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Control, Cure, and Prevention:
Situating Global Response to Tuberculosis in San Diego County

A dissertation submitted in partial satisfaction of the
requirements for the degree of Doctor of Philosophy

in

Communication

by

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2016

The Dissertation of Laurel Hodges Friedman Ayteş is approved, and it is acceptable in quality and form for publication on microfilm and electronically:

Chair

University of California, San Diego

2016

DEDICATION

For Samantha “Mance” Renfroe Wilson and Carolyn Cusic Hodges,
two strong women whose memory I keep with me wherever I go.

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LIST OF ABBREVIATIONS

ACET – Advisory Council for the Elimination of Tuberculosis

CDC – Centers for Disease Control and Prevention

CDI – Communicable Disease Investigators

DOTS – Directly Observed Therapy, Short-course

HHSA – Health and Human Services Agency of San Diego County

HIP – Home Isolation Program

INH – isoniazid

PHN – Public Health Nurse

TB – Tuberculosis

TCP – Tuberculosis Control and Refugee Health Program

VDOT – Video Directly Observed Therapy

WHO – World Health Organization

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VITA

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ABSTRACT OF THE DISSERTATION

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by

Laurel Hodges Friedman Ayteş

Doctor of Philosophy in Communication

University of California, San Diego, 2016

Professor Brian Goldfarb, Chair

There are many stories of tuberculosis: of its causes and consequences, of social injustices, of public health reform, and of the communities, individuals and families impacted by the disease. By considering the multifaceted narratives of tuberculosis, this research aims to develop a better understanding of how representations of the disease are

connected with their materializations across global and local contexts. My mixed-methods research combines an ethnographic study of the Tuberculosis Control and Refugee Health Program at San Diego County's Public Health Department; analysis of contemporary media; and historical research on public health debates and policy related tuberculosis control locally, regionally and globally.

In my dissertation, I examine the frictions between regional public health efforts and universally mandated protocols that define the problem of tuberculosis and the solutions to its control. A central focus of this project is an interrogation of normative culture and expectations for cure by shifting focus away from the micropractices of illness prevention that are implicated in the regulation of non-normative, othered bodies. Looking at misfits between globally defined public health regimes and local clinical public heath practice, my research questions the logic of the current model of "cure as prevention" with its focus on [non]compliant individuals, including how this focus sidelines consideration of the aspects of the disease and its containment that are socially produced or that vary across cultural and geographic place.

Investigating the various boundary positions of tuberculosis helps articulate the kinds of negotiations involved in enacting control programs, while reimagining tuberculosis control as a communicative space brings to life the ways that struggles over meaning reflect struggles over the maintenance of power. If dominant discourses of health and cure reinforce the bounds of the abject by positioning the disease as a conundrum of the problem body, reimagining tuberculosis control as a communicative space pushes at the rough edges of normative representation.

INTRODUCTION

A hallmark of Western medicine is the figuring of disease as something that is located within the body and separable from it. This central tenet is informed to a large degree by the Enlightenment's "discovery" of the modern subject as ensouled and sovereign, as expounded in Descartes' metaphysical work that posited a mind-body dualism.[1] Before the 18th century, Western medicine largely described disease according to the ways internal sensation reflected the inner workings of the body and manifested itself outwardly as external revelation. Diagnosis, meanwhile, was largely based on a patient's self description (Leder, 1998). In the modern Western medical tradition, however, our understanding of the relationships between the body's interior and exterior have shifted. Leder explains:

> At the core of modern medical practice is the Cartesian revelation: *the living body can be treated as essentially no different from a machine*. Though any good clinician also engages the patient-*as-person*, the predominant thrust of modern medical therapeutics has been upon such mechanistic interventions. (p. 121)

This understanding of the body positions it as an instrument of the mind that is in need of "careful training and discipline" (Lupton, 1995, p. 7).[2]

A mechanistic view of the human body served as a basis for the birth of a new kind of medicine that was said to be able to control disease, even defeat it.[3] A product of

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[1] See, for example, Descartes *Passions of the Soul* (1989 [1649]) and *Treatise on Man* (1972 [1664]).

[2] See also Judy Segal (1997), who identifies the body-as-machine metaphor as one of the most salient metaphors that informs contemporary biomedical practice. This framing is deeply entrenched in Cartesian mind-body dualism and a soul that is separate from the body. But it extends beyond medical practice to inform policy, public health decision-making, and the languages used to think about everyday life. For example, when we are diagnosed with medical problems we adopt mechanical ways to describe our situations (e.g., getting "wound-up," "run down," or "worn out") (p. 221).

the Enlightenment, the emergence of positivism and a valuing of rationality (as opposed to religion/metaphysics) helped constitute biomedicine as the central framework of medical practice. Known primarily for its application of biological principals to the domain of clinical practice, biomedicine also functions as a symbolic system that is formed through reciprocal relationships with aspects of culture that are often presumed to exist beyond its formal borders. Komesaroff (1995), for example, offers:

> The technical outcomes of medicine and its conceptual forms may convey far-reaching social effects; conversely the social forms find their expression in both medicine's theoretical structures and its practical techniques. Accordingly, medicine is not just an adjunct to culture, a tool or an implement produced by it; rather, it itself contributes actively to cultural development and change. (p. 5)

That is, medical knowledge and our understanding of disease from a biomedical perspective are shaped by and help to shape the cultural context in which they are embedded. Likewise, decisions about how to use medical knowledge to control disease are similarly constituted by and constitutive of their cultural contexts.

