which is

not Cruz's case. The guidelines add, "The decision to prolong therapy in these patients should take individual side effects, the quality of life and the patient's motivation into account" (Digestive and Liver Disease 2010:84).

Discussions of side effects, quality of life, and patient motivation never enter Cheinquer's statement, however. When it comes to re-treatment of patients who were previously treated with pegylated interferon and ribavirin, as Cruz was, the guidelines write, "Given the low probability of clinical benefit, the decision to retreat subjects infected with HCV genotype 1 should be assessed on an individual basis" (Digestive and Liver Disease 2010:85). Nowhere is re-treatment with a 72-week regimen recommended or even considered. While cost-effectiveness is certainly a consideration in the Brazilian Ministry of Health's treatment protocols, even if a merely as a conceptual tool in its drafting, the use of cost-effectiveness stems from an attempt to address a very real and difficult set of questions of when treatment is both worthwhile and appropriate, given resource limitations but also the limitations of treatment. Surely, however, cost-effectiveness alone is a poor tool to address these questions, and patients' individual life circumstances and necessities must also enter into consideration. Nevertheless, Cheinquer never addresses Cruz's life circumstance, outside of her biology; he merely pushes for the most aggressive (and costly) form of treatment available. The question is whether she is best served by this approach.

In the introduction to their guidelines on hepatitis C, the authors write, "the management of special patient categories originally excluded from phase III registration trials needs to be evaluated" (Digestive and Liver Disease 2010:81). Phase III trials are the type of randomized controlled trials, referred to above, that are used to produce

evidence that will authorize a drug's entry into the market. These trials, as I previously discussed, typically enroll relatively healthy and treatment naïve individuals. The recruitment of healthy subjects increases the safety of the trial, by excluding individuals who may be more likely to react poorly to the drug, and also eases the identification of efficacy, by selecting patients who may be more likely to respond favorably. Once a drug enters the market, a more heterogeneous population than included in the study is typically exposed to the drug without a clear knowledge of what the particular risks and benefits may be. The need to identify "special patient categories" is a response to the limitation of the current approach to phase III trials and also an attempt to mediate population-level guidelines with individual-patient circumstances. This approach is distinct from the reference center approach to researching clinical effectiveness because it does not lump individuals from a particular region together, but attempts to identify which factors make individuals more or less likely to respond favorably to treatment in order to inform clinical practice. Cheinquer says he is more willing to consider individual's particular circumstances, but does little in actually considering them, indiscriminately prescribing the most aggressive treatment option for Cruz and Alencar.

In the debates carried out within lawsuits, "evidence-based medicine" appears closer to a rhetorical technique than to a model of treatment. Anthropologist Stefan Ecks, who has worked on healthcare providers' notions of evidence in treatment practice, writes, "The debate about EBM is one more example of the fact that health is a field of *multiple* truth claims, instead of a simple opposition between doctors' knowledge (in the singular) and patients' beliefs (in the plural)" (2008:S87). A critique of evidence-based

medicine's potential to restrict physician's authority is complicate by the fact that physicians may utilize evidence-based medicine to back contrary positions.

Though Cheinquer's recommendation does not seem to fit the latest practice guidelines, his prescriptions are not wholly absurd considering the existing evidence. A patient who is retreated with a 72-week treatment certainly does have a greater chance to be cured than a patient who is not re-treated, though the re-treatment may come with serious adverse effects and incurs great costs, which Cheiquer never addresses. Whether Cruz should be eligible for treatment considering the potential harms of the drug and the resource limitations of the state are real question that must be addressed. The use of medical ethics to argue for the most aggressive treatment option ignores the complex and incomplete effects of technology on patients, health systems and budgets. The physicians involved in Cruz's case come to different conclusions through different conceptions of existing evidence that emphasize different findings and put into practice different conceptions of the benefits and risks of treatment, the nature of disease and the role of experimentation. These physicians never explicitly address these differences, however. Rather, they present litanies of studies, staging evidence without discussing its applicability to local contexts or particular patients, in such a way as to further their positions. What results is an anarchy of interpretations bolstered by the irrefutability of evidence.

The point is that an evidence-based approach is insufficient to inform beneficial treatment since it merely declares the primacy of scientific evidence without addressing the difficult questions that arise in the attempt to implement evidence. As anthropologist Helen Lambert (2006) writes concerning evidence-based medicine, "EBM, then, is an

indeterminate and malleable range of techniques and practices unified not—as its proponents and critics alike have tended to assume—by particular kinds of methodological rigour, but by the pursuit of a new approach to medical knowledge and authority" (2639). To say an approach is evidence-based is to say nothing about nature of evidence, how and about whom it is produced, how it informs practices and is informed by them. An "evidence-informed" approach must be, at least, combined with a people-centered approach that makes evidence accountable to people's broader needs as well as local realities of health and social systems. To say only that treatment practices should be informed by evidence does not begin to address the difficult questions that sensible proposition generates.

A critical consideration of Cruz's case demonstrate that what appears as a conflict resulting from the limitations of a resource-strapped state in light of a constitutional guarantee of health is also a contestation of the role of evidence and experimentation in treatment and the uses of a technology once it has entered the market and health system given knowledge-limitations. Evidence will never allow us to predict treatment outcomes. In the space between evidence and treatment, conceptions of disease and technology inform decision-making. These conceptions must, therefore, be brought into critical view. Resource-scarcity is an important factor in lawsuits, as the state's willingness to provide treatments is likely to decrease with the treatment's success rate. However, a focus on which patients are excluded from treatment based on considerations of cost-effectiveness elides what may be seen as a more widespread and significant tactic in avoiding treatment cost, that is, the virtual absence of efforts to encourage testing for hepatitis C and the

structural exclusion of most infected individuals from treatment, including intravenous drug users.

While lawyers from the Solicitor General's Office contested Cruz's lawsuits, the public defender wrote to the judge that the emergency injunction had not been put into effect. According to the legal papers, Cruz did not begin receiving treatment until five months after the injunction was granted. The court eventually appointed an independent physician to evaluate Cruz's case. This physician sided with the doctor from the Solicitor General's Office, but the judge did not order the treatment terminated. Cheinquer continues to press for the regimen and Cruz continues to receive it. I have participated in interviews with judges as part of an ongoing to study into lawsuits for access to medications with Professors João Biehl and Adriana Petryna. We have noted that judges profess a lack of technical understanding of the subject matter of lawsuits necessary to consistently make informed judgments (Biehl et al. 2009). As seen here, physicians also demonstrate an inability to make clear the substance of their disputes. Through these lawsuits the medical prescription, as a conclusive recipe for treatment and as a symbolic artifact of authority, comes into question, in part replaced by the expert physician's medical report and the lawyer's arguments and petitions. The next section will examine what conception of health is sought after and guaranteed through these lawsuits.

The Right to What Kind of Health

Paula Pinto is the public defender responsible for opening all health-related cases in Porto Alegre. Pinto, who is in her mid-thirties and previously worked defending

homicide suspects who could not afford legal representation in Porto Alegre, is fierce and fastidious. I spent several weeks in July and August of 2009 accompanying her appointments with patients seeking to open lawsuits. “This is the judicial hospital,” Pinto told me. Pinto takes note by hand on the outcome of every case she opens, reads the rare cases where the patient loses and adjusts her legal arguments to strengthen her position the next time around. She relentlessly encourages individuals who come to her to pursue their right to health through these lawsuits, frequently places phone calls to admonish health workers for not providing patients with the proper documentation to open a lawsuit, and ruthlessly criticizes the state government for not doing enough to guarantee the right to health. Her cubicle is almost bare, except for a framed poster of a pasture scene printed with words from Psalm 23, “The Lord is my shepherd, I shall not be in want.”

Lucenira Barros is 34-years old. Her mother Isabel Barros came into the Public Defender’s Office to obtain Revatio, a medication for pulmonary hypertension also marketed as Viagra. About a year after having a heart attack, Lucenira has been unable to leave the bed, except to go to the bathroom. Her doctor prescribed her 6 medications, five of which are provided through the public health system and Revatio, which is not. The doctor suggested Isabel seek the public defender’s office. “Is this were I get the medication?” Isabel asked as she handed the Pinto the doctor’s prescription. The lawsuits may take years to reach a final conclusion, but Pinto requested an emergency injunction to force the state to provide the treatment while the lawsuit is underway. Isabel said she has gone several times to the state pharmacy to obtain the other medications but they are always out-of-stock.

Isabel and Lucenira Barros live in a brick shack in one of Porto Alegre's *vilas* where they share a single room with Lucenira's two daughters. The neighborhood has become so dangerous Isabel says she will not leave at night even to the corner store, which is about 20 yards from her home. Isabel's husband died of cancer. The shack, whose roof is beginning to crumble, belongs to her mother-in-law, and she worries about how long she can continue to live there. The treatment with Revatio costs about 1,000 dollars per month. Isabel, who is retired with a pension, has been purchasing small amounts of the medication for Lucenira with borrowed money, indebting herself to family members. Isabel is a *mãe-de-santo*, a priest in Afro-Brazilian religions. She makes a little extra money performing rituals in her home and at times receives a food basket from her religious organization. In the shack was an offering, filled with packaged sweets, Isabel made to ask that all patients win their lawsuits for medication. At first it seemed Revatio was meant to make Lucenira able to walk and work again. Speaking to Isabel in her home, however, she said Lucenira will likely need a heart transplant, and the drugs are meant to keep her alive long enough to receive one. Before her heart attack, Lucenira had a job and did all the housework. "I feel sick," Lucenira said, "sick from not being able to do things." Lucenira's brother, who lives in a wooden shack in the back of the lot, uses his computer to check on the status of her case. The judge issued an emergency injunction for the drug to be delivered within days. Two months later, however, the medication had still not arrived.

As Lucenira Barros's story shows, the lawsuit for access to Revatio addresses only a small part of her life circumstance, which is full of needs and inequities. Her housing and income are already fragile but are further destabilized by the pursuit of the

medication, as her mother Isabel borrows money from family members to pay for it. Ingo Sarlet, a vocal judge and law professor in Rio Grande do Sul, argues that, despite the problems these lawsuits present, they allow patients to be heard, to become seen before the state. Sarlet (2008) argues for the adoption of the legal concept of the "existential minimum" in deciding these court cases. The existential minimum refers to the material conditions necessary to permit and encourage human dignity, not merely survival. These conditions, Sarlet argues, are variable and, thus, cannot always be guaranteed through legislation. "That which constitutes the existential minimum, therefore, necessitates an analysis or, at the very least, the possibility for inquiry, in light of each person's individual and familial needs" (Sarlet 2008: 198). Though Sarlet argues for an expansive consideration of human dignity and an adoption of social rights as fundamental rights, the form and effect of lawsuits for treatment access are extremely limiting.

In contrast to the AIDS activists who pioneered lawsuits for HIV/AIDS as a form of not only access but also social mobilization, the individuals who come to the public defender's office have no express interest in social mobilization. The right-based and judicially achieved drug access pioneered by AIDS activities is seen in the public defender's office as routinized and bureaucratized. Nevertheless, the lawsuits are putting tremendous pressure on public health officials to improve pharmaceutical distribution schemes (Biehl et al. 2009), indicating that they are not without significant political force, despite the absence of political goals on the part of patients.

While patients' broader life circumstances are at times mentioned in cases, the lawsuits only ever achieve access to a medical technology. And while patients may speak in the public defender's office, and may be heard, their voices in the lawsuits are largely

absent. In fact, Pinto saves all lawsuits she writes to serve as templates for later ones. Judicial arguments based on patient circumstance are highly patterned. In addition, there is no one following up with the judicial patients to see if they are taking their treatments or if they work. Pinto, the public defender, was surprised when I reported to her that two months after Lucenira Barros won her emergency injunction she was still not receiving medication.

While rights are generally conceived of as absolute and inalienable, efforts aimed at their fulfillment can expose people to uncertain circumstances and temporalities. Emerson Alencar lost his job as a bus-driver after his interferon treatment left him partially blind in one eye. Despite the devastating side effect, the treatment was ineffective and Alencar's doctor advised him to sue for a longer regimen of interferon. Alencar was granted an emergency injunction to begin the longer regimen. Alencar also sued the state to retire and received another emergency injunction to begin receiving retirement benefits. Alencar's longer treatment regimen could conceivably conclude before any final decision took place in his lawsuit. Similarly, a judge may find he is not eligible for retirement and discontinue his judicially achieved benefits. Alencar was not pursuing his rights exactly, but the same things he had always been pursuing, perhaps described as health, security, and fulfillment. A rights-based legal pursuit had become the latest avenue in which to pursue these. It was less that Alencar was somehow empowered, and more that he was pragmatic and persistent. At the same time that Alencar hoped his retirement would remain permanent, his wife's pursuit of continued education opened a distant possibility for new opportunities and financial stability.

Even as Lucenira and Isabel Barros sued for the expensive drug, the publicly provided medications Lucenira needed were out of stuck in state pharmacies. Physicians seem to be primarily responsible for determining which medications patient sue for. “I trust Dr. Hugo,” Cruz, the patient I introduced in the previous section, told me concerning her 72-week treatment regimen. Even as physicians may see their authority as being threatened by the state, it is in many ways intact with their relationships with patients. Cruz’s treatment would cost a total of about 70,000 dollars. Public health officials typically see patient-litigants as taking advantage of the public healthcare system. Cruz says she spends about $60 dollars a month on medicines outside her hepatitis C treatment. Why did she not sue for those as well, I asked. “I don’t mind paying for my medicines, as long as I can afford them.” One can only imagine what the sum of 70,000 dollars could do for Cruz, who lives in a bare brick shack with her daughter and granddaughter, if spent elsewhere.

Lawsuits have been criticized for being, not only technology-centered, but also highly individualized. Pinto, the public defender, explained that collective lawsuits are risky, since a single loss may close the door for access for a population of patients. Nevertheless, while I was in Porto Alegre, she began preparing for a possible lawsuit against the city for the provision of treatment for crack addiction. There is an on-going crack “epidemic” in Rio Grande do Sul (Kessler and Pechansky 2008). Frequently, individuals addicted to crack or their family members come to Pinto to ask for emergency injunctions for hospitalization in Porto Alegre, where hospital beds are in short supply, so they may attempt to “break” their crack addictions. On one day, two brothers came in brought in by their mother, to sue for hospital beds. The older brother, 32, has already

been hospitalized four times during his eight year addiction. “Our lives are all we have left,” he said. “And hope,” the younger brother, 24, added. Pinto is considering suing Porto Alegre in order to necessitate the city to create a comprehensive, multi-disciplinary addiction program, which exists in the private system, Pinto says, but not in the public one. Though attempts to create collective lawsuits are beginning to appear, they are few and individual cases for access to medications are still the overwhelming majority.

In all, lawsuits for access to medication further a hyper-individualized and technology-centered understanding of health provision (Biehl et al. 2009; Biehl 2007a; Petryna 2009). Patient’s broader needs, such as housing and livable income, are not addressed. The right to health is put into practice as a right to medical technologies, primarily expensive ones that are not provided through the public health system. As a result, such lawsuits do not merely activate the state but expand markets. Physicians seem to be the principal actors in determining the content of lawsuits. Though the AIDS movement pioneered such lawsuits as a form of social mobilization, the practice of opening these lawsuits has been routinized, with the judiciary becoming, in effect, a parallel administrative body for the provision of medications. Despite this routinization, social mobilization of NGOs, as the next section will show, is also significant in defining the terms in which hepatitis C is conceived of and addressed by the state.

Technology for an Invisible Population

“Brazil is sitting on a viral time-bomb,” Carlos Varaldo said. Varaldo is the director of one of Brazil’s largest hepatitis C non-governmental organization, named

Grupo Otimismo, or the Optimism Group, as well as the vice-president of the World Hepatitis Alliance. I spoke with Varaldo in his beachfront apartment in the neighborhood of Copacabana in Rio de Janeiro on a sunny morning in July of 2009. Varaldo is Argentinean by birth, his father was an active politician in Argentina and his grandfather died in the revolution against Perón, he told me. He left his native country when friends began being "disappeared" by the military government there.

Varaldo discovered he had hepatitis C while donating blood in 1995, when much less was known about the disease or the optimal treatment given existing tools. Varaldo traveled to Spain to meet with the world's expert on hepatitis C at the time. "He told me the treatment in Brazil was the same as in Spain. He only suggested I find a doctor with empathy. That stayed with me." He returned to Brazil where he consulted several more doctors, one of which told him he would die in six months. Varaldo, who is trained as a chemist and economist, closed the perfume factory he owned and put his possessions in his wife and daughters' names. Varaldo also consulted a physician from Schering-Plough, where he had worked as a financial executive for 10 years. He found a physician who he said would followed the treatment course he wanted and booked them two registrations to an international hepatitis C conference. Varaldo then began a long and uncertain regimen of conventional interferon, since pegylated interferon did not yet exist, and ribavirin, which Varaldo had to specially import to Brazil. Varaldo also tried homeopathy, various herbal remedies, multivitamin regimens, acupuncture, regression therapy, and Reiki treatment. He began "spiritual treatment" with a Spiritist center, which he continues today, he said. "Is the medication necessary? Yes. But much more important is our thinking, our will to be cured."

Varaldo says he made several mistakes. The vitamins pills he took, up to 24 per day, worsened his liver inflammation and he began taking iron supplements in secret from his doctor, believing it would help him stay on treatment. He lost hair, several teeth and 40 pounds on the regimen, became anemic, but was able to obtain a sustained viral response. He continues to take a test every year to confirm his response to treatment. After completing the treatment, Varaldo gradually came to realize several people he knew were also infected. The more he learned of government policies towards hepatitis C, or their absence, the more concerned he became, he said. Varaldo, who is now retired, founded Grupo Otimismo and runs it from his laptop at home. He funded the organization himself for its first few years. “Someone with a full-time job can’t run an NGO.” Referring to himself, he said, “When you find someone who is already retired, financially secure, who does not depend on money, who has time to dedicate, and who has an address book that will open a lot of doors, it will work.”

Varaldo frequently explained his challenges and strategies in light of the HIV/AIDS movement. “HIV had this visibility. It infected people of in the public eye, artists, who went to the streets. They generated a great noise and the government responded. Hepatitis doesn’t kill fast. It kills slowly and over time. Most infected individuals don’t know it, so it is not possible to organize large demonstrations.” The invisibility of the disease is the largest challenge to social mobilization, Varaldo says, and he faults the government for not doing enough in terms of surveillance.

Indeed, the government does little to incentivize testing, Varaldo says. For World Hepatitis Day, the government promised to print 5 million pamphlets and distribute them to NGOs, but only ever made 100,000, he recalled. There is no anonymous hepatitis C

testing, as there is for HIV, Varaldo also pointed out. When a case is found, medical staff must fill out by hand a long and complex notification form for the government. Varaldo says he spoke with the director of a prestigious hospital who told Varaldo they have not filed a form in three years because of a lack of staff. In 2007, the Ministry of Health reported a hepatitis C detection rate of 6.17 per 100,000 individuals, or 0.006% (Ministério da Saúde 2008), a far cry from the World Health Organization's estimated prevalence of between 2.5% and 4.9% for hepatitis C in Brazil (WHO 2000).

At the same time that Varaldo draws from the AIDS movement for strategies, he harshly criticizes the present state of social mobilization around AIDS as well as hepatitis C. "I no longer help to form new NGOs because 80% of them form based on personal interests. The government likes this; it helps fun movements in order to co-opt them." Indeed, in his work with HIV/AIDS in Brazil, Biehl discusses the case of Caasah, an informal community of people living with AIDS that became an NGO. As part of the transition, Caasah became a "house of passage," altering the form of care provided from one of informal and flexible support to transient and regimented assistance accompanied by pharmaceutical dispensation (Biehl 2007b). Varaldo contends that the government, through funding NGOs and hiring former NGO staff in the AIDS program, has been able to co-opt the social movement, which has compromised its ability to be critical of government policies. Public health officials in Brazil widely criticize patient associations for accepting industry funding. "They tell me it's a crime to accept money from pharmaceutical companies. I say it's a crime to receive it from the government," Varaldo told me. Varaldo challenges a straightforward conception of the state as safeguarding the public good and corporations merely pursuing their own interests. The state or, more

precisely, those working within it, have interests as well, to keep costs low and maintain an appearance of good governance. Varaldo is more concerned with distinguishing those who make their interests transparent and those who do not.

Varaldo carefully manages his relationships of interest. Schering-Plough offered to donate a monthly amount to the organization and he declined. He accepts only one-time assistance in order to avoid becoming dependent on the industry. “For instance, if I need to print fliers, I design them and allow a company to print them in large numbers for me.” Varaldo only accepts monetary donations from pharmaceutical companies for World Hepatitis Day and posts the amount received and their sources on the organization’s website. Last year, Schering-Plough and Bristol Meyers-Squibb each donated approximately 25 thousand dollars, and Roche donated approximately 15 thousand. Outside of World Hepatitis Day, the organization spent only about 9 thousand dollars, which come from member donations. Grupo Otimismo has also received assistance from the Gates Foundation and the Clinton Initiative. Through varied funding sources, Varaldo says he is able to maintain his independence. As the manager of an international member-based health technology assessment organization told me during a phone interview in 2008, “If you go deep enough in any relationship you’ll find a conflict of interest. The issue is how do you deal with it? Do you recognize it and manage it, in which case everyone benefits...or do you pretend it doesn’t exist in which case it comes back to bite you later.” In a political atmosphere where funding is understood to signify allegiance, transparency serves not as a marker of impartiality but of good faith. What is remarkable is the over-reliance of funding sources for judging the legitimacy of political

positions and scientific claims, which seems to indicate that we lack the tools or sophistication to critically analyze these positions and claims on their own terms.

"I have a love-hate relationship with the pharmaceutical companies. They admire me because I've helped them expand their market in Brazil. But I also call them out whenever they do something wrong. " While he is criticized for working with pharmaceutical companies, Varaldo sees several problems with the way pharmaceuticals are developed and marketed. Companies have more incentive to develop drugs that treat rather than cure diseases, he says. "We are all turning into diabetic hypertensives because you have to take medication for life." He says the hepatitis C researchers he has spoken with are doubtful a vaccine will be developed, since there is little commercial incentive. While Varaldo says he is against breaking patents, and is criticized for this position, he also does not buy the argument that high drug prices are needed to recoup research spending. "I defend patents but not the industry's profits. Patients are overcharged to fund future research," he says.

Varaldo is also critical of how drugs are marketed to doctors and, more essentially, how medical information is disseminated in conjunction with medical practices. "If you prescribe 20 patients with interferon from the same company you will get invited to a national congress. With 40 prescriptions, you are invited to an international congress. That's the price. There are many patients being treated who don't need to be. It's criminal." Lakoff (2006) has documented such practices in Argentina, where pharmaceutical companies monitor physicians' prescriptive habits and utilize them to exclude physicians from events they organize. Varaldo sees these practices as hindering knowledge dissemination and much-needed continuing medical education. "The doctor

who works in the public service from seven in the morning until five in the afternoon, and then receives 15 dollars per visit if he works with an insurance plan, can he afford to go to a congress? No. No matter how much time he spends treating hepatitis, he will be a bad doctor." Being a good doctor involves having access to the latest information, which is mediated by pharmaceutical companies through prescriptive habits. However, as I have demonstrated in the previous section, access to information alone is not sufficient to justify any one approach to treatment or to guarantee effective care.

Though Varaldo occasionally organizes demonstrations, it seems he conducts most of the advocacy himself, through disseminating information on his website and meeting with high-level officials. Though he has posted sample court cases for access to hepatitis C drugs on his organization's website, he says he does not involve the organization directly in these cases. Varaldo and others, including public health officials in Rio Grande do Sul, credit court cases with the introduction of pegylated interferon retreatment in the protocol revision of 2007. The judicial demand for medications does seem to have the potential to alter national policy and collective treatment access. However, even this kind of gain is limited, as it does not fundamentally alter the regulatory institutions and practices responsible for the incorporation or use of medical technologies in the public healthcare system (Biehl et al. 2009). For better or worse, the revised protocol did reduce the number of lawsuits for hepatitis C. According to Picon, an on-going study at CAMMI will show very few patients benefit from retreatment, a finding that is already reflected in the practice guidelines discussed above.

Judicial Surveillance

Rather than become involved with cases for access to medications, Varaldo has recently contacted and encouraged a few lawyers to begin bringing lawsuits against the government for indemnity for patients who were infected with hepatitis C after at a time when public health measures, he says, could have prevented it. This approach represents a new strategy, in which the state is made accountable, not only for current and actual patient circumstances, but also for alternate public health eventualities based on a different approach to public health in the past. For Varaldo, the idea is to bring these patients, and their pathologies, into view in order to force the government to improve surveillance. “We don’t want to win money with this. Each patient will receive 30 thousand dollars if he wins. Like with HIV, we are seeking the publicity. We want the government to begin moving, to begin investing. There will be thousands of cases.” Through these cases Varaldo hopes to thwart the state’s “averted gaze” (Scheper-Hughes 1992) toward hepatitis C. Unlike Ingo Sarlet, the judge who sees cases as bringing individual patients’ particular circumstances into view, Varaldo sees the lawsuits as an opportunity to demonstrate the collective circumstance of the population infected with hepatitis C. In this formulation, the judiciary becomes not a parallel administrative institution for drug access, but a kind of parallel surveillance system for disease, demonstrating state failures to produce evidence concerning the scope of infection.

Marcos Sommer Santos, an expert in indemnity cases for HIV/AIDS, is the lawyer in Rio Grande do Sul who is pursuing these hepatitis C indemnity cases. We spoke in Santos’s office in August of 2009, when he had just won two of these cases. In

one case, a judge who is known as an HIV/AIDS advocate initially ruled against Santos, who said the judge had a bias towards HIV/AIDS and did not acknowledge the same rights to people of other diseases. Indeed, judges have significant independence and latitude in deciding cases. Interviews with judges reveal that they put in practice individual and idiosyncratic rationales in deciding court cases (Biehl et al. 2009). Santos then won the case on appeal. In the past, Santos has also represented pharmaceutical companies. “I have worked for all sides. I merely take advantage of opportunities.”

According to Varaldo, the challenges of mobilization do not merely result from the nature of the disease, from the lack of surveillance and the state of NGOs, but also from Brazilians’ notion and experience of citizenship. “If people come to the pharmacy and aren’t able to get their medication, they do a half-turn and walk home. I say, ‘Guys, don’t go home. Break this shit, set it on fire, because then the newspapers will show what’s happening.’ The Brazilian lacks this citizenship.” Indeed, as previously discussed, patients who access the judiciary to obtain medication seem little concerned with their rights as citizens and more concerned about filling their prescriptions. Even so, court cases exert enormous political pressure on the state. The role of NGOs and pharmaceutical companies in encouraging such court cases is as of yet unclear (Biehl et al. 2009).

Varaldo, who works with Hugo Cheinquer, is critical of the form of care the protocol’s use implies, arguing treatment must be individualized. The criticism speaks to the challenge discussed earlier of implementing a public health program that acknowledges individual medical needs and circumstances. In order for this to happen, Varaldo says, doctors must be better informed. As Lambert (2006) notes, evidence-based

medicine has been widely criticized for stifling physician's authority. This is not precisely Varaldo's argument. He is interested in finding ways to implement a freer and more equitable dissemination of knowledge so that physicians need not rely on a protocol that limits the flexible individualization of treatment. At the same time that he criticizes the protocol for being inflexible and infrequently updated, Varaldo criticizes pharmaceutical companies for organizing congresses in which only doctors can attend who prescribe medications or can afford registration. His arguments raise the issue of not only evidence production but also of how to appropriately disseminate it. As new hepatitis C drugs come into the market, he predicts hepatitis C treatment will become more akin to HIV treatment, necessitating the use of complex drug cocktails.

Atul Gawande discusses the challenges of making sense and use of the colossal amount of medical information available. "I have been trying for some time to understand the source of our greatest difficulties and stresses in medicine. It is not money or government or the threat of malpractice lawsuits or insurance company hassles—although they all play their role. It is the complexity that science has dropped upon us and the enormous strains we are encountering in making good on its promise" (Gawande 2009:10-11). Gawande makes his point in part through anecdotes where well meaning, well trained, and intelligent physicians struggle with the complexity of patients' medical circumstances and, at times, fail. His point is that even when information is readily available, the presumption that physicians can apply it appropriately to every case is faulty. Even while Varaldo's criticism concerning the availability of information is apt, then, it does not address how to put information into practice.

Varaldo is not only concerned with medical professionals' access to information, however, but also patients'. He criticizes medical care on basis it does not involve patients enough in treatment. "The doctor runs a series of tests and one comes back positive. He prescribes a medication. But since the patient does not receive any information about the disease, he is not satisfied and stops taking the medication. Wouldn't it be better to teach patients about the medications, how they should be taken, the side-effects and possible reactions?" Though he does not know of the specifics of treatment within CAMMI, Varaldo's comments reflect the center's "philosophy of care." Even so, his activism is not concerned with altering forms of treatment and care, but only expanding access to medicines.

"Hepatitis C is a disease in extinction," Varaldo says, noting that since blood testing has been implementing relatively few new cases emerge which are concentrated in certain populations, primarily intravenous drug users. Varaldo, who is 62 years old, is frustrated. "The government talks about prevention. Prevention of what?" he asks, keeping in mind the relatively few new cases of hepatitis C. "I am already tired. I am sincere about that. I don't know how much longer I will continue." Varaldo particularity and pragmatism demonstrate that discussions and criticism based solely on interests and sources of funding are poor proxies for a discussion of the merits of policy and evidence, and for a consideration of the actual complex nature of interest-laden relationship, which could certainly benefit from more transparency. Varaldo is keenly aware and concerned about how knowledge is created, disseminated and used, but he does not identify his approaches as "evidence-based." Rather, Varaldo's positions call for a focused

consideration of the forms and uses of knowledge, and more active measures concerning its fair and equitable dissemination.

Knowledge Access and Evidence Dissemination

In all, treatment access and provision is contested through the nature and content of evidence. Evidence-production is central to CAMMI's operation as both a treatment center and as a center for research on clinical effectiveness. Through CAMMI's evidence-producing practices, public scientists mount a criticism of existing scientific literature and medico-scientific practices in order to hold scientific evidence accountable to local environments of care. In so doing, however, they hold patients captive as an experimental population in order to pursue public policy interests. Judicial challenges to the treatment protocol CAMMI implements do not stem out of a conviction to treat all patients, since they are not concerned with the vast populations that cannot access healthcare. Rather, these lawsuits result from a different interpretation of scientific evidence held by physicians who encourage lawsuits and an aggressive approach to treatment that views disease as necessitating immediate eradication. Lawsuits under the banner of the right to health put into practice a hyper-individualized and technology-centered conception of health provision that fails to take into account patients' broader social needs. Social mobilization around hepatitis C is similarly geared towards access to medical technology. In judicial and scientific disputes, actors criticize each other's positions as being based solely on interest. Substantive discussions on the role of experimentation in treatment do not take place. It appears there is a dearth of tools,

frameworks or experience necessary to meaningfully consider the applicability of different forms of evidence to particular treatment circumstances.

3

The Social Science of Side Effects

Introduction: The Centrality of Side Effects

"This treatment shakes the familial structure," Rodrigo Peixoto, a CAMMI patient I introduced in chapter 1, told me. Peixoto is married and has a 12-year-old son. "The medication causes a transformation in the body. There are days that if a pin drops you feel like turning everything upside down. Today I am dealing with it better, but in the beginning it was worse. The son suffered, the wife suffered. If anything happened you blow up, you fight, but that is normal, understand? The family is important in those times." Peixoto makes little effort to distinguish between the medication's effects on the body and the family. "The wife" and "the son" suffer just as "the body" suffers, as if they are all part of a single, but fragmented, experience. Indeed, many patients report feeling irritable and say family members can have difficulty understanding. The experience highlights the importance of "extending care," as Alma, the head nurse, put it. The staff at CAMMI instructs patients to bring family members to injections and offer to speak with family members about the side effects of the medication.

Biomedical evidence production is concerned with very specific measures concerning patient circumstances. The side effects Peixoto experiences are documented in the clinical trials for pegylated interferon. However, the prediction of the side effect, or the knowledge that it occurs, says nothing about its effects on the life circumstances and lived experience of patients and their loves ones. Anthropologist Annemarie Mol (2006) writes, "Disease, illness, technology, treatment, life. They come as a package, so it would be better to study them in this way" (412). If we care about the health and wellbeing of patients in treatment, we must bring these other dimensions of treatment-effects into view.

As we do so, we must seek to understand what, outside the health system, makes treatment and healing achievable.

In this chapter, I will present materials from interviews, observations and home-visits with patients being treated at CAMMI. The main obstacle to treatment adherence is the pernicious side effects most patient experience. Anthropological efforts to understand the consequences of disease for patients have typically focused on “illness”, the patient’s experience of disease (Kleinman 1988). This approach fails to complicate the effects of treatment, and particularly “side” effects, on patients, their experience and life possibilities. There is, in other words, no social science of side effects. Beginning to take side effects into consideration complicates a simple distinction between disease and illness, as the disease comes into view in part out of an availability of treatment and the “disease experience” is also a “treatment experience.”

Through its side effects, treatment disrupts income-generating activities and frequently threatens existing social relations, since patients find themselves unable to fulfill social roles. Patients seek, with varying degrees of success, to find alternative sources of income and must, at times, alter or refashion social relations within the family as a result of the encounter with the technology. In addition, many patients communicated the importance of religion to the healing process. Religious pursuits seemed to allow patients to transcend a strictly biomedical understanding of health, within which they were highly vulnerable, in order to more comfortably place it within a broader understanding of wellbeing. Patients did not deny or depart from biomedicine, but sought to contextualize it.

“Hepatitis C Never Did Me Any Harm”: The Sociality of Adherence

Sandra Faust’s husband Roberto always accompanies her to receive her injections at CAMMI. “She gets very annoyed,” Roberto said. “There are times when I want to be locked in a room, alone, locked in, not talking to anyone. Tomorrow is one of those days. After doing my injection today, tomorrow is a day when I’m very irritated, on bad terms with life. It passes, I take lots of fluids, then it passes, and sometimes that feeling returns. I know it’s hard. The people around me are the ones who feel it and it must not be easy,” Sandra said. The side effect from the treatment, not the disease, can damage social relationships. “I don't have even time to think about the disease. Now that I am taking the medication I get irritated. Even my granddaughter is affected. She says, ‘Ay, grandma, you’re in a bad mood, huh?’” Though this irritability is a “side” effect, it is central to the treatment experience. Even so, the full force and ramifications of side effects are not visible through clinical trials, which report only on biomedical factors. If these treatments are to be given to people with the intention of improving their health and wellbeing, we must seek to put into practice a more meaningful conception of side effects as implicated in patients’ social circumstances and lived experience. We must allow patients to speak, to participate in the making of knowledge that concerns their health, *to be knowledge-actors rather than merely knowledge-subjects.*

The medication does not merely threaten or damage social relationships. Indeed, it may create opportunities for reframing existing relationships, possibly in a way that strengthens or renews them. Sandra says she relies on an old friend who lives nearby. “Sometimes, when I get very irritated, there is a squeezing feeling in my chest; it

suffocates me. So then she comes over, even three or four times a day. So she talks, helps and it passes. It helps. I have a lot of support, from family and friends, and this is helping me." Side effects do not just destabilize social bonds. They present opportunities to re-create them, even as an effect of treatment. CAMMI staff's effort to educate patients helps them make sense of side effects so that they are not disembodied forms of suffering but part of a coherent treatment experience (see chapter 1). Patients' comments reveal another transformation that may take place, easing adherence. Through support from social relations, side effects may become a source or effect of relationships. The side effects move from being an adverse component of treatment to evidence of its importance communicated through relationships of support and care.

Levi, the private sector doctor who is also a patient at CAMMI, said he considered stopping the treatment a few months before we spoke. "I started feeling very bad physically and psychically. You feel bad all the time so you begin to lose perspective. If it were up to me, I would have stopped," Levi says. The loss of "perspective" speaks to a loss of understanding of the purpose of the treatment, of its value. As he was considering stopping treatment, Levi's wife called Alma, CAMMI's head nurse, who spoke with Levi and encouraged him to continue the treatment, to have patience. Levi says he also spoke with his private physician who gave him support.

"You must have a network otherwise you cannot do it," Levi, who continues on treatment, said. Levi's comment communicates not only the patient's need for a support structure, but also the far-reaching and potentially devastating effects of disease as well as treatment. The "diseased" and "treated" population includes not only the population of infected individuals but also those who come to be affected around them. "Isn't it enough

to know the treatment is good for you?" I asked Levi. "No," he replied. "Hepatitis C never did me any harm. I may get liver cancer in twenty years but I might also not get it. So I am here for 11 months feeling terrible. The treatment makes me feel terrible."

As anthropologist Sjaak van der Geest and colleagues write in their review of the anthropology of pharmaceuticals, "Hundreds of studies have been published about compliance in taking medication. In nearly all of them, compliance is viewed from a medico-centric perspective, and noncompliance—not following professional instructions about medication—is considered a problem" (Geest et al. 1996, 165). The authors note that non-compliance is not typically the result of misunderstanding medical orders. Rather, patients have their own rationales concerning treatment adherence. "Understanding noncompliance requires an anthropological approach to capture the patient's viewpoint. In noncompliance, patients express their rationality vis-à-vis the doctor's" (Geest et al. 1996, 165-6). Levi, an accomplished physician, demolishes conceptions of adherence based solely on medical rationality. What comes into view is what Susan Reynolds Whyte and Michael Whyte call the "sociality of treatment," that is, the social relationship that make treatment viable. The Whytes discuss this concept primarily in relation to how people gain access to health care, but remaining on treatment can also prove to be a formidable challenge (Whyte and Whyte n.d.). When it comes to hepatitis C treatment, the sociality of treatment proves crucial to an understanding and facilitation of adherence, as social relationships transform side effects into sites of support. CAMMI's staff recognizes the importance of these social relationships to adherence and work to harmonize them through education and care.

In AIDS treatment, the use of "supporters" has shown to be successful in improving treatment adherence (Ware et al. 2009). These supporters are "laypersons nominated by patients to help with treatment adherence. They remind patients of dosing times, and often (though not always) witness dosing. They are not health care workers, but individuals with close personal ties to patients. As family members or friends, treatment supporters often live in the same or a nearby household. Treatment supporters are not specifically trained or paid, but nonetheless make a formal commitment to their role" (Ware et al. 2009:40). In CAMMI, there is no formal commitment for family members to help with adherence in the same way, where patients must take complicated pill regimens. The challenges to adherence in hepatitis C treatment are different. Family members are important not to remind patients to take their medicine, but help them make sense of their treatment experience in positive terms that bolster adherence. "My whole family prayed for me daily," one patient told me during an interview in his home. "I felt the force of their support. They all sent me optimistic messages, which helped me very much."

Undesirable Effects and Informal Economies: Paying for Free Treatment

Just as the treatment's side effects can disrupt or remake social relationships, they can have a devastating effect on income-generating activities. Alencar looked for work for years until he finally filed a lawsuit against the state in order to retire early. Even though the treatment was ineffective, the treatment contract patients must sign releases the health system from any responsibility for harms incurred as a result of treatment. The

form states that patients understand the potential risks of treatment and will not hold the Ministry of Health accountable for harms. “I express my consent in submitting to treatment and I assume the responsibility and the risks for resulting undesirable effects.” Though Alencar’s injury was a direct effect of treatment, he was now beyond care. His inability to find work could not come into view before health care professionals, for whom his suffering did not occur in the appropriately biomedical register. Nor was he recognized as eligible for retirement despite the effects of the treatment and his inability to find new work. When he finally sued the government in order to retire, forcing recognition on the part of the state of his circumstance, it was not under the banner of the right to health. Social determinants, however, play a significant role in determining health (CSDH 2008). We may ask to what extent should health systems be responsible for addressing these determinants. The answer is simply the better we address social determinants through an integrated system of care, the closer we come to putting health within reach for people.

In order to address the effects of the treatment on income, patients frequently resorted to informal economies. Like several other patients at CAMMI, Carlos Soares is co-infected with HIV and HCV. He became very ill in 1996, was hospitalized and discovered the HIV infection. Soares, who worked as a business manager, borrowed from co-workers and family members to pay for the treatment while in the hospital. The universal ARV policy then came into effect about 8 months later and he began receiving the treatment for free and soon went back to work. Once Carlos began hepatitis C treatment, however, he found himself again unable to work. Carlos first received the conventional interferon but when we met he was 4 months into his pegylated treatment.

Since beginning treatment, Carlos had lost over 20 pounds. When he began the pegylated treatment, his worst side effect was severe paresthesia, the feeling of pins and needles, in his legs. “He stayed lying down all day and, as a consequence, became depressed, and I started getting depressed too,” his wife Nina Soares said. “I was distressed because there was nothing I could do to help, no matter how hard I tried.” During this time, Nina had learned from a friend how to make small figurines out of calabash gourds normally used to drink mate, a traditional tea. “One day I was at home lying limp and Nina came and said, ‘Come on, try to do some crafts.’ I started making the figurines and it was the best medicine I had at the time. My attention shifted from my head to the manual work.” Carlos spoke at length about the importance of manual work in his healing process. It seemed this type of work allowed him to exercise agency over his body, which was under siege by the effects of both disease and treatment.

Carlos found he had a talent for making the figures. He retired on disability but now rents a stand at the Sunday market where he sells his work. Nina’s brother’s tourism company, for which Nina worked, closed soon after Carlos began treatment and the figurines are now a crucial source of income for them and their teenage son. I spoke with Carlos and Nina in their modest first-floor apartment in a low middle-class area of downtown Porto Alegre. Their young poodle fidgeted at my feet as we spoke and their teenage son occasionally moved through from his closed-door room to the kitchen and back. At the time I visited them in August of 2009, Carlos and Nina had begun making Santa Clauses to prepare for Christmas. “Ability is something we have within us. I was enchanted to see he had this ability parked inside of him.” Through his relationship with his wife, Carlos was able to discover a new opportunity for income that also eased his

side effects. The work has also strengthened their relationship, Carlos said. “Most people don’t understand. They ask how we can spend so much time together. It’s simple and complex at the same time. If you like someone, you will want to spend time with her. There are fights, of course. But we are committed to talking them through, and we learn and grow as a result.” Social relations mediate both economic opportunities and forms of care that alter and mitigate the effects of treatment. A view of each of these as divorced from the others, misses the complex way they function and their value in patients’ lives.

When all else fails, patients may appeal to the courts. In these cases, hepatitis C may prove a resource. Ricardo Vasconcelos, who is one of twelve siblings, has cared for his 45-year-old brother who has Down Syndrome for 22 years, since their father died. Vasconcelos and his brother live in an airy one-story brick structure on the bottom of a slanted dirt lot surrounded by some houses and residential buildings. Vasconcelos worked as a cook in an industrial kitchen for 26 years. As a company employee, he was subject to a series of medical exams every six months. In 2006, Vasconcelos was fired. It took him three months, he said, to discover the cause. The latest series of exams had revealed that Vasconcelos was infected with HIV. Vasconcelos returned several times to the company to press to be rehired but was always denied. A woman from human resources suggested he sue the company and Vasconcelos hired a lawyer, but ultimately decided against it.

Instead, Vasconcelos, whose family does not know of his status, preferred to apply for disability benefits. His benefits ran out in 6 months and Vasconcelos remained an additional 3 months after that without income. He applied again for benefits, which he was granted for another six months, and then once again after that. “I continued looking for work but no one would hire me after the initial medical check-up revealed my HIV

status." During this time, Vasconcelos was receiving treatment at a local hospital. After being on benefits for a year and a half, Vasconcelos's next claim was denied on the basis that his medical exam showed him in good health. Though Vasconcelos may have been able to work, his HIV status prevented him from being hired. The HIV/AIDS treatment that prevented the infection from worsening also contributed to Vasconcelos's denial of benefits on the basis that he was in good health, revealing a crucial and crushing social side effect of the life-saving universal antiretroviral treatment policy. His disease prevented him from working while his treatment prevented him from being eligible for social benefits.

Vasconcelos hired a private lawyer and sued the state. During this time, he began feeling terrible abdominal pain. He went to a doctor and found out he had hepatitis C. The abdominal pain continued but Vasconcelos had to wait for his HIV viral load to decrease in order to begin hepatitis C treatment. He originally lost his court case but, after the hepatitis C diagnosis, won on appeal. "It was only because I had both problems that I won the case," Vasconcelos said. In her work with survivors of the Chernobyl disaster, Petryna considers "illness as a form of work" (Petryna 2002). For Vasconcelos, who was running out of options, the hepatitis C infection came as a mixed blessing, signaling a transformation from a treated patient with HIV to a sick citizen in need of care. The disease requires work in order to obtain recognition. Before the law, however, the disease is a declaration of humanity at its most vulnerable, beside which other concerns shrink in importance. Being retired has afforded much-needed security for him and his brother. Vasconcelos also rents out a smaller shack on the lot he inherited from his parents in order to bolster his income.

As demonstrated by patients' stories, engagement with a medical technology has complex, uncertain and difficult-to-resolve effects on social relations and income-generating activities. Patients mobilize various resources at once, including their social relations and constitutional rights, in order to maintain their livelihoods. These are messy yet deeply meaningful processes that demonstrate patients' pragmatism, resilience, desperation and faith, and that yield mixed results. Though the health system participates in creating these situations, it does not take any responsibility in addressing them. The health system's "selective gaze" results from a pharmaceutically-centered practice of public health (Biehl 2007a), a conception of medical technologies as having primarily positive or neutral effects, and a biomedical epistemology that elides social dimensions of care. CAMMI's staff attempts to address the social effects of treatment to a limited though valuable extent, but are not positioned to address the treatment's longer-term effects.

The World Bank's *World Development Report 1993: Investing in Health* proposed cultivating economic development as a means of improving health, recommended redirecting government spending to "more cost-effective programs," and utilized disability-adjusted life years (DALYs) to quantify disease burden (World Bank 1993). Attempts to quantify disease burden or effects on "quality of life" en masse, though potentially important for bringing suffering into view, are inadequate substitutes for an appreciation, awareness and respect of the complex ways in which, not only disease, but treatment alters and affects patients' wellbeing through the delivery of care. These effects are not due to hepatitis C treatment alone, but are tied to other pathologies and circumstances. Important for the patients at CAMMI was an opportunity to enter

informal markets and commercial arrangements, such as through Carlos's figurines and Vasconcelos's rented shack, and the chance to have recourse to the courts, though not under the banner of the right to health.

"The Drug is the Basic": Patient Knowledge

Patients not only must respond to the social and economic effects of treatment, but to its implications for their very conceptions of wellbeing and personhood. Several patients told of how they sought religion when they became sick and discussed its importance to their healing process. In practicing religion, patients exercised pragmatism and valued flexibility.

Once he became sick, Peixoto felt that he needed to engage more with religion and began attending a Spiritist center. Spiritism, which has the greatest number of followers in Brazil, is a religious doctrine founded in 19th century France that is principally concerned with communication between humans and spirits. Peixoto says that, through Spiritism, "you enter in the cycle of helping people. That's very gratifying and you end up putting your problem aside and you begin to see others' problems that are worse than your own." At the same time that he refocuses his attention towards others' problems, he accesses an empowering sense of self-awareness and personal responsibility. "There is a greater self-knowledge. You begin to see things you didn't see before. If this conversation helped me, some time ago I wouldn't think of thanking you. But now if I don't thank you I wonder why not. You will feel good if I thank you and it will do me good to thank you."

This self-reflection is made meaningful only through engagement with others. It at once makes possible greater inner peace and improved social relations “Spiritism doesn't change your life; it changes your person. What is meant for you is meant for you. God will not drop at your door what is meant for my door, and He will never give you a load you cannot carry, so we will carry it as long as we can.” Peixoto does not fault others for their failures. He accepts his lot while remaining committed to acknowledging and addressing others plight through a “cycle” of care. Peixoto’s understanding of a “cycle” of care reflects the head nurse Alma’s conception of wellbeing as something to be “exchanged” rather than “had,” something to be created through relationships.

“In whatever situation you happen to be in, you have to have a belief, no matter what it is, be it Candomblé or Catholicism. Spiritism keeps most with what we believe,” Peixoto told me. Peixoto communicates that there many paths to healing and defends a robust conception of agency. Peixoto, who has private health insurance, entered CAMMI, a public health center, unwillingly. Within the context of his treatment, Peixoto’s health is quantified in the flesh through medical exams, the results of which he cannot control. Though he has been pleased with CAMMI, outside of the biomedical treatment, he regains a consumer-like agency, choosing between different religions as possible fields of personal realization. Even as Peixoto is eager to communicate the particulars of Spiritism, he holds that its benefits can be accessed in a variety of ways. “Alone, alone, really alone, we can’t get anywhere. We need some mental, spiritual, psychiatric support, whatever it may be, something to hold on to.”

Within a purely biomedical conception of health, Peixoto is highly vulnerable, his agency limited and his situation uncertain. Through Spiritism, Peixoto accesses

continuity, stability and perspective. He does not deny biomedicine's importance; he merely places it and the disease in a wider framework of personhood and wellbeing. This move allows Peixoto to acknowledge the value of treatment but also its limitations and uncertainty. Peixoto does not utilize religion as an arena in which to rescue his agency. Rather, treatment, particularly in light of its side effects, is a decision that must be continuously remade outside of the clinical setting. His religious practice is not only a way of facilitating biomedicine, however. It has significance for his understanding of his responsibilities within numerous social relationships.

Religious scholar Robert Orsi considers how American Catholics have historically appealed to cult of saints in time of sickness through letters to saints, which he identifies as a work of theodicy. "Theodicy making is an oppositional practice in which distressed people draw on the language and gestures of the cult of the saints to construct a world of meaning and practice in opposition to the meaning and practices the dominant cultures—medical, technological, religious—impose on them" (Orsi 2005:30). The individuals writing these letters, Orsi contends, use religious language, ideas and objects to "[re-imagine] their experience" through the categories of time and space. "In this way they can reappropriate it" (30). This re-appropriation of patient experience demonstrates a need to make sense of the disease experience, but also, as in the case of hepatitis C patients, a need to cultivate a sense of agency and control in relation to disease. In Orsi's study, the meaning of the disease is made in opposition to medicine. As he writes, one of the main functions of the "devotion" to saints is to "authorize the decision not to go to the doctor" (39). In contrast, as Peixoto's experience demonstrates, engagement with religion is not necessarily in any way a rejection of biomedicine.

Orsi (2005) contends part of the significance of appealing to saints is to allow individuals to imagine a time beyond or outside of sickness. Peixoto is conscious that he may be dealing with this disease for many years. “You may be able to stabilize the viral growth but you’ll never know for how long, otherwise you may have to come for another treatment. We have hope this treatment will be decisive, but there’s no security, it’s not a certain thing. Some people get better, others don’t, six months and you’re back. So we have a long path ahead and it’s an uncertain one.” As Peixoto’s previous statement demonstrates, through religion, Peixoto makes this “disease time” into a time of contemplation and personal improvement. He is also notably able to extend the “disease time” indefinitely when he notes he has “a long path ahead,” acknowledging rather than fleeing the uncertainty of his circumstance. This acknowledgment is possible because Peixoto is at once within and already outside disease time. While he continues to be ill, his biomedical health is only part of his pursuit of health. Religious practice does not only facilitate engagement with biomedicine. Several features of religion observance reflect or co-opt biomedical technologies and rationales.

Carlos and Nina Soares began to attend a Spiritist center when her father was ill. Now, every Thursday night, before his Friday morning interferon injections, Carlos goes to a Spiritist center to listen to a lecture and receive a blessing from a medium. He takes a plastic water bottle to the center and places it before the medium to be energized. Carlos identifies the energized water as a key component of his religious practice and healing process. As anthropologists Sjaak van der Geest and Susan Reynolds Whyte (1989) write, the “charm of medicines” results largely from their concreteness. “If the problem is physical, then the remedy should be physical. Medicines appear the perfect answer to the

problem" (355). The water, as an object to be regularly ingested in order to help with healing, has features of a medical technology. However, it also contrasts with the interferon in significant ways that provide insight into interferon's limitations as a technology of care in relation to patients' needs.

In contrast to the pegylated interferon injection, which is administered once a week, the energized water is to be taken slowly throughout the week, Carlos told me. "We bring the water home and I take a sip once or twice a day. Why? Because it does good for my body, it will do good for my mind, it will do good for my spirit. When I drink the water, I try to concentrate, I try to pray. I understand that this will do me good." Unlike interferon, which is understood to act directly on biology, the energized water involves positive action, the intent to heal, which involves agency. Also unlike interferon, the energize water is created in collaboration, rather than merely administered. Carlos and Nina take tap water from their home in plastic bottles to be energized in the center and then bring it home again. The "intent" involved in the use of energized water can be understood as an attempt to mobilize a placebo effect in treatment.

Historian Anne Harrington (2006) traces the history of understanding of the placebo effect from "medical humbug" to "scientific confound" to "powerful mind-body intervention." Harrington (2006) writes, "So a phenomenon that began as an impediment to rational scientific inquiry is now increasingly accepted by mainstream medicine as a legitimate and productive object of scientific inquiry. A phenomenon that began as quackery, deception and domination is now embraced by various counterculture strains in our society as a means of healing and personal empowerment" (191). Throughout this history, medical professionals attempt to make sense of what appears as a threat to their

authority. Unable to deny its significance, biomedicine has seemed to co-opt the placebo effect, recognizing its potency in order to construct its biochemical mechanism as still to be understood. Harrington (2006) states, "What I think is most important for our purposes here is the extent to which all this apparently hard-nosed biochemistry and neuroscience would, quite quickly, become a critical resource for the critics of technocratic medicine, the advocates for patient empowerment, the celebrants of holistic medicine" (191).

The recognition of a materiality underpinning the placebo effect legitimizes it, making it into a tool to empower different groups against biomedical establishments. Even as these groups criticize biomedicine, however, they reaffirm its fundamental premises by making use of the "hard-nosed biochemistry and neuroscience" to bolster their claims. In contrast, Nina and Carlos Soares do not talk about the energized water's significance in terms of a strictly biomedical conception of health. The water's benefits are real but not biological. As Carlos states, the water is "good" for his "body, mind and spirit." The distinctions between the "body, mind and spirit" are deemphasized. The water's potency does not lie in the biomedical domain.

It is significant that Nina, who is not infected with HIV or hepatitis C, takes the water as well. "The water is not a medicine," Nina says. The water feeds a person and addresses a kind of wellbeing that exists regardless of the presence of disease. By stating the water is not a medication, Nina protects water from possible biomedical claims of its ineffectiveness. She protects its potency from a biomedical establishment that has co-opted the placebo effect and that is already on the warpath against "alternative medicine." As New England Journal of Medicine editors Marcia Angell and Jerome Kassirer write, "It is time for the scientific community to stop giving alternative medicine a free ride.

There cannot be two kinds of medicine — conventional and alternative. There is only medicine that has been adequately tested and medicine that has not, medicine that works and medicine that may or may not work" (Angell and Kassirer 1998). Angell and Kassirer (1998) claim the increasing use of alternative medicine is explainable in part by "disillusionment with the often hurried and impersonal care delivered by conventional physicians, as well as the harsh treatments that may be necessary for life-threatening diseases." Patients in CAMMI are pleased with the care they receive, however, and the "harsh" treatment they take is not for a "life-threatening" disease. A more reasonable hypothesis is that biomedicine, as a result of its epistemological rigidity and commitment to being a totalizing system, is unable to address patients' needs. A person is not only her biology nor is disease only biological. It is no surprise, then, that patients continue to seek treatment outside of biomedicine, which fails to recognize these realities.

I accompanied Carlos and Nina Soares to the Spiritist center one Thursday night. We met in their apartment and walked a few blocks to the center. On the way, they instructed me to the as quiet as possible once inside. As we entered the Spiritist center lecture hall, we were each given a numbered chip. After the lecture, numbers were called and individuals waited to enter to rooms adjacent to the lecture hall to receive blessings. In the room were three chairs, on which we sat. Three spirit mediums dressed in lab coats put their hands over us for a few moments and then we were dismissed to leave. As we walked out of the Spiritist center on Thursday night, Carlos pointed out a poster in the entrance purporting to show a scientific study conducted in Japan of the effect of human emotions on the molecular structure of water. Even as religious practice allowed Carlos

to transcend biomedical measures of health, the Spiritist center made use of medical technologies of legitimization, through lab coats and the poster of the scientific study.

In his essay *Religion As a Cultural System*, Clifford Geertz (1973) writes, "As a religious problem, the problem of suffering is, paradoxically not how to avoid suffering but how to suffer, how to make of physical pain, personal loss, worldly defeat, or the helpless contemplation of others' agony something bearable, supportable—something, as we say, sufferable" (104). In this construction, as in Orsi's, people are pressed to give meaning to conditions they cannot control. The patients in CAMMI, however, are making their conditions, defining the terms of their disease and constructing their own "treatment" regimens, with energized water, for instance. Geertz (1973) writes, "For those able to embrace them, and for so long as they are able to embrace them, religious symbols provide a cosmic guarantee not only for their ability to comprehend the world, but also, comprehending it, to give a precision to their feeling, a definition to their emotions which enables them, morosely or joyfully, grimly or cavalierly, to endure it" (104).

Patients, however, make use of both religious and biomedical symbols, as seen in the lab coats Spiritst mediums wear or the scientific poster in the Spiritist center's entrance. Religion, biomedicine and other fields have always already contaminated each other's signs. One of the tasks of analysis should to be identify where individuals guard certain distinctions, such as between "medicine" and "energized water," and ease the dissolution of others, such as between "body, mind and spirit," all of which benefit from the energized water. Beyond the concept of a "cosmic certainty," we should ask how patients achieve, despite the seeming incompatibility of fields such as medicine and religion, a *confluence of knowing* that is always subject to revision.

Vasconcelos said he searched for religion when he had become depressed after learning of his HIV infection. Vasconcelos, who says most of his friends have died of AIDS, began attending the Universal Church of the Kingdom God, an international Pentecostal religious organization founded in Brazil in 1977, after seeing it on television. He now attends church three times a week and frequently reads from the Bible. “I needed it, you know? I needed to search for something for myself, for my spiritual life. I needed to strengthen myself, because if my spiritual life is shaken my problem becomes worse. I’ve felt that. One thing pulls the other.” Vasconcelos wept as he told me the pastor’s words to him. “‘You’ve come this far. Don’t abandon it now.’ And I never did.” I accompanied Vasconcelos to service one afternoon. The preacher hopped and hollered at the front of the 5,000-seat cathedral, which looked part church and part sports arena. At one point the preacher began selling CDs to “defeat Satan” and, at another, his aides handed out envelopes for people to put 10% of their salary in order to secure their “parking spots in heaven.” Vasconcelos gave me ironic looks at these moments and spent much of the rest of the time sending text messages from his cell-phone. When it came time for songs, however, Vasconcelos rose and sang loudly and out of key, as I stood uncomfortably by his side.

“If you take treatment and don’t look for anything beyond it, you’ll go nuts. I know because I’ve known people who have died this way. I’ve been able to assimilate the two things, the treatment with spiritual life. I know the drug is the basic, you can’t do without it, but you must search for the other side also. You must have an accompaniment; mine is my spiritual life.” Assimilation is not a description of the relationship between biomedical, religious and other systems of knowledge, as Vasconcelos could not

articulate a synthesis of these systems, nor is he interested in doing so. Assimilation refers, rather, to the experience of engaging these seemingly opposed systems in a way produces a *confluence of knowing*. Even though the Pentecostal church does not offer the same doctrinal flexibility as Spiritism, Vasconcelos communicates that religion is *his* accompaniment, leaving room for other practices to complement treatment. The challenge, Vasconcelos sees it, is to "assimilate" the two. He does not attempt to synthesize biomedicine and religion, but fluidly integrates them in practice, allowing components of each to exist and act with the other. This assimilation allows Vasconcelos to engage with multiple forms of care and realization without conflict or contradiction. In addition to attending church, Vasconcelos volunteers as a cook in two day care centers. "It is therapy for me," he said.

"The emptiness a person feels in his heart is the absence of God," Beatriz Luz, a nurse technician at CAMMI, told me. "A person can live searching, searching, searching for things without knowing the reason. When the person gets it, he wants more. It's never enough." Luz is careful not to speak of religious matters with patients. However, she understands patients' search for retreatment through judicial means as a misplaced desire for hope. "I think the individual doesn't want to accept it. In the moment someone discovers he has the disease, he thinks he is going to die." To Luz, religion allows patients to see that hope and wellbeing can exist outside of biomedicine and that disease is not an all-consuming threat. Without this perspective, patients may feel imprisoned within biomedical measures of health, according to Luz. The sense of imprisonment is expressed as an intense fear of death before which all medical measures must be exhausted. Luz's understanding of religion's place with regard to treatment is highly

compatible with patients' experiences in religious practice. She is also implicitly mounting a criticism of the aggressive approach to treatment physicians who encourage lawsuits advocate, in which disease must be eradicated at all cost and regardless of potential harms of treatment.

We find, in these accounts, that religious practice allows patients to transcend biomedical measure of health and cultivate a sense of agency. The effect is not to deny or disqualify biomedicine, but to ease patients' engagement with it through contextualization. "I am sick. I must be medicated," Carlos says, "There's no use in sitting here drinking water and praying. Faith and belief but also the doctor." Religion and biomedicine are not exactly part of some well-defined larger system of wellbeing, but serve as each other's partial contexts. Individuals occupy, then, an inter-contextual space, in which they utilize, alter and recombine components of systems in endless ways. Other dimensions of practice are also significant, such as volunteer work and charity. At first site, what results may seem somewhat like a division of labor, biomedicine treating the body and religion the mind or spirit, or disease causing suffering and religion making sense of it. What *actually* occurs is more like a dialogue mediated by patients and through which patients address their needs and forge a sense of agency and wellbeing in relation to the disease and treatment but also in the greater context of their lives independent of biomedical health.

Health Already Outside Medicine

In all, patients' engagement with a medical technology altered social relations, threatened income-generating activities and, in some cases, opened new income opportunities, all the while encouraging a reexamination of notions of agency and wellbeing. CAMMI staff-members were largely conscious of the technology's effects but their ability to address them was constrained by the health system's biomedical mandate. While the health system is responsible for exposing patients to the contingencies the medical technology creates, it does not take responsibility for addressing these. Patients can appeal to other institutions, social security institutions and the judiciary, but the patient is alone in these efforts. Alternatively, the treatment institution could already include staff and ways to address the effects of side effects and treatment failure, through the presence of counselors and social workers, for instance.

Even when patients must appeal to the judiciary to attempt to remedy the medication's effects, it is not under the banner of health, exposing a gap between how health as it conceived within biomedical treatment and how patients experience health within their broader life circumstances. The role of social determinants to health have been rigorously documented, but the possible forms for their provision are as of yet poorly elaborated. Religious practice played a crucial role in many patients' treatment experience. For these patients, health was already outside medicine. Religious engagement eased engagement with biomedicine and patients protected the significance of religious practice independent of biomedicine, even as they "assimilated" the two fields. While healthcare providers and public health officials struggle with the

uncertainties and limitation of evidence in implementation treatment, patients are knowledgeable of treatment effects and its role in healing. They forge confident, insightful and resilient understandings of treatment and health that allow them to access various fields of care and realization.

The Way Forward:

A People-Centered Approach

"Is what I imagined really possible?" pharmacist Karine Amaral, CAMMI's director since its inception and the person largely responsible for the center's compassionate care ethic, asked out loud as she recollected CAMMI's beginnings. As I have shown in this thesis, CAMMI, a reference center for hepatitis C treatment in southern Brazil, is in large part the result of efforts to "rationalize" treatment through "evidence-based medicine." A prolonged and participatory engagement with patients and professionals at the center reveals that patients are not only being treated but also sincerely and sensitively *cared for*. A view of CAMMI's practices from the perspective of health policy, international intellectual property rights, and scientific research norms shows that patients are not only being cared for but also *experimented on*. And a more concerted engagement with patients in their own spaces demonstrates that they are not only being experimented on but also *redefining treatment and healing outside of the clinical walls* and according to their own interests and imperatives. What began as a project to rationalize drug dispensation unfolded as a complex set of initiatives and operations that produced particular forms of care, evidence, experience and knowledge that are implicated, interpret, and alter global public health conceptions and practices around science, law, experimentation and wellbeing.

Brazil's universal antiretroviral treatment policy has created a precedent for the large-scale provision of high-cost and complex treatment through Brazil's ailing public health infrastructure. Experiences with HIV/AIDS and its treatment, more generally, have informed the way actors, from public health officials to NGO members to ordinary patients, understand their positions. Vasconcelos and Soares, patients at CAMMI, are both co-infected with HIV and hepatitis C. They both reported having had no problems in

their treatment of HIV. Over 10 years after the massive rollout of antiretroviral drugs in Brazil, HIV/AIDS treatment within the public health system seems to have become normalized for many. However, through continuous engagement with the health system, other pathologies are identified and other medical needs created. During the interferon treatment, Peixoto, another patient, went from 203 pounds to 185. People have asked him if he has AIDS. He explains that he is undergoing a medical treatment and that hepatitis C is not transmissible. “I feel bad telling people I am sick. It seems as if you are asking for help.” Learned attitudes and behaviors from the HIV/AIDS epidemic mold interactions with other pathologies. Just as Varaldo from the NGO Grupo Otimismo struggled to bring the hepatitis epidemic into public view and secure a state commitment to addressing it on the scale of HIV/AIDS, patients struggle to assert a disease identity independent of AIDS and the stigma that accompanies it. Public health officials and healthcare providers, too, are adjusting their approaches to treatment rollout for particular pathologies. Social scientists must be sensitive to how public health practice, treatment provision and disease experience change with these shifts.

Julio Frenk (2010), Mexico’s former Secretary of Health and current dean of the Harvard School of Public Health, proposes the strengthening of national health systems as the “next step in global progress” on health (1). Frenk’s recommendation signals a break from a recent intense history of short-term vertical global health programs. In order to improve health systems, Frenk holds, we must first expand our view of them. This expansion involves thinking of health systems “not only in terms of its component elements (like human resources, financing, hospitals, clinical, technologies, etc.) but most importantly in terms of their interrelations” (Frenk 2010: 1). Anthropologists, with their

ability to move between several fields of knowledge and practice, are well equipped to bring these complex inter-relations into critical view. This thesis demonstrates anthropology's ability to reveal how technologies are used, contested and understood by patient and healthcare providers inside and outside clinics, how evidence and science inform public health policy, and how human resources can be managed and altered to produce effective care.

Frenk (2010) also stresses that one of the goals of health systems must be to "enhance the responsiveness of the health system to the legitimate expectations of the population for care that respects the dignity of persons and promotes their satisfaction" (2). In order to do this, we must have accounts of care and its effects outside of clinical walls as well as the place of the health system in the context of how patients pursue healing in a broader way. Anthropology is, again, well positioned to provide such accounts and perspectives. Care was a central concern to staff members in CAMMI, who put into practice nuanced conceptions of adherence and wellbeing. Patients, for their part, had specific expectations of their treatment, which was already placed in a wider pursuit of health, livelihood, personhood, housing, agency, dignity, and faith. If health systems have as their goal the improvement of patients' wellbeing, then we must develop people-centered measures and accounts of how these systems operate and of treatments' effects on patients within and outside of health systems (Biehl and Petryna n.d.).

There has been increasing appreciation in academic literature on policy for the importance of "knowledge" in development and governance (Evans 2008; Foss 2007; Cooke and Leydesdorff 2006). As sociologist Peter Evans (2008) writes, "In short, to facilitate 21st century bit-driven growth, the state must be agile, active, resourceful and

able to act independently of private interests whose returns depend on restricting the flow of knowledge" (18). Such knowledge imperatives are already being widely elaborated and implemented in the field of public health. To realize the potential of health systems, Frenk (2010) writes, "it will be necessary to mobilize the power of evidence to promote change" (2). These calls for increased "knowledge governance" by top scholars and policy efforts do not yet address how knowledge is created, implemented, or what effects it can have on people. There seems to be a presumption that evidence created will be invariably true to the "real" circumstances of health systems. As an investigation of the role of evidence in hepatitis C policy has revealed, however, *evidence is always interested*. Public health officials, health care providers, and social scientists must be sensitive not only to the content of evidence, but the structures, methods and underlying premises involved in its creation, presentation and use. In particular these actors must consider the effects of evidence-production itself, especially the areas of experimentation and forms of regulation it creates, and must develop a respect and appreciation for the first-hand knowledge and experience that patients have already accrued.

While anthropology has much to contribute to the improvement of health systems and the investigation of the role of knowledge in governance, in the realm of health, as I have showed throughout the thesis, anthropologists must renegotiate their relationship with biomedicine as it is in flux. As anthropologist Annemarie Mol (2006) writes, "All too often social science researchers study the meaning of illness by interviewing patients about their hopes and fears, without going into the technicalities and the specificities of their bodily impairments and their treatment regimens" (412). We must move past tidy constructions of biomedical treatment as opposed to social healing, must refrain from

viewing social repercussions of disease and treatment solely from a biomedical viewpoint, but must not ignore or scorn biomedical measures and practices, focusing solely on social dimensions as if they were bounded. Mol (2006) writes, “The practices of living with one treatment differ from those of living with the other. These practices deserve our attention if we are interested in good care. But beware: They are as material as they are social” (407). Anthropologists must not be satisfied with examining meaning but must also consider materiality, which is always part of the making-sense of life. As I have shown, despite the real threats biomedicine poses to patients, they do not exit biomedicine, retreating to ‘”pre-modern” systems (as some would think of religion, for example). Rather, patients deliberately engage biomedicine and other systems, as disease threatens the immanence of life. In so doing, they may achieve a *confluence of knowing* that involves an understanding of their circumstances as well as an ability to fulfill materials needs and desires.

CAMMI lies at the intersection of numerous significant trends and experiments: the restructuring of health systems to improve the quality of care, a shift in treatment concerns that places more emphasis on “humanization,” strategic uses of evidence to reduce public costs, and highly-individualized forms of access-oriented social and legal mobilization. Uncertainty pervades efforts and practices meant to improve life and deliver health. Even judicial claims based on an incontestable right to health only ever secured access to medical technologies that brought to some more harms than benefits. In continuing to produce knowledge concerning these practices, we must be suspicious of panaceas and claims of rationality. An in-depth consideration of efforts to ensure “rationality” brings us into fragile institutions, areas of experimentation, islands of

excellence, spheres of legal ambiguity, and sincere relationships of care. People must negotiate these systems, areas, and institutions, exposing themselves to great risks and uncertain benefits, in order to access treatment. We will not be able to eliminate these risks or guarantee benefits. However, we will also not be able to manage them effectively without an understanding of their substance and repercussions for patients. People are not merely consumers of treatment or recipients of care. They bring value to health systems through their intelligence, histories, logic, and sensibilities. A people-centered approach to research, treatment, and care holds the potential not only to make global health theories and institutions accountable to patients' pressing needs, legitimate desires, and knowing concerns. A people-centered approach offers the opportunity to remake these theories and institutions in the image of patients' expertise and in the service of their humanity.

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[1] Pegylation is the attachment of a polyethylene glycol chains to a molecule, which is thought to mask pharmaceutical molecules from the immune system, improve their solubility, and decrease their renal clearance, resulting in a more effective drug.
[2] The World Health Organizations estimates the prevalence of hepatitis C infection in Brazil to be between 2.5% and 4.9% (WHO 2000). The number 539,000 is merely 4.9% of 11 million. It should be noted that even if the infection rate is this high, many infected patients never require treatment.
[3] Varaldo's comment reveals an obvious disregard for intravenous drug users. Hepatitis C infection rates among drug users are extremely high and are not likely to decrease without concerted action (Shepard et al. 2005).
[4] HTA has developed as a way to assess the effectiveness, safety, and cost of technologies in order to inform health and policy decisions. HTA has many definitions (Goodman 2004), but as a set of practices it includes various forms of evidence creation, analysis, and review.
[5] Rodrigues (1994) notes that one patient treated in Rio de Janeiro in the 1930s recalls in his memoir how letters from friends and families began to diminish in frequency in the first month of his stay and soon stopped. "I haven't died yet and they've already forgotten me" (Kritski and Rufinno-Netto 2000).
[6] Petryna (2009) discusses how patients at the reference center for Gaucher's disease in Porto Alegre pooled their medication when the state could not afford to pay for the recommended dosages. Ultimately, researchers at the reference center conducted research that supported a lower dosage regimen that lowered state costs. The situation in CAMMI is different, as the recommended dosages are given but bringing patients into a single center allows medication to be pooled.
[7] The Brazilian Ministry of Health organizes medications it provides in lists according to funding and distribution responsibilities between the different levels of government. The state and federal government are jointly responsible for funding exceptional medications though the state is solely responsible for their distribution.
[8] Brazil has produced vaccines, a type of bio-pharmaceutical, for many years. The production of interferon involves more complex industrial-scientific processes and is the first bio-pharmaceutical for treatment rather than prevention FioCruz has produced.

I pledge my honor that this thesis represents my own work in accordance with Princeton University regulations.

Alex Kerbel Gertner