Introduction

TB and Sociology

THE MAN was 54 years old, short and slight of build, a heavy smoker, and a habitual drinker. One day in early winter, while working in the detached garage outside his small home, he slipped and smashed his chest against the side of the car. When the pain in his chest did not go away, he went to the doctor. He was told that he had a tumor, that it was most likely cancer, and that he needed surgery. It was almost Christmas, so they told him to wait until after the holidays. The impending event hung over the family. The surgery was scheduled at a large private hospital in downtown Chicago, twenty miles from his working-class neighborhood, on the far South Side. The last time he was hospitalized was for an emergency appendectomy more than twenty years earlier.

Following the surgery, he was placed in a postoperative recovery room with another patient. Then, suddenly, he was moved to an isolation room. Nobody explained why. His son's fiancé was a nursing student and had rotations in another hospital on the North Side. She was the first to visit him after the room change. In her presence he cried, not knowing what was happening to him. He didn't understand why he had been shut away in a room by himself, or why people were walking in and out with masks on. He was confused, alienated, and afraid.

When they cut him open they found something in his lung, but it wasn't cancer after all. It was an old colony of disease which he had contracted when young, a disease that had killed many thousands, a disease which had once been considered incurable. It was tuberculosis, or TB, and for many it was a disease of the past, a disease of tenements and factories, of crowded ships and sweatshops. Like others who suffered from TB in the days before antibiotics, the man had recovered his health after a stay in a residential sanatorium. His immune system had contained the deadly bacteria, encasing them in thick scar tissue. But age and stress can weaken these internal defenses, and he now had "consumption" once again.

This was the reason why he had been suddenly switched from an open bed to an isolation room. It was a standard precaution in possible cases of infectious TB, one that is still followed to this day. Unfortunately, no one had bothered to explain. The large modern hospital, with its multi-

tude of personnel and procedures, was overwhelming to this simple and mild-mannered man. If not for the familiar presence of the student nurse, who investigated and explained the situation to him, he might have remained in the dark, unsure of his own fate, scared and alone.

The year was 1962. The man was my grandfather. The young nursing student was my mother, and she related this story to me in the mid-1990s. At the time I was a health worker specializing in tuberculosis control, working for a large public hospital in downtown Chicago. I recount the tale here for several reasons, not only to show my own family's connection to the long and tragic history of this disease, but also to demonstrate that the issues discussed in the following pages are nothing new: the alienating experience of the hospital, the fear of a deadly diagnosis, the cultural distance between the neighborhood and the medical institution, the impact of poverty, addiction, and social class, and the persistent problem of compliance. I did not know my grandfather—he died when I was only four years old—but after many years of working with TB patients in the field, his story seemed familiar enough.

My own involvement with the disease began when I was in my twenties. In 1992, I was one of many individuals hired by the city of New York to aid in the struggle against a resurgent wave of urban tuberculosis. I was a field-worker, and my duties included interviewing patients with active, infectious TB, tracking "delinquent" tuberculosis patients, returning them to clinical care, and threatening "noncompliant" patients with involuntary detention, or quarantine. In late 1993, I accepted a job working with tuberculosis patients back in Chicago, the city where I was born. From November 1993 until July 2000, I went out every day to meet TB patients and to watch them swallow their pills, ensuring their successful treatment and thereby limiting the spread of the disease. After hearing that story from my mother, I wondered what it would have been like to attempt to do this job with my own grandfather. According to my mother, he was a nice man, but he was a lousy patient. He was the unschooled son of Polish immigrants, a steel worker for more than three decades, a shot-and-a-beer kind of guy. In later years, he was diagnosed with advanced emphysema, but still kept up his old ways, smoking and drinking with his buddies in the neighborhood. If not for the strong hand of my grandmother, who was also known to drag him out of corner taverns on occasion, he might have been "just another skid row bum." I had dealt with homeless, alcoholic Polish men in both New York and Chicago, and I knew how difficult and stubborn they could be. When I saw these guys on the street, I couldn't help but imagine that they were fathers, uncles, brothers, husbands, that they were also a part of a family and community, as my grandpa had been.

Seeing TB patients as members of families and communities was not always easy. As a public health worker, I was conditioned to see them in terms of their infectiousness, their treatment regimen, and their willingness to cooperate. I was not a doctor, but I was working out of a medically defined paradigm. In the standard medical interview, the practice of taking social history is an accessory to the doctor's main goal of isolating the condition or infectious agent, and treating it through direct intervention, either chemical or surgical (Waitzkin 1989, 231). Social context and personal biography are considered seriously only insofar as they affect the likelihood of successful medical treatment. Addressing social conditions takes a back seat to the more immediate task of isolating and eliminating the germ within the body. This is especially true when the practices of medicine and public health take place within institutional domains, such as offices, clinics, or hospital rooms.

However, when you leave these controlled settings and enter "the field," you can no longer ignore the other factors involved, because they stare you in the face wherever you go. You see babies sleeping on blankets on wooden floors, wearing nothing but soiled diapers, and playing with their siblings, cousins, and neighbors in fenced-in yards of dirt. You see boarded-up windows and gang graffiti layered like scabs and scars on once-resplendent houses and buildings. You see neighborhoods with no grocery stores or bookstores, but liquor stores and currency exchanges on nearly every corner. And, in my case, you can't help but notice that you are often the only white person there.

At the same time, you also notice that the vast majority of people treat you with the same respect that you treat them. You see that they are honestly trying to deal with their lives and get through each day in the best way they know how. But you also come to understand, through the evidence before your eyes, that the circumstances they face are worlds apart from those taken for granted by people who reside just miles, or even blocks, away. In another time, another place, another society, the person sitting before you, sick with TB, infected with HIV, addicted to drugs, saddled with a felony conviction and hard memories of years behind bars, the shadows of poverty, violence, and racial or ethnic exclusion following them wherever they go, could have been your brother, sister, father, or mother, and could one day still be your own child.

As a public health field-worker, employed first in New York City and subsequently in Chicago, I tracked the disease of tuberculosis across the urban terrain for more than seven years, treating it in the social soil where it grew. From this perspective, I saw that tuberculosis was only a small part of a larger problem for many individuals, and that medical treatment, while effectively curing the disease, often failed to address the conditions

that actively undermined their health. Due to the duration of tuberculo-
sis treatment, ranging from at least six months to as long as three years,
field-workers charged with administering medications for tuberculosis
enter into long-term relationships with TB patients. Lacking the expertise
and the authority of physicians and nurses, these workers are nonetheless
confronted with the personalities and daily physical troubles of patients
in ways that many medical professionals are not. Within the more med-
icalized environment of the hospital or clinic, it is relatively easy to ignore
or overpower patient concerns, and poor patients in particular may have
few means for contesting the ways in which they are treated. Patients who
are truly upset may simply leave the hospital or clinic (proving to some
that they were not "really" sick to begin with), and patients who are
acutely ill will stay because they have little choice. But the TB field-worker
must adapt to the patient's environment, and this poses a different set of
problems.

Success in the field was often a by-product of intangible negotiations,
social relations that determined whether or not a person would be trusted,
even if an institution was not. Accomplishing this required some degree
of empathy, some willingness to see things from the point of view of the
other person. To borrow a phrase from one of my supervisors at the
Health Department in New York City, patience and persuasion were our
only tools. Concerns of patients that might have seemed trivial from the
standpoint of the hospital took on more weight when one entered the
neighborhood or home where a person might be existing in extremely del-
icate circumstances: sleeping on a friend's couch, for example, worried
about being kicked out on the street if the nature of the illness is known,
or existing on a daily basis within a street environment dominated by ille-
gal activities, where discretion and respect are fundamental values, and
the threat of violence is a constant.

Seeing the disease within this socially embedded context was what
finally led me into another field—that of sociology. I entered a doctoral
program in 1994, while continuing to work the streets, treating tubercu-
losis. As a sociologist by night, analyzing my day job in public health, I
traversed much theoretical terrain, ranging from the sociology of health
and illness to the sociology of poverty and inequality, from urban sociol-
ogy to the sociology of occupations. I discovered that the theoretical per-
spectives found in sociology were quite comparable to those employed by
individual patients, health workers, and the media. Beyond this, sociol-
ogy provided a means of addressing questions that were not even raised
by a purely biomedical account of tuberculosis.

Biomedicine is commonly defined by sociologists as the reductionist
analytical mode which views "health" as the absence of disease or pathol-

ogy in the individual human body. Through its use of technology, modern medicine provides a means of identifying, isolating, and eliminating the sources of disease within the biological body, in the same way that a mechanic removes a faulty part or system from a malfunctioning machine. Specific illnesses or syndromes are caused by specific agents such as germs, viruses, or toxins and modern medicine spends much of its time and energy developing chemical or surgical weapons specifically designed to destroy or remove these agents. The diagnostic microscope of the medical eye tends to systematically cut away all but the specific targets of those weapons. In the process, human beings may be neglected, even when their own bodies are under the gun.[1]

The sociological critique of medicine usually takes one of two forms. The first might be called the *social forces* position, because it focuses on large-scale, structural factors, such as poverty, racism, economic depression, or environmental degradation, examining their impact on the health of whole communities rather than individuals. Some of the best examples of the social forces position relate directly to tuberculosis. Medical sociologists McKeown (1979) and McKinlay and McKinlay (1986) have demonstrated through historical studies that dramatic decreases in rates of tuberculosis in the United Kingdom and United States occurred prior to the development of effective medical treatment. They attributed these decreases to improvements in material well-being and public hygiene rather than improvements in medicine. The "heresy" thus advocated by medical sociologists like McKinlay strongly asserts that medicine as a professional practice actually has very little to do with the health of populations as a whole (McKinlay and McKinlay 10). Rather, the most important improvements have come as a result of social or political movements or environmental improvements which have addressed basic inequities in the distribution of resources and services.

The second critique, which I shall call the *illness experience* position, considers the subjective accounts of individuals who are coping with disease, disability or death, placing emphasis on the meanings of illness within specific contexts, and how these are mediated through interactions with institutions, communities, and others. Social histories of tuberculosis, such as those by Bates (1992) and Rothman (1994), examine the specific experiences of tuberculosis patients and their physicians in social and historical context, demonstrating how the patterns of both disease and treatment were shaped by the society in which they occurred. These works provide ample evidence that medical care never takes place in a vacuum, as much as it might aspire to do so. Many sociologists see the practice of medicine as containing an implicit ideology which, by focusing exclusively on individual symptoms, treatments, and behaviors, actively inhibits a

more expansive social definition of health. Problems defined as "medical" are assumed to be properly addressed by medical means and medical expertise, which effectively removes them from contestation within the social domain. Occupational injuries, for example, may be treated medically as individual ailments, through physical therapies, behavioral interventions, surgery, or drugs. In the process, the cultural or class dimensions of these conditions may be obscured.[2] Like the social forces position, the illness experience position highlights dimensions of health and illness that fall outside the purview of standard medical practice, and lie instead in the realm of the social. This book is informed by both critiques, as I consider historical and economic forces, the intervening influences of hospitals, neighborhoods and public health agencies, and the accounts and experiences of individuals afflicted with tuberculosis in the urban United States in the 1990s.

After years of working in the field, I concluded that tuberculosis necessitates sociology in order to be understood. It cannot be separated from its social trappings. Like many other afflictions, TB primarily affects the poor. What makes TB different is the fact that it is infectious and airborne. In general, people do not worry that schizophrenia or alcoholism will be passed along to them on a subway train. But the fear of lower-class contagion in public places profoundly affected the response to resurgent TB in the 1990s. Such fears, informed by deep social divisions, were reflected in disease control practices at both the institutional and state level. As a disease that is only "a breath away," TB carries a fear component potentially greater than that of HIV/AIDS. This fear is easily transferable from the germ to those individuals (or classes) most commonly associated with it. In fact, as a high proportion of both TB and AIDS patients are from similar demographic groups, attitudes towards them have often been conflated. TB and AIDS, like other high-profile social problems associated with "the underclass"—homelessness, street crime, drug addiction—have in their time been both causes for public alarm and targets of public policy. Because TB cases are directly monitored by government agencies, the relationship between medicine and the state is also an important part of the picture. Seeing tuberculosis sociologically, therefore, requires not only a consideration of large social forces such as race, poverty, and inequality, but an analysis of the discourse and practices of institutions such as medicine and public health, which are empowered by the state.[3]

All of these forces play out dynamically within the contexts of actual human lives. To catch them in active interaction, I have used narrative and ethnographic methods. By focusing on the level of lived experience and seeking to capture relations in vivo, within a concrete chunk of geo-

graphic or experiential turf, ethnography provides an array of means for locating and illustrating the multiple overlapping linkages between individuals, the immediate social contexts that surround them, and the larger social landscape (Dyck 244). Though theoretically informed, this approach can sometimes yield results that complicate rather than confirm the expectations of social theory. In a 1980 interview, Robert Coles quoted Flannery O'Connor, who stated that "The task of the novelist is not to resolve mystery, but to deepen it!" Coles then went on to say: "The danger with social science, the danger with any kind of intellectual process, is that we take ourselves too seriously, and that we forget the difference between products of our own thinking and the world itself. We impose our own notion of reality on the world and see only our notion of reality rather than the defiant complexity of the world—and of course the mystery of the world" (Coles 66). As both a writer and a social scientist, like Coles, I wish to explain social reality and to describe complex human situations. I employ ethnography and narrative as tools to express, however imperfectly, the ways I related to and documented these human situations.

In a sense, the view of disease revealed by the tools of ethnography is both broader and more fragmentary than that provided by biomedicine. Seeing people as complex human beings, living within meaningful social worlds, grants us a greater appreciation of their creativity and individuality. Narrative accounts show people as nuanced and complicated individuals, both fascinating and frustrating in their idiosyncrasies. At the same time, narrative returns illness and suffering to its "natural" environment: embodied, social, and embedded in daily life. Through them we can see the specific ways in which social forces impact people. As Brody (1987), Kleinman (1988), Frank (1995), and others have extensively argued, stories constitute the stuff of which everyday life is made. They are not optional, but necessary components of human life (Frank 1998a, 330). Narrative can help to return to people some of their power and their agency, which may be marginalized by professional discourse. According to Foucault: "The chronicle of a man, the account of his life, his historiography, written as he lived his life formed part of the rituals of his power. The disciplinary methods reversed this relation, lowered the threshold of describable individuality and made of this description a means of control and a method of domination" (Foucault 1977, 191). The restoration of the human chronicle, then, can potentially counteract those very forces of domination that Foucault so meticulously describes in all his writings on power and knowledge.

For evidence of this, those working in the field of health and illness need only listen to patients themselves. Wherever they encounter the

health system, people tend to use their own experience as a critical measure of the efficacy of medicine. As one TB patient said to me, "I live in this body twenty-four hours a day. I know everything that goes on here." He was using his own bodily awareness as both a counterweight to medical expertise and as a yardstick for its success. The social concept of "health"—as it is defined subjectively and contextually—therefore provides a means of criticizing "legitimate" or "official" medical knowledge (W. Wright 13). Sociology can be a vehicle for such protests, voiced by individuals in dialogue with institutions, professions, and other organs of organized expertise on a daily basis, to gain legitimacy of their own.

In *The Alchemy of Illness*, Kat Duff compares the experience of being ill to that of occupying some subterranean land—an underworld: "There is, perhaps rightly so, an invisible rope that separates the sick from the well, so that each is repelled by the other, like magnets reversed. The well venture forth to accomplish great deeds in the world, while the sick turn back onto themselves and commune with the dead; neither can face the other very comfortably, without intrusions of envy, resentment, fear or horror" (Duff 11). On the social level, poverty, especially when intertwined with race, has a similar alienating effect, on both the people who suffer from it and those who don't. The ghetto, in particular, has a relation to "mainstream" American culture which mirrors the underground world of illness. It turns inward, sharply conscious of its own exclusion, while those who venture into the ghetto from outside its unguarded but very real borders are always conscious of their intrusion.

Health and wealth are often accompanied by an unspoken arrogance. Those who have look down on those who don't, often without realizing it. We don't identify our own daily lives with the struggles of poor and sick people, we tend to morally judge them for their failure to conform to the norm. Such an uneven relationship can be unwittingly replicated by the research process. Prescriptions—both medical and social—are usually made from the high ground of relative health and wealth, from which position it is quite easy to believe that one possesses the right answers. "After all," the logic goes, "this problem that we are studying is not a problem for *us*. It is a problem for *them*." In the same sense that the opinions of the poor and the sick regarding their own condition are relegated to a category of "subjective" knowledge, so does the *stigmatization of subjectivity itself* contribute to the continued subjection of the poor and the sick. In a study such as this, which deals primarily with the stories of poor, sick people, it is doubly important that the actual words of subjects share space with those of the author.

In addition to providing a context for suffering, narrative is a mode of conveying sociological information which allows the sick, the poor, and

the otherwise excluded to determine at least some of the terms by which they will be known. This is in direct contrast to the usual modes of biomedicine and positivist sociology, which routinely place individuals—or their words—within categories or typologies, as though an entire complex and contradictory existence could thus be collapsed into a ready receptacle. The same argument might be made concerning the academic or professional treatment of the colloquial spaces where many people spend their time. Again, this is especially true in poor urban communities, where physical decay of the built environment, economic devastation, cultural identity and spiritual despair go hand in hand, and where the stigmas placed on individuals, groups and places often become interchangeable. Such entangled processes of deterioration and adaptation, over time, have profound consequences for health.[4] This complex set of relationships comes together within the context of the local life-world as revealed in individual experiences and accounts of illness.

For this study I conducted more than twenty semiformal audiotaped interviews, ranging in length from forty minutes to three hours, and countless more informal interviews in all manner of locations and situations. My interviews dealt directly with the tuberculosis experience: how the disease was first diagnosed, what the symptoms were like, the experience of treatment, and so on. In the process of examining these issues, however, I also asked about the social circumstances that surrounded the emergence of the disease. Oftentimes, I would pursue these other threads. As I did so, I saw certain themes emerging repeatedly: the omnipresence of violence, the interaction with institutions and bureaucracies of various kinds, the influence, both positive and negative, of local social ties and networks, including the presence and absence of family, gender roles and sexual relations, and the all-pervasive influence of race, poverty, and economic struggle.

In my interviews, I sought to probe the connections between neighborhood social characteristics, and individual lives and fortunes. I paid close attention to references to violence, stories of family stability and disruption, daily dramas of microeconomics (jobs, hustling, welfare benefits, and so on), influence of local social relations, and regular interaction with local and state institutions and bureaucracies: police, hospitals, prisons, jails, welfare offices, schools, and so on. As a field-worker, I also observed these interactions first-hand, both in the institution and in the street, and I took extensive notes during more than seven years of fieldwork in the area of tuberculosis control. Some of these notes were written before I officially began my dissertation project, but remained relevant nonetheless. In the end, my shelves contained more than twelve hand-written journals, in addition to copious notes made on my home computer.

Organizing this amount and variety of data was a potentially daunting task. In the end, I used the disease as a guide and the role of the public health field-worker as a lens. I saw the data falling into discrete, yet organically linked, domains. As a TB control specialist, I learned the "facts" about the disease before I ever saw any patients. I met TB patients in the hospital initially, and then followed them into the community, where I saw the raw conditions of their lives revealed more clearly than I otherwise would have. This study follows the same path, from facts to experiences, from social theory to direct observation and back again. Important concepts are discussed as they arise, and tied to the general themes that persist throughout. The theme of observation runs throughout the book, linking the use of ethnographic method to the practice of Directly Observed Therapy, or DOT, which was central to the TB control efforts of the 1990s. In both ethnography and public health, observation is an activity that is charged with issues of social power. By placing an emphasis on the active role of the observer, I wish to highlight the crucial importance of vantage point as a component of interpretation: where we stand affects what we see and how we see it. This is true of doctors, patients, and sociologists.

In putting the book together, I was concerned with telling stories of individual humans and their thoughts and struggles, and of a more general predicament, faced by millions living within impoverished conditions. In the end, it is hoped that this study will achieve several ends. By taking the reader on a sort of sociological journey through the world of tuberculosis control in the United States in the 1990s, it may provide a view of an epidemic as seen from the ground floor, through the eyes of a public health worker engaged in daily interaction with the patients who suffered from it. In doing so, it offers insight into the sociological aspects of that epidemic, which was so powerfully shaped by prevalent conditions of political, social, and economic inequality. It demonstrates that there is an important role to be played by workers who traverse the borders between medical institutions and the communities where people live. Finally, this work argues that an ethnographic perspective, based on principles of respect and reflexivity, may inform and improve the methods currently employed by medicine, epidemiology, and public health.

I am not interested in disputing the benefits of modern medical technology, or the fine work of trained professionals who are engaged in both clinical and social struggles for health. Doctors and nurses, while identified here as part of a larger system, are not necessarily in control of it, any more than I was as a TB field-worker. They all labor within the same paradigm, just as plant managers and assembly line workers both serve the dictates of the market and the clock. Visionary physicians, from Rudolph

Virchow and Alice Hamilton, to Norman Bethune and Paul Farmer, like Hippocrates himself, have all sought to include the society as well as the individual in their diagnoses and prescriptions. No one can question the urgency of helping those individual human beings who are already sick, and seeking to relieve their most immediate afflictions. But if, after doing so, we fail to look up from the bottom of the cliff where the bodies pile up, we will continue to place Band-Aids on broken bones. This, I believe, is one of the lessons that TB has to teach: look up the cliff, follow the causal stream to its source, and question what brings people to the edge, where illness pulls them under. TB must be seen not only as a problem in and of itself, but as an index of graver social ills. Though we may treat the disease in isolation, we must recognize that it has its roots in soil we all share.

1   Bugs in the Big Apple
Chasing TB in NYC

I REMEMBER several works of popular culture distinctly influencing my decision to move from Laramie, Wyoming to New York City in the summer of 1992. First was the 1991 Terry Gilliam film *The Fisher King*, a surreal story about a radio disc jockey who is suddenly plunged from the heights to the depths of life in 1990s Manhattan, where the streets were haunted by living specters of AIDS, homelessness, and mental illness. That film captured the growing chasm between the privileged and the disenfranchised, even in an environment where they could reach out and touch each other at any moment. Mario van Peeble's *New Jack City* and Spike Lee's *Jungle Fever* also painted nightmarish portraits of 1990s New York. In these films, the devastating impact of crack cocaine on the inner city was depicted as a logical, if awful, consequence of the wholesale isolation and abandonment of communities afflicted by poverty. Such images might not make the big city seem inviting to most, but to me at age 24 they exerted a fascinating pull. If there was a gulf between races and classes I wanted to cross it. I remember repeatedly listening to U2's *Achtung Baby* album, and the lyrics to the song "Zoo Station," which said something about being ready to take it to the street.

After four years of college and two years of graduate school, I decided I was ready for a full immersion in urban reality. I had just completed a master's degree in American Studies, and now I wanted to study America up close. In New York, I thought, I could find the best and worst of everything. I hoped to find work in the Big Apple's social service sector, hopefully doing some sort of outreach with the homeless population. I had spent the previous summer working at a small homeless shelter in Santa Fe, New Mexico. After that I journeyed to San Diego, where I volunteered at a much larger shelter, and spent one night sleeping on the street with some homeless guys, whom I had met at a food line. These experiences were my sole preparation for doing social work in America's biggest city.

Before my departure from Laramie, my thesis advisor cautioned me about the "wicked cases of TB" that were going around New York at that

time, and which had already received some attention in the major media. I promised not to catch any nasty bugs. Several months later, I sat on a bench in Battery Park, at the southern tip of the island of Manhattan, eating a bagel and staring over the spangled water at the Statue of Liberty. I had just urinated in a cup and presented the product to a nurse for drug testing. It was the last hurdle to clear before I started in my new position as a fieldworker in the Bureau of Tuberculosis Control.

As it happened, a series of articles was then running in the *New York Times*. It was called "Tuberculosis: A Killer Returns," and detailed the resurgence of TB in New York City. The first installment of the series announced: "Neglected for Years, TB Is Back with Strains That Are Deadlier." Another article, with the similar title "The Return of the Big Killer," appeared in the October 10, 1992 issue of *New Scientist*. It quoted Tom Frieden, then Director of New York's TB Control Bureau, concerning the resurgence of TB disease in New York: "This was a time bomb constructed by social and economic inequality and ignited by the HIV epidemic" (Phyllida Brown 31). In the same article, Frieden also declared that the number of health workers employed by the city would increase dramatically in the following months. According to these reliable sources, I was entering New York in the midst of a public health crisis. Despite my degree in an apparently unrelated field, my lack of health-care experience, and my shaggy, shoulder-length hair, I was headed to the front lines in the latest campaign against this deadly disease.

As dangerous and exciting as all of that might sound, the reality of my daily routine—like that of most soldiers, I suppose—was much more banal. My first weeks working as a New York City Public Health Advisor (PHA) were spent in three activities: learning the textbook facts of tuberculosis, "shadowing" more experienced PHA's, and sitting around a cramped office at our base hospital in lower Manhattan. The last activity was the dominant one—or at least it seemed so to me. We had textbook training downtown each morning, after which we were supposed to return to our field offices, where we spent the rest of the day studying the Core Curriculum on Tuberculosis, a series of instructional modules developed by the Centers for Disease Control (CDC). These covered every aspect of our work, from the diagnosis, treatment, and epidemiology of TB to the techniques of conducting patient interviews and field investigations. Before we ever saw any actual sick people, we learned the difference between tuberculosis infection and tuberculosis (one is symptomatic and contagious, the other is not), and we learned to categorize all of humanity into one of six classes, based on their TB status. These classes were:

Class 0: No tuberculosis exposure, not infected.
Class 1: Tuberculosis exposure, no evidence of infection.
Class 2: Tuberculosis infection, no disease.
Class 3: Tuberculosis: current disease.
Class 4: Tuberculosis: no current disease.
Class 5: Tuberculosis suspect.

The category of patient determined what the Health Department's role was in regulating and monitoring them. Class 3s had the highest priority and demanded the most attention. These were the public health risks, and our job was to ensure that they were converted from a harmful category to a harmless one through the supervised administration of medical therapy. Though one of our primary goals was that of *helping* patients with TB, our work was everywhere infused with the suspicion of transgression. Our job was to prevent it if we could, record it if we saw it, and to carry with us always the warning of potential punishment—the shadowy arm of the state, policing the irresponsibly ill.

Once in a while, we were allowed to accompany another PHA "into the field." This was what we waited for, because it meant escaping the confines of the office and actually seeing TB patients in the flesh. We did home visits in the community when it was necessary, and ventured into hospitals to see patients and review medical charts. As I made my way through the formal classroom training and worked my way into the field, it was these latter activities which came to predominate. There, in the medical records department (usually located in the basement of the hospital), we spent days turning the pages, piecing together the fragments into something resembling a cohesive narrative, describing a human life. I remember thinking to myself: behind all of this chicken scratch there breathed a real person. One man I watched, through the daily progress notes, creeping closer and closer to death: more and more medications were administered with fewer and fewer results, the drama of his demise obscured by the dry notation. The medical notations were full of arcane abbreviations: DNR—do not resuscitate, SOB—shortness of breath, IVDU—intravenous drug user, ETOH—alcohol abuser. Through the gauzy web of records we peered at the evidence of others' suffering, translated into medical code.

We learned how to pick out and record relevant symptoms, medications, and test results, as well as notes on social history, drug abuse, sexual habits, and so on. We were engaged in the practice of observing others, albeit indirectly, and of enmeshing them within yet another layer of documentation. The goal of this observation was the direct or indirect medical monitoring of every single case of tuberculosis diagnosed and treated within the political boundaries of the city. It was done through a variety of methods, most

of them enacted by "foot soldiers" such as myself and reported back in writing to a central surveillance authority. In this manner the TB surveillance system aspired to be a sort of Panopticon. One of the central concepts in the work of French social theorist Michel Foucault, the Panopticon is defined by him as: "a generalizable model of functioning; a way of defining power relations in terms of the everyday life of men . . . It is polyvalent in its applications; it serves to reform prisoners, but also to treat patients, to instruct schoolchildren, to confine the insane, to supervise workers, to put beggars and idlers to work. . . . *Whenever one is dealing with a multiplicity of individuals on whom a task or a particular form of behavior must be imposed, the panoptic schema may be used*" (Foucault 1977, 205, emphasis added).

The first manifestation of a panoptic mentality, according to Foucault, was the plague-stricken town of the seventeenth century. In *Discipline and Punish,* Foucault recounts at length the process by which the population of such a town was segmented and systematically observed by town officials. This process, this system, is paradigmatic for Foucault: "The plague-stricken town, traversed throughout with hierarchy, surveillance, observation, writing: the town immobilized by the functioning of an extensive power that bears in a distinct way over all individual bodies—this is the utopia of the perfectly governed city" (Foucault 1977, 198). It is no coincidence, therefore, that the practice of urban infectious disease control would resemble, at some level, Foucault's description of Panopticism.

At the time of my public health training, I had not read Foucault, although I was learning his ideas all the same. In doing our chart reviews, for example, we were implicitly guided by the medical gaze, seeing people as systems and symptoms to be tested, rated, and recorded. In Foucault's words, "The examination leaves behind it a whole meticulous archive constituted in terms of bodies and days. The examination that places individuals in a field of surveillance also situates them in a network of writing; it engages them in a whole mass of documents that capture and fix them" (Foucault 1977, 189). The process usually begins when the physician is confronted by a suffering human being, seeking help for something that they can't address on their own. The doctor forms a diagnosis, a medical judgment, which is further legitimated by appropriate medical technology.[1] This new "fact" is then recorded on a piece of paper, in a chart, in computers, and so on. If that diagnosis is TB or another communicable disease, it may fall within the domain of the public health surveillance system. The agents of that system start not from the patient, but from the paper, the received knowledge, the diagnosis—which is the first thing they see and the first thing they know. At that time it is the *only* thing that is real to them. Yet the diagnosis itself may not tell you very much, as the following field notes illustrate:

11/14/92

I've been working for a month and a half and have yet met only two patients in person, one Marvin Jackson and one Manuel Hernandez. Marvin Jackson lay shivering and suffering like Christ in his bed, brown body bare except for a sheet covering his groin. He was coughing and had a hard time talking. Manuel Hernandez, on the other hand, was watching movies and looked like he was ready to go home. He's being held in respiratory isolation because he has MDR TB, and his sputum smear results are still slightly positive, despite months of therapy.

1/3/93

Diana Green had almost an air of elegance when we picked her up in front of her apartment on 11th Street on New Year's Eve. She is tall and byzantinely thin and was wearing a long coat and a beret type of winter hat. It wasn't until after she got in the car that the true cheapness of her clothing became apparent—the thin canvas tennis shoes, the scarf knit out of furry pink yarn. Under her coat she wore a plastic rosary and some olive drab pants and a sweatshirt, all of which somehow hung on her ethereal body. She talked to us with a deceptive familiarity, considering that she had only met me once (in the hospital) and hadn't met Isabel at all. She freely called us by our first names and described her problems with Medicaid, methadone, and the medications in an unremitting stream.

1/8/93

Today I met Emilio Moreno, a man with green hair who recently went crazy. His wife gave me a long list of friends with odd names, saying, "All these people are poor, they're all artists, they live on the Lower East Side." I assured her that there would be no cost for any TB medical care if she received it through the city clinics. She seemed reassured. She wasn't wearing any mask in the room, even though her husband was in respiratory isolation with infectious TB. She said she didn't want to alienate him in his last moments. She held his hands and he trembled, and when I left he actually said good-bye.

In these narrative snapshots, one can detect traces of human volition, as one might glimpse the movement of a deer in the woods. From the silent suffering of the man imprisoned in his bed, to the woman who refuses to comply with infection control recommendations, to the friendly cooperation exhibited by a patient toward people whom she has barely met, all these brief instances indicate the presence of real, individual people, and not simply cases or categories. In each case, we see a public health worker, empowered by the state, entering into the private world of another's suffering, and attempting to grapple with it, not as a medically trained professional armed with diagnostic knowledge and potent pharmaceuticals, but as an ambiguous intermediary. The popular image of

medicine usually involves two basic parties: the sick, and the doctors and nurses who treat them. In actuality, in the modern medical system there are a range of other people involved in carrying out the "doctor's orders." As public health workers, we were situated between the individual patients and the large institutions of medicine and government, and were accountable to all of them. We were entrusted with the task of controlling a deadly disease, and we had been well trained in the basic facts of that particular affliction. But that did not necessarily prepare us for the complex array of people and situations that we would confront.

Around this time in my training, a doctor at a public methadone clinic told me, "I didn't go into the field of addiction control to become an infectious disease doctor." He said that twenty years earlier he would have seen three or four people die in a given year at a given clinic; now it was more like thirty or forty each year. He said that it was a different world now, and he got to spend the twilight of his career "watching young people die." On Emilio Moreno's ward the next day, I was struck by the thought that he might have died since I last saw him. His name plate was still up there next to his door, signaling that some life yet throbbed on inside. If he had indeed "expired," the name on the door would have changed. From my perspective, the difference between life and death was made manifest in such superficial details. The whole reality of the thing had not, at this time, hit me. TB still seemed to be a sort of phantom that stalked behind the walls and under the beds, pulling people down, leaving only their names and medical records floating on the surface like the flotsam of a ship. It all remained abstract somehow.

One day, after work, while sitting in a café in the East Village and reading *Moby Dick,* I saw a flyer tacked to the wall. It was a homemade missing poster, and the young man pictured on it was somebody I knew. I had met him only a couple times, through an old friend of mine. He was a very polite and friendly guy, about my age, who had moved to New York to begin an acting career. Then one day, after leaving a New Year's Eve party, he disappeared and was never seen again. As I sat there in that café, I was suddenly struck with both the inevitability and the unpredictability of death. A passage from *Moby Dick* expressed this beautifully, as the narrator Ishmael discusses the ropes that encircle the crew of a whale-boat: "All men live enveloped in whale-lines. All are born with halters around their necks; but it is only when caught in the swift, sudden turn of death that mortals realize the silent, subtle, everpresent perils of life. And if you be a philosopher, though seated in the whale-boat, you would not at heart feel one more whit of terror, than though seated before your evening fire with a poker, not a harpoon, by your side."[2] In a similar way, public health workers employed in the control of a fatal disease had to be aware of the

dangers posed by hidden microbes, and the thin lines between health, disease, and death. It was only a mask or a shaft of sunlight or an open window that prevented bacteria from leaping from another's lungs into our own. Given the proximity of our work to these hazards—or perhaps because of that very proximity—we were also to some extent oblivious to their very real impact on our patients' lives. I remember asking my supervisor, when I first started, about the frequency of death among our TB patients. He just said, "Oh, yeah, a lot of our patients die." This was simply a fact, and did not in itself mean that we had failed. The Health Department's primary concern was with the TB, not the TB patient.

Later I learned that most of these deaths were not directly caused by TB. This explained the apparent nonchalance exhibited by public health workers when informed that a patient was, in fact, dead. My first assigned case illustrates this. I was given a file for Miguel Ochoa, which had several phone numbers on it. Calling these in succession, I was able to learn that the individual in question had recently been incarcerated. I then called the jail at Rikers Island and talked to an employee there, who told me that Miguel had "expired" while in jail and while receiving treatment. This seemed a very strange term to use. When I relayed it to my fellow health workers, they simply congratulated me on having tracked him down and told me I could close the case, since there could be no more sure end to the trail of TB than death in a jail that had decent infection control practices and clinical facilities. So, without ever meeting this guy, I could take credit for having tracked him down and "completed" him; thereby generating more proof that the system worked. A lot of tuberculosis surveillance was done in exactly this way, working the phones, nailing people down to a location or condition that could be verified and recorded, so that the criteria for treatment could be satisfied, and cases slid down the scale of urgency, from class 3 to class 4.

When Foucault speaks of the "petty machinations of discipline," he is referring to this kind of snooping, intrusive power (Foucault 1977, 170). I became more aware of this particular function of public health, in February of 1993, when I was given a new position. The Bureau was being reorganized and all PHA's were assigned to one of three units: the hospital-based Interview Unit, who saw patients in the hospitals and maintained relations with social workers and discharge planners; the office-based Patient Monitoring Unit, who were responsible for keeping track of all patients currently on TB therapy, and the field-based Return to Supervision (RTS) Unit, who would spend the majority of their time tracking down "delinquent" cases of TB and bringing them back "into the system" (which usually meant reconnecting them with some form of clinical care). I was named to this

unit, the so-called TB "SWAT Team." As such I became an agent of both discipline and surveillance. I was not quite twenty-five years old, and assigned to police New York City for disease. Out of the forty-seven PHA's assigned to Lower Manhattan, there were only eight in the RTS unit. Meanwhile, there were 3,811 cases of TB diagnosed in New York in 1992, and 1,296 of these were in Manhattan, which also had the highest concentration of multi-drug-resistant (MDR) TB in the country. We were given use of city-owned vehicles to help us accomplish the task of finding and retrieving people. We were also assigned the responsibility of documenting noncompliance and delivering legal orders of quarantine or detention, signed by the Commissioner of Health.

To be considered officially cured of TB required a professional examination and judgment. A previously diagnosed person, with no evidence of active disease, with no symptoms or positive bacteriology, was nonetheless considered an *active case* until a physician declared otherwise. There are sound reasons, of course, for allowing this final authority to rest with a physician, but it also reveals how the authority of biomedicine extends itself through the public health system to scattered human bodies. As an agent of this discipline, I was made very aware of the close relationship between care and coercion, and what seemed a straightforward task was repeatedly complicated by both social and environmental forces and the vagaries of human will. In the case of TB control, the target population consisted of individuals who had to be physically located, then examined in the form of an interview and processed through the medical system if possible, then placed in a category: living, dead, TB, not TB, cured, compliant, noncompliant, or UTL—Unable to Locate. Until they were officially cured, and as long as they resided within the boundaries of the defined political body, their business was ours: where they lived, where they worked, what they did in their daily lives.

In *Moby Dick,* the narrator Ishmael declares, "No, when I go to sea, I go as a simple sailor, right before the mast, plumb down into the forecastle, aloft there to the royal mast-head." As a young field-worker in New York City, this statement struck a chord. I was out there, in the midst of the vast metropolis, just trying to do my part in the mission. Like the sailor on the whaling ship, or the soldier on the line, the field-worker has only a narrow set of skills and a small degree of power, while faced with forces much larger than him or herself. As whales lurk unseen in the sea, so did the disease lie below the visible surface, enfolded in the layers of a dense and sprawling city, then folded again into layers of fluid and skin. And the city, like the sea, exerted a power all its own. The following selections from my journals illustrate some of the circumstances that we faced:

3/30/93

I finally busted out and flew solo to the Bronx today. It was some housing project way up there off the Major Deegan Expressway, and I wasn't sure what to expect. Turns out it was harmless enough. But the guy wasn't there, the one I was looking for. It was his brother's place, and of course they hadn't seen him in over a month.

Next stop was back in Harlem, where I seem to be spending a lot of time these days. I found an older man on West 140th Street, in a main floor apartment at the rear of the building. It took him quite a while to get to the door; I was about ready to leave when these guys outside told me the old man could barely walk. So I went back and sure enough when I knocked again the lock started to turn. He opened up and let me in.

Now I know the definition of roach-infested. Bugs were crawling across the floor, the walls, and the furniture as I sat there and talked to this sloppy old guy in stained gray long-johns and dull dirty black jeans with silver jewelry looped around his scrawny wrists and fingers. His hair was pushed up straight from his forehead in a mini-Don King, more a result of untidiness than style. Half-eaten dishes of food rested on the coffee table, in the kitchen the sink was piled full.

The roaches were having a field day. And it was dark and there was the feeling that the air had not shifted position in ages. Surprisingly enough there was no stench, at least not that I could detect. He said he would go to the clinic if he had a ride. I told him he had a deal and beat it out of there.

On the street was a younger guy with a missing tooth and a baseball cap. When I approached the building he had ceased his conversation and stared at me, but he turned out to be helpful. I asked him if Mr. McDonald had anyone to help him out in his apartment and he said, "Yeah, he's all right." I said, "the place is a mess," and he said, "he won't let anyone in to clean it, he likes it like that."

I shrugged and said, "What can you do?"

The suspicion one earns just by being white in some places is still startling even after you get used to it. I haven't seen those kinds of slit-eyed tough guy looks since walking into the john at the wrong time in the wrong part of the building in high school.

4/1/93

I woke up to steadily falling rain turning the world to grey. It was quite a change from yesterday. I got up early to make it in to clinic in time to meet a patient. She didn't show. Later she told me she had overslept. "First thing Monday I'll make it Mr. Paul." Uh-huh.

Around noon I got a call for "Dr. Paul." They had my man down at the methadone clinic. When I arrived he was sitting on his plastic window-washing bucket still waiting to be medicated. Apparently they wouldn't let him get his stuff until I got there. I don't think he was too pleased about that, but it was hard to tell.