Situating the Study of Tuberculosis Beyond the Body-as-Machine Metaphor

If the object of contemporary biomedical practice is the human body as machine, its primary ambition is restoring individual bodies to healthy status (Komesaroff, 2005;

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[3] In *The Birth of the Clinic*, for example, Foucault (2003 [1963]) writes that the period just before and after the French Revolution was marked by "the birth of two great myths with opposing themes and polarities: the myth of a nationalized medical profession, organized like the clergy, and invested, at the level of man's bodily health, with powers similar to those exercised by the clergy over men's souls; and the myth of a total disappearance of disease in an untroubled, dispassionate society restored to its original sate of health (p. 36)."

See also Sharf and Street (1997) who explain, "The biomedical model that has dominated health care and its institutions in the United States and other first-world countries throughout the 20th century has at its core an emphasis on pathophysiology; pharmaceutical, surgical, genetic, and other biotechnical approaches to eradicating and controlling disease; and an acknowledgement of the power of practitioners, most notably physicians" (p. 1).

Leder, 1998). In the realm of tuberculosis control, a biomedical worldview has profoundly influenced standards of care, practices of control, and public policy. Scientific advances, such as the discovery of the tubercle bacillus at the end of the 19th century and the development of effective antibiotics during the mid 20th century, contributed to entrenching this perspective as dominant (Gandy & Zumla, 2002). The biomedical legacy is also reflected in public health measures that figure disease control and personal health primarily as a responsibility of the rational individual who is obliged to maneuver through a system in which the person with the disease bears the burden of disease management.[4]

Certainly, any effective tuberculosis management plan must be informed by biomedical perspectives in order to help public health care providers and policymakers better understand the biological conditions that help the disease flourish. However, as important a role as the biomedical approach to tuberculosis control has played in developing public health and medical policy, improving treatment technologies, and informing public opinion, one of its primary weaknesses is that it centers the problem of disease management on individual patients and cannot adequately account for the aspects of the disease and its containment that are socially produced. Hurtig, Porter and Ogden (1999) warn that focusing on individual compliance without also accounting for the socioeconomic and cultural issues that impact the lives of patients and their experience of

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[4] It is also important to note that idea of personal responsibility (and control) is situated alongside aspects of public health that involve larger scale social regulation and control, and the built environment (sanitation, ventilation, etc.) that have been important aspects of public health in the 20th century.

See Chapter Two for a discussion of the history of public health and Chapter Three for an examination of the ways contemporary manifestations of tuberculosis control emphasize patient [non]compliance over many other potential strategies of management.

the disease is not apt to lead to the development of interventions that are effective or supportive of the healthy lifestyles they ask of the people they address. In addition, personal experiences of tuberculosis treatment reveal a great deal about the ways tuberculosis control requires much more of patients than simply following a medication regimen. They also highlight the ways that disease management similarly involves more than managing microbes, medications, and people.

This dissertation examines the multiple and often competing discourses and practices related to tuberculosis control in San Diego County and beyond by interrogating the frictions between local public health efforts and universally mandated protocols that are responsible for defining the problem of tuberculosis and the solution to its control. There are a number of unique considerations that must be taken into account in the study of tuberculosis and its management. In the 21st century global north, tuberculosis is often described as fatal only when it is not treated properly.[5] However, the paradox of tuberculosis is that it is simultaneously curable and a leading cause of death in many parts of the world (Farmer, 2000). This situation is particularly befuddling to tuberculosis public health and policy experts in light of tremendous gains for global public health in recent years in technical domains such as antibiotic development and genetic mapping.

For the global community of tuberculosis researchers and care providers, the figures reflecting the impact of tuberculosis are by now familiar, though no less sobering: according to information compiled by the World Health Organization (WHO), about 8.6 million people worldwide developed tuberculosis in 2012, and 1.3 million died from the

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[5] For examples, see Chambers (2015), Centers Disease Control and Prevention (2014), and World Health Organization (2014b).

disease. These staggering numbers reflect a global downward trend in the rate of new tuberculosis infection, and a decreased tuberculosis mortality rate of forty-five percent since 1990 (World Health Organization, 2013), although these figures are all the more striking considering that effective antibiotics exist to treat the disease.

Despite these numbers, tuberculosis is often misconceived by people in the global north as a health concern of the past, even while it is recognized by health organizations such as the WHO as a leading cause of mortality throughout the underdeveloped world (World Health Organization, 2014b). Although tuberculosis is second only to HIV/AIDS in terms of deaths caused by infectious disease worldwide, it is far less widespread in the United States (WHO, 2014b). While the Unites States is generally considered a low-burden country, several states have rates of tuberculosis that are significantly higher than the national average, including Florida, New York, Texas, and California (Miramontes, Pratt, Price & Navin, 2013). Across the board, tuberculosis continues to have higher rates of prevalence in the United States within traditionally endemic populations that include the nation's immunocompromised, poor or disenfranchised communities, immigrants, and people who are un- or under-insured. In this regard, my study is especially concerned with the ways in which the geographic and demographic distribution of tuberculosis contributes to dissonance among variously situated contemporary discourses on this disease.

The study of tuberculosis is also important because of the significant literary and cultural attention devoted to the disease. Despite current tensions related to public awareness in much of the global north, few diseases have captured the attention and imagination of the public with the kind of enduring legacy that is attached to tuberculosis.

In the 19th century, there was no cure for tuberculosis. Although it was a deadly and dreaded diagnosis that was generally regarded as a death sentence, its status represented something of a paradox. Considered metaphorically as a disease of the (aristocratic) soul, tuberculosis was to a large extent romanticized during the 19th century, canonized in works of literature, art, and music.[6]

Sontag (1990) explains that during this time, disease was popularly thought to match the mental and moral disposition of the patient, and tuberculosis in particular was understood as an external expression of one's internal character. Consumption, as it was known at the time, was thought to fill people with a burst of energy just before their deaths that made men more creative and women more beautiful. Poets were regarded as especially prone to consumption because of an internal predisposition and creative sensibilities. Sontag was among several to note the glamorous imagery attached to this severe illness.[7] Women of means aspired to achieve a tubercular look and a tubercular body – one that was being consumed by emaciation, fever, and coughing. As Sontag describes it, the 19th century's relationship to tuberculosis was one of the first widespread examples of "that distinctively modern activity, promoting the self as an image" (p. 29). She also notes that the tubercular look emerged as an aristocratic ideal at precisely the moment in which aristocratic power was diminishing. In this sense, the beautiful and aristocratic body was dying from within.

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[6] Tuberculosis has been figured prominently in works of art, notably during the 19th century. Examples include Puccini's opera, *La Bohème*; Verdi's opera, *La Traviata*, and the novel and play based on it by Alexandre Dumas, *The Lady of the Camellias*; and several 19th century Russian novels including Dostoevsky's Crime and Punishment.

For scholarship on this subject, see Byrne (2001), Chalke (1962), and Morens (2002) among others.

[7] See also Lawlor (2006), Lawlor and Suzuki (2000), and Ott (1996).

The romanticization of tuberculosis during the 19th century belied its devastating realities. Despite the aristocratic sentimentalizing of the disease (and perhaps in an effort to negate some of its negative associations), tuberculosis was simultaneously stigmatized as a disease of poverty, uncleanliness, or moral corruption (Shrestha-Kuwahara et al., 2004). In 1882, German born physician Robert Koch discovered and isolated the tuberculosis bacillus and was awarded the Nobel Prize for his work. Although it was several more decades before an antibiotic was developed and available for distribution, not until the 1940's, Koch's discovery offered a new vision for the containment of the disease. In addition, scientific identification helped contribute to the rapid reversal of the disease's romantic representation at the turn of the 20th century along with new public health approaches to combat the disease, with many countries mounting a "war" against the disease that lasted well into the first half of the 20th century (Reichman & Hershfield, 2000).

The Etiology of Tuberculosis

Tuberculosis exists at the intersections of people, policies, and institutions. Because of this, the disease presents a set of subtle yet complex characteristics that contribute to challenges in diagnosis and treatment from a public health perspective. A contagious disease most often affecting the lungs, tuberculosis and humanity "evolved together" over time, each impacting the other (MacGregor, 1993, p. 101). What we today call tuberculosis has been a part of the public imaginary dating at minimum to

Babylonian references in 1700 B.C.E[8] and more famously in medical writings by Hippocrates depicting the state of phthisis in Ancient Greece[9] (Geffen, 2001).

Known as a "successful pathogen," the bacillus that causes tuberculosis most often in humans, *M. tuberculosis*, is a robust organism with the ability to remain alive in the air for several hours, resist many antibiotics, and wait dormant in the body for long periods of time, often for many years (Koch, 2011).[10] *M. tuberculosis* enters a person's airways and multiplies so slowly that the body's immune system does not quickly recognize the organism, much less the need to respond, often taking six to eight weeks to do so. When the body finally responds, it produces white blood cells to fight the bacilli. But when a body's defense system is unable to adequately fight off the bacteria, a person forms active tuberculosis disease, which begins damaging the infected area.[11] Tuberculosis in this case becomes communicable, meaning that is transmissible to others.

For most people, the body is able to destroy all but a few of the bacilli, which remain dormant in the body for variable amounts of time. During dormancy, germs are not usually able to spread to others (MacGregor, 1993, p. 104). Notable for its lack of

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[8] See, Code of Hammurabi, 1754 BCE.

[9] See, Of Epidemics, 400 BCE.

[10] A bacillus is a rod-shaped bacterium. *Mycobacterium tuberculosis* is just one of several bacilli in the *Mycobacterium tuberculosis* complex, the genus of mycobacterium species that can cause tuberculosis. These bacterium can cause tuberculosis in humans and other organisms (Schaaf & Zumla, 2009). Although *M. tuberculosis* is the most common bacillus to cause tuberculosis, other types associated with tuberculosis are *M. africanum* and *M. bovis*, the latter of which is spread to humans through unpasteurized milk. Although *M. bovis* comprises less than one percent of all tuberculosis in humans (MacGregor, 1993), it is still a concern in Southern California. For example, the Tuberculosis Control Program of San Diego County has created a public education pamphlet to distribute information about *M. bovis* available online at http://www.sandiegocounty.gov/hhsa/programs/phs/documents/TB-457TBQuesoFresco.pdf.

[11] Pulmonary tuberculosis is the most widespread form of the disease in humans. Common symptoms of active tuberculosis of the lungs include chronic coughing, often with blood, weight loss, fever, or night sweats.

symptoms, latent tuberculosis infection represents a “state of equilibrium” between bacteria and their host: the body is able to keep infection under control but is unable to wholly eliminate the bacteria (Lin & Flynn, 2010).[12] As medical science has learned more about the biological etiology of the disease, it has recognized that active tuberculosis disease and latent tuberculosis infection are not fixed states with distinct boundaries but exist actively along a spectrum (Wallis et al., 2010).

San Diego County as a Site of Study

As California’s most densely populated border community, San Diego County is a unique site for the study of the medical, political, and cultural discourses and practices related to tuberculosis control in the early 21st century. First, San Diego has a complex and rich history of migration. Its status as a border region with an increasingly diverse refugee population and comparatively high rates of tuberculosis situates it both as a locus of critical medical intervention and a site of competing discourses of contagion. The constellation of communication and activity that has formed around tuberculosis in the region resonates with current cultural dynamics, ongoing political tensions, and historical narratives.

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[12] Tuberculosis infection most often progresses into active disease within the year following initial infection, although after the first year people with infection have a five to seven percent risk that the infection will develop into active tuberculosis disease sometime over the course of their lifetime, particularly during times when the immune system is suppressed or compromised (MacGregor, 1993, p. 104). Although patients with latent tuberculosis cannot spread the disease to others, five to ten percent of people go on to develop active tuberculosis. Particularly susceptible are children under the age of five and people of all ages or people who are immunocompromised. In low-endemic regions, reactivation is a serious concern. In the United States, for example, reactivation of tuberculosis accounts for the majority of all tuberculosis cases, while new infection is a more serious problem in traditionally highly endemic regions (Lin & Flynn, 2010).

San Diego's relationship with tuberculosis dates to the city's boom years during the final part of the 19th century and the first decade of the 20th century, when the city's population swelled from just 650 residents in 1850 to nearly 40,000 by 1910 (Miller, 1982). During this period of rapid growth, San Diego, like Southern California more generally, became something a hub for tuberculosis treatment (Abel, 2007). As germ theory took root as the dominant paradigm at the beginning of the 20th century, doctors at the time were prescribing open-air treatment consisting of sunlight, a mild climate and proximity to an ocean or another body of water as treatment for a variety of illnesses including tuberculosis. Like miasma theory before it, germ theory conveyed the value of open and well-ventilated spaces. Because Southern California was abundant with the key elements of this prescription, city developers promoted the region as an ideal destination for treatment and recovery. During its boom years, thousands of people traveled to San Diego for treatment, often along with their families, many making the region their permanent home (Miller, 1982).

The costly travel and extensive period of care necessary for open-air treatment in a resort-like sanatoria environment was affordable only to patients of an elite income bracket. While Southern California certainly drew these kinds of patients, many people who traveled to the region did so not to seek a luxurious location for cure. The region was also known as the final stop for people who had journeyed west and lost their money or health along the way (Stanford, 1970). By the first decades of the 20th century, public sanatoria and state hospitals for patients who could otherwise not afford care became more prevalent across the United States (Ott, 1996). The people establishing systems and services for low-income and indigent patients in San Diego were themselves often of means, many of them doctors and lawyers who had relocated to San Diego in search of climate cure (Stanford, 1970). Mirroring national trends at the turn of the 20th century that focused on interpersonal hygiene and self-knowledge as techniques of disease control (Armstrong, 1983), the city's leaders increasingly worked to curb tuberculosis not just through medical treatment but also through legal intervention. This included the registration and surveillance of patients with tuberculosis and the development of targeted educational programs aimed at reducing the spread of the disease (Sanford, 1970).

By the early 20th century the tide had shifted even more dramatically, and it was San Diego's low-income, health-seeking population that had boomed. Public health officials began to advocate for a stricter policy of exclusion, pointing to outsiders, and foreigners in particular, as a major source of the disease in the region (Abel, 2007). While San Diego's early identity was formed in part by its reputation as a destination for cure, a distinction that helped grow its population, in the time since the region's initial population boom, the narrative of "imported infection" has entrenched a fear of (certain kinds of) outsiders (Abel, 2007).

Since the latter half of the 20th century, tuberculosis has become a relatively invisible disease to much of the Southern California region, as it has throughout a great deal of the United States and Western Europe. Yet tuberculosis is still considered a scourge by those with a vested interest in public health. While the overall number of tuberculosis cases has continued to drop nationwide during the past two decades, tuberculosis still disproportionately impacts the most economically and socially marginalized populations (Centers for Disease Control and Prevention, 2010; Grange, 1999). Regional tuberculosis rates reflect uneven access to healthcare or healthy living conditions among the community's disenfranchised populations. For these reasons, San Diego County has continued to rank as a region with some of the highest rates of tuberculosis at approximately twice the national average (Brodine et. al, 2010).

Current popular and public health discourses about tuberculosis in San Diego County tend to be preoccupied with identifying external sources of the condition, most often focusing on the groups or people who are to blame for bringing the disease into the region. Juxtaposed with the desired cultivation of an elite group of outsiders/cure seekers during its boom years (even if the reality was far more varied), current finger pointing at poor, disenfranchised, and largely immigrant populations seems to reveal the race and class assumptions and prejudices prevalent across many domains of public health disease control.

Situating Theoretical and Methodological Orientations

In order to achieve a more nuanced understanding of the factors that shape the discourses, practices, and experiences of tuberculosis, I found it necessary to reach across disciplinary boundaries. As such, a defining feature of my research is that it is informed by multiple communities of scholarship that examine the sociocultural and institutional domains of public health, civil law, and constructions of selfhood. As I discuss in detail in Chapter One, I employ interdisciplinary analytic approaches drawn from critical health communication, public health, and disabilities studies in order to consider how social and public health norms frame dominant and alternative understandings of categories such as behavior, advocacy, or risk. It is my hope that my interdisciplinary approach will allow my research to make a significant contribution to contemporary conversations about the impact of disease, including the material and psychosocial implications for what it means to be well or ill as a marker of identity and normalization.

When I first began this research, I was interested in the intersection of personal narratives and public discourse on tuberculosis as they related to current efforts to contain the disease in San Diego County. I hoped to understand how experiences with tuberculosis impacted the ways patients understood themselves as selves and how this identification interfaced with the established system of tuberculosis management. As such, I envisioned my involvement at the Tuberculosis Control and Refugee Health Program (TCP) at the Health and Human Services Agency of San Diego County (HHSA) strictly as the conduit for meeting patients and hearing their stories: a necessary stepping-stone but not necessarily central to my inquiry.

Not long after beginning my work in the field, however, my perspective and research began to fundamentally shift toward thinking through the relationships between global public health structures and the specific needs and responses of local communities and actors. Importantly, my fieldwork quickly revealed the many ways that public health professionals, care providers, and other community supports disagree with how to define the disease, how it should be controlled, its impact, and the extent of their roles in the process of tuberculosis management. While there was seeming agreement in the criteria that mark a tuberculosis diagnoses or that structure its control, I observed that there were also many ways such distinctions could not cannot contain the disease, particularly in the face of local variation. In response, I began asking questions about how the current model of tuberculosis control accounts for the aspects of tuberculosis and its containment that are socially produced or that vary across cultural and geographic place. I also began to wonder how current best practices account for patient non-compliance and how communities diagnose, treat, or meet the health needs of disenfranchised populations such as homeless, mentally ill, drug using, or undocumented residents. These questions are each related to how the system is designed to deal with detecting and preventing tuberculosis and how it accounts for (or does not) what actually happens at the ground level. I had a sense that locally defined moments of elasticity, along with moments of breakdown, did much to reveal the limits of current global formulations of tuberculosis control. With this in mind, I began formulating a theory of tuberculosis that positions it as always already multiple, and I tried to approach it not only as a disease but also as a lens through which we can view society, its fears, and its values.

In order to better understand how public health entities approached tuberculosis and its control in San Diego County, I also needed to understand how the disease was situated within larger geopolitical and historical contexts that have helped shape what kind of disease it has become today. In light of this new orientation, the TCP emerged as an important resource in its own right. I began to more fully consider all of the stories, practices, and people in this institutional setting and recognized that organizational structure, global public health protocol, local community needs, and even the physical space of the TCP itself were each important to understanding how tuberculosis and its prevention are actualized locally and globally. Although this new orientation included the perspectives and experiences of tuberculosis patients, it also comprised the experiences and expertise of the very diverse group of people who work at or with the TCP, including doctors and nurses, administrators, translators, drivers, intake specialists, case investigators, laboratory technicians, and more.

My research questions changed in response. As my research developed, I began to ask how public health defines the problem of tuberculosis and the solution to its control. Looking at misfits between globally defined public health regimes and local clinical public heath practice, my dissertation questions the logic of the current model of "cure as prevention" with its focus on [non]compliant individuals, particularly how it sidelines a consideration of the aspects of the disease and its containment that are socially produced or that vary across cultural and geographic time and place. By extension, an additional focus of this work is my interrogation of the micropractices of disease prevention that are implicated in the regulation of non-normative, othered bodies. Finally, my project also considers the ways that embodied experiences of illness, including interactions with institutional and lay systems of care, are also culturally located and intersubjectively expressed.

Chapter Overview

In this dissertation I engage ethnographic, historical, and literary approaches to account for how, as a social condition as much a biological one, tuberculosis draws together medical and other institutional formations, the ill person, their family, and the sociocultural context in which they are all embedded. In the current framework, health systems and public health interventions are oriented around the individual as rational actor. Ultimately, however, profound contradictions exist within this system that lauds personal responsibility, particularly in the context of health, and at the ability of people to fulfill these dictates. The understanding of agency that it is founded upon fails to take into account the ways people are constrained by social hierarchies such as gender, race, or income inequalities or by personal power relations such as family relationships or obligations. My aim is to draw connections between the particularities of experience and the larger structures of dominant institutions, political logics, and public health and biomedical best practices in order to highlight the (often uneven) reciprocity between macro and micro orientations to tuberculosis.

Each of the chapters in my dissertation examines the multiple and often competing discourses and practices related to tuberculosis control in San Diego County. In each, I interrogate different aspects of the frictions between local/regional public health efforts and universally mandated protocols that define the problem of tuberculosis and the solution to its control while also engaging with the ethnographic data I collected as a way to highlight the multiple spheres and experiences of tuberculosis control that are unique to San Diego County.

Chapter One, *Theoretical Orientation and Research Design*, introduces the theoretical emphases and methodology of my research. I detail my interdisciplinary approach that draws heavily from critical health communication scholarship as well as from work across the fields of disabilities studies, narrative, and ethnographic theory. In this discussion, I explore how my theoretical orientation grounded my situated approach to research, which aimed to appraise local conditions that are distinct to San Diego County while also considering the ways that tuberculosis is simultaneously located within broader sociopolitical and geopolitical frameworks. Finally, I provide an outline of my mixed-methods, ethnographic research methodology, including my use of (1) in-depth, open-ended interviews with tuberculosis care providers, community supports, and patients, (2) direct and limited participant observation at San Diego County's TCP, and (3) historical and contemporary document review including public health policy statements, news and media campaigns, internal public health treatment documents, and community-based advocacy briefs that help define the problem of tuberculosis and the solution to its control.

Chapter Two, *Situating Tuberculosis Control in San Diego County* builds on my discussion of the theoretical and methodological orientations that shaped my research by locating my inquiry in relation to my fieldsite at the TCP. I begin with an analysis of the TCP's organizational structure, including its primary tasks and goals, major players, and my place within it as an ethnographer and volunteer. I conclude with a vignette drawn from my time at the TCP that gestures toward the local context of global tuberculosis-control efforts and introduces some of the primary people and themes that I carry through this dissertation.

Chapter Three, *Cure as Prevention – Considering DOTS as a Strategy for Tuberculosis Control*, raises questions about the universal application of the tuberculosis control strategy known as Directly Observed Therapy, Short-course (DOTS). Regarded as the international gold standard of tuberculosis control and used by more than 100 countries, DOTS focuses on the biological and behavioral components that are central to risk management and approaches tuberculosis control from a philosophy that cure forms the best form of tuberculosis prevention. The ethnographic work explored in this chapter demonstrates that such an explanatory model, which often situates individual patients as either uneducated or uncooperative, cannot adequately account for a range of important social, systemic and discursive factors that shape tuberculosis. The hyper focus on the generalized patient flattens understanding of tuberculosis and limits potential impacts for its control. It also raises questions about the other forms of care and collaboration can be understood alongside (or in place of) current public health models.

Chapter Four, *Global Public Health Policy and Local Frictions with the Cure as Prevention Framework*, considers the variation that happens when global control strategies are implemented at the local level. In particular, this chapter looks at the fine lines that TCP staff must negotiate as they navigate the semantics and logistics of enacting tuberculosis control in a local setting, including the tensions that arise between the responsibility to enact public health as conceptualized by DOTS and the treatment of individuals, which can only ever be actualized at the local level. Ultimately, this chapter advocates for a community-centered approach to tuberculosis control that reassesses current policy and resource distribution (financial, infrastructural, organizational, emotional) and takes seriously the informal acts of outreach and advocacy that are already being carried out at the TCP.

Chapter Five, *Tuberculosis as a Boundary Object – Negotiating Among Situated Understandings of Disease*, examines the multiple and often competing definitions of tuberculosis that are at play across the domains of global health policy, local practice, and patient experience. This chapter makes the case that tuberculosis functions as a boundary object, an entity with interpretive flexibility whose meaning shifts according to context and perspective. Interrogating the various boundary positions of tuberculosis is important for describing nuance across the broad scopes and scales that comprise public health disease control. Understanding tuberculosis as a boundary object is also valuable for articulating which perspectives are emphasized within the official discourses and practices of tuberculosis control and which perspectives are marginalized or written out of official accounts.

Taken together, these chapters raise important questions about tuberculosis and the way we approach its control. While there are more questions than answers, the conclusion of the dissertation reflects on several of them. How might analytic understandings of tuberculosis change if the disease was treated not primarily as a problem of individual perception, education or behavior, but also as a problem of institutional, community, or state responsibility? What kind of disease would tuberculosis become if scenarios for its control conceptualized biomedical interventions alongside, rather than separate from, a reciprocal set of individual, institutional and sociopolitical interventions? What do our treatment protocols tell us about the kinds of selves that we imagine ourselves to be? And, how might tuberculosis be a different disease all together if we approached it from the perspective of therapy or care as opposed to control and surveillance?

As it exists, the current system of tuberculosis control is primarily equipped to develop policy towards always already techno-medical oriented solutions. But effective tuberculosis control measures must be socially aware and flexible enough to ensure that treatment protocol do not further entrench already existing inequalities. The intimate relationships between higher rates of tuberculosis and conditions such as poverty, inadequate housing or crowded workplace conditions, lack of access to health care, drug abuse, or homelessness is a signal that deeper structural issues need to be addressed. Kim et al. (2005), for example, write, “Tuberculosis is not simply a matter of infection; it is a reflection of patterned resource distribution. Understanding social inequalities, and even social theory, is central to understanding the persistence and re-emergence of TB" (p. 848). Ultimately, an overemphasis on the processes of bacterial infection (and by extension cure via individual compliance) is unable to account for experiences of embodiment, community specificity, regional need, structural shortcomings in their understanding of tuberculosis and its control.

In my conclusions, I re-examine is the "cure as prevention" framework that currently shapes tuberculosis policy today. I interrogate the version of cure formulated by the cure as prevention paradigm in order to think about how understandings of health change when treating disease not just as a problem of antibiotics or compliance, but also as an intersubjective experience of people who negotiate a social world in which their illness is often not theirs to narrate. Developing a richer understanding of tuberculosis requires us to think beyond the ways biological agents such as microbes or antibiotics perform inside of individual bodies. While the cure as prevention framework that guides tuberculosis control today minimizes moments of agency already enacted at the local levels, reimagining tuberculosis control as a *communicative space* invites tuberculosis patients, care providers, researchers, community leaders, and public health advocates to contribute to the development of measures for disease management. It positions the individual patient as something other than risk to be managed or subdued, and it understands doctors and other care providers beyond their managerial functions by reinventing what cure and control can look like in the context of tuberculosis management.

CHAPTER ONE: THEORETICAL ORIENTATION AND RESEARCH DESIGN

Global public health organizations and international development institutions, such as the World Bank and the World Health Organization (WHO), charged with the articulation of approaches to disease management have determined a relatively unified platform of priorities and best practices for tuberculosis control. While the value of synchronized efforts is perhaps obvious, the centralized and circumscribed nature of the work of these allied entities has also led to notable blind spots and limitations within the prevailing globally articulated tuberculosis control framework. In particular, the functions and governance of these entities are characterized by intersecting ideological, political, and economic orientations that restrictively define the possibilities for addressing the vulnerabilities faced by the diverse local institutions and individuals confronting the threat and effects of tuberculosis.

This dissertation represents an investigation of the ways that centrally defined tuberculosis management protocols proscribe alternative possibilities for preventing, treating, and understanding to the disease. Through a critical examination of the reigning ideology of control via cure, I raise questions about how tuberculosis control itself could better serve communities. I ask how conceptions of patienthood might be expanded by defining the disease beyond the bacillus and how we can delineate a more holistic form of care by expanding our understanding of control beyond the existing focus on antibiotics and patient [non]compliance. To do this, my study focuses on moments of socially constructed exclusion, inclusion, and interpellation that are engendered through tuberculosis control best practices, and it explores the discursive, material, and representational practices surrounding tuberculosis and its care at the Tuberculosis Control and Refugee Health Program (TCP), which serves San Diego County. As a result, my inquiry develops a situated analysis that is distinct to San Diego County but is necessarily in dialogue with the ways this region and this disease are located within broader sociopolitical, cultural, and historical frameworks.

Given that my study aims to engage with discussions from across several disciplines, I have by necessity adopted a hybrid methodology that can support my rapport with the intersecting, yet distinct, theoretical concerns that I take up. In what follows I outline the key arenas that my research enters into, beginning with a consideration of my relationship to the field of critical health communication as an interdisciplinary scholar who is also informed by narrative and disabilities studies. Next, I articulate how my work intersects with scholarly debates about representation and power in ethnographic research. In particular, I consider how facing the ethical challenges raised by working with marginalized and potentially stigmatized populations in my research is an ongoing process. A significant realization of this undertaking has been the difficulty I confronted in discerning the subjugated knowledges of those most affected by tuberculosis, and in grasping the agency conveyed in subjects' refusal to speak or participate in my study.

The interdisciplinary theoretical orientation of my research methodology has shaped my methodology, leading me to employ a mixed-method ethnographic design. The latter half of this chapter provides an account of the modes and scope of data collection I engaged in, including: (1) in-depth, open-ended interviews with tuberculosis care providers, community supports, and patients; (2) direct and limited participant observation of care providers and patients at San Diego County's TCP; and (3) historical and contemporary document review including public health policy statements, news and media campaigns, internal public health treatment documents, and community-based advocacy briefs. In consideration of my role as a researcher whose relationship to the various participants of this study is mediated by differences in class, culture, professional status, and institutional location, I discuss the reflexive strategies that I employed with the goal of providing a more transparent framing of the factors that shaped my understanding and analysis of my subject.

An Interdisciplinary Critical Health Communication Framework

The design of this study reflects my evolving relationship with critical health communication as an orienting theoretical framework for analyzing the discursive and material domains that shape medical and public apprehension of tuberculosis. My background in narrative and disability studies has played a formative role in the development of this inquiry by providing a means of bridging theories of disease, disability, and otherness with the situated responses to the needs that arise in the everyday operation of a public health disease control program. At the same time that illness narrative and disability studies have been important frameworks for my research, critical health communication emerged as a way to provide a multidimensional understanding of tuberculosis with an emphasis on how disease control is negotiated and operationalized in San Diego County and elsewhere.

Illness Narratives

My embrace of illness narratives has been formed in significant part "from the inside" following my personal struggles to fashion accounts of my own encounters with life-threatening illness. Adopting a strategy for coping with the standardized and often depersonalized dimensions of medical care, I sought out and witnessed the stories of others. I was attracted to the ways that illness narratives helped me to imagine, enforce, or even contest social worlds and selves.

One primary way illness narrative has been taken up in the academy is within the field of narrative medicine, utilized as a tool to transform medical practice into a kind of care that is performed with narrative competence.[13] Rita Charon, a medical doctor with a PhD in Literature and one of the key figures of narrative medicine, explains that narrative competence moves beyond the standing requisite that doctors develop scientific capacity. In addition, she contends that physicians must also develop the facility "to listen to the narratives of the patient, grasp and honor their meanings, and be moved to act on the patient's behalf" (2001a, p. 1897). Narrative medicine aims to bridge clinical and interpretive ways of knowing and to improve the effectiveness and quality of care through a deliberate focus on literature, narrative ethics, and life history narration. Charon argues that narrative competence develops the capacity of care providers and therefore offers a way to improve medical care overall.

While the goals of narrative medicine to develop a more integrated approach to medical practice are important, the pushback by scholars who question its instrumental

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[13] Charon (2001b) defines narrative competence as medicine practiced with the "competence to recognize, interpret, and be moved to action by the predicaments of others" (p. 83).

approach has also been a valuable resource to my research. Bishop (2008), for example, argues that claims of a causal link between narrative and improved medical efficacy often involve a detrimental conceptual tradeoff that limits the value of narrative to its ability to improve the instrumental function that doctors perform. In this sense, medical legitimacy can potentially reduce understanding of narrative to the terms, standards, or agendas of biomedicine and, by extension, devalue the many potentially productive uses of narrative to contribute to medical practice in alternate ways. In particular, Bishop highlights the potential of narrative to disrupt staid boundaries and represent the radically heterogeneous experience of care. Narrative, for Bishop, is valuable for its potential to unite rather than further entrench the division between biological and cultural ways of knowing by revealing the ways that language about biological properties is constructed as "biopsychosociologisms" that at the very least mediate (and worse, can distort) the experience of patients (p. 24).[14]

My use of illness narratives in this research has drawn on a range of genres that include but extend beyond the single-authored published text, including the more

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[14] See also Rees (2010), who suggests that narrative provides a valuable contribution to medical practice, not for its potential to instrumentally improve care but rather for its use as a tool of critique. He also suggests that the medical humanities have the potential to critically engage with medical ways of knowing by asking ethical questions that upset the status quo. The objective, as Rees sees it, is to "formulate an ethical imperative of medical humanities that calls into question any ethical imperative one can formulate" (p. 271). That is, scholars working in the medical humanities must look beyond the discipline's foundational premises in order to better understand them and move beyond their limits.

Davis and Morris (2007) also suggest a reflexive stance for scholars working at the intersection of narrative and medicine, offering that such scholarship must consciously work to disrupt traditional disciplinary boundaries that separate science from the humanities. For them, either domain without the other "is doomed to be reductionist at best and inaccurate at worst" (p. 411). In staking a claim for the role of narrative in better understanding illness experiences, they also propose, "a better and stronger science can emerge from a productive engagement with the knowledge base developed over the past hundred years in the humanities and social sciences" (p. 141). But this is different than the instrumental approach proposed within the field of narrative medicine in that it recommends developing a reciprocal engagement rather than a unidirectional acquiescence.

amorphous and dispersed discourses such as oral accounts and contributions to online forums. In this way, I have tried to approach illness narratives as intersubjective processes that are productive of the very people, objects and moments that they seek to describe. When told from the perspective of patients, illness narratives offer embodied accounts of disease, illness, or disability and can offer important correctives to the limitations of accounts articulated by the medical model (Frank, 1995). In my work, the narratives told by patients, family members, care providers, and community supports have functioned as cultural interventions by bridging internal life worlds of feeling and thought *and* external social worlds "of observable actions and states of affairs" (Mattingly & Garro, 2000, p. 1). As co-constructed, dialogic negotiations that reflect and inform shared conventions, values and beliefs (Levy, 2005), the narratives I collected and witnessed also performed a kind of self-work as mediators in peoples' participation in and perception of the world around them.[15] They were also valuable for the ways they revealed some of the most dominant and enduring discourses of health and patienthood in the context of treating and being treated for tuberculosis.

Disabilities Studies

My project is also indebted to scholarship in disabilities studies that provides counter narratives to the biomedical ways of knowing. Scholars following in the wake of

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[15] Many scholars have pointed to the ways that autobiographical narratives in particular work as communicative processes of self-fashioning that help shape the ways people approach and think about their own experiences and life events (see, Bruner, 1990; Lieblich, Tuval-Mashiach & Zilber, 1998; Ochs & Capps, 1996). Jerome Bruner (2004), for example, describes autobiographical narrative as "life making." He follows Ricœur (1984) to argue that, while both privileged and troubled because of its reflexivity, narrative is one of the best methods we have to describe lived time.

the disability rights movement have continued to push back against definitions of disability that position it as a kind of sickness or biological lack for which a cure should or will (eventually) be developed. As a diverse field that has narrativized experience “from the vantage point of the atypical” (Linton, 1998, p. 5), disabilities studies highlights the status of disability as unstable and continuously constructed category in an effort to influence policy, resist social oppression, or draw up new maps for social practice.[16] In this light, disability is seen as a discursive construction formed in negative relation to social norms, and experienced as a material and performative disjuncture between bodies and their environments, including the meanings we ascribe to difference (Linton, 1998; Sandahl, 2002). Ultimately, it is the regulating institutions and discourses of normalcy that actually “create the ‘problem’ of the disabled person” (Davis, 1997, p. 9).

Disability theory has a great deal to offer a study of tuberculosis, particularly when thinking about how shared conceptions of the disease have resonances at the level

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[16] Disability rights scholars and activists often figure disability in terms of its sociohistorical construction or theorize it as an issue of minority rights (Union of the Physically Impaired Against Segregation, 1976; Sandahl and Auslander, 2005) and have described it as an unfinished project of biological and social making. Similarly, Burch and Southerland (2006) remind us of the malleability of discourses and identity markers, writing that a history of disability demonstrates that “even the most fundamental and apparently enduring categories as ultimately artificial and imposed” (p. 138).

We see this idea at play within the historical shifts in rights and the struggle for political recognition for people with disabilities in the United States. For its part, the disability rights movement worked for years against institutionalization and segregation of people with disabilities from mainstream populations. Victory began with the passing of PL94-142 in 1975, which secured the first official guarantee of education for American youth with disabilities (Linton, 1998). Activists saw another victory when The Americans with Disabilities Act (ADA) was signed into law fifteen years later in 1990 (Shapiro, 1994). The ADA was put into place to prevent discrimination in the domains of employment, state and local governmental activities, public and commercial accommodations from restaurants to clinics, transportation and telecommunications (US Department of Justice, 2005). Each of these victories owes a debt to the many years of struggle by disability rights activists who worked to confront limitations placed on people with disabilities and biosocial conceptions that frame disability as fundamental lack. From this perspective, disability is as much a cultural practice as it is a form of biological difference.

of communities and selves. Historical shifts in conceptions of disability provide an important lens for understanding the evolution of social and medical constructions of tuberculosis, and by extension strategies for its control. Articulating those shifts to social, economic, and political institutions has been important to situating the status of tuberculosis in particular times and spaces. Disability theory also offers the study of tuberculosis ways of accounting for the lived-in body and its experiences that is often missing from policy and academic discussions of tuberculosis control.[17] Because post-enlightenment philosophical and theoretical scholarship of the global north has often neglected the body altogether *or* has treated it as an entity wholly separable and distinct from the subject, subjectivity is often treated as disembodied. This cleaves a divide between individual experience and social accounts of life and the accounts of the material body articulated by disciplines of medicine and the hard sciences in the case of illness, disease, or disability (Shakespeare, 2006; Williams, 2000). Such a framing removes the body from the lived world and treats it instead "as a pre-social, inert, physical object, as discrete, palpable and separate from the self" (Hughes and Patterson, 1997, p. 329). This legacy is exemplified in many discussions of public health policy surrounding tuberculosis control in which the body and the disease has largely been formulated through the priorities and ways of seeing of medicine.

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[17] In disabilities studies, this body of work is growing. For examples of work in this mode, see Corker and Shakespeare's (2002) *Disability/Postmodernity: Embodying Disability Theory*; Paterson and Hughes' (1999) *Disability Studies and Phenomenology: The Carnal Politics of Everyday Life*; Sandahl's (2002) *Considering Disability: Disability Phenomenology's Role in Revolutionizing Theatrical Space*; Siebers' (2008) *Disability Theory*; or Snyder and Mitchell's (2001) *Re-engaging the Body: Disability Studies and the Resistance to Embodiment* as examples among many.

For work on disability and phenomenology in sociology, see Frank's (1990) *Bringing Bodies Back in: A Decade Review*, Kelly and Field's (1996) *Medical Sociology, Chronic Illness and the Body*, Turner's (2001) *Disability and the Sociology of the Body,* or Zola's (1991) *Bringing Our Bodies and Ourselves Back In: Reflections on a Past, Present, and Future "Medical Sociology."*

Critical Health Communication

Scholarship in critical health communication has offered a valuable account of the role of western medicine in projects of public health and disease control that have helped me describe and situate current public health formations within larger historical configurations. Distinguishing between critical and traditional health communication approaches to scholarship helps highlight the commitment by scholars working from a critical framework to interrogate existing power imbalances in an effort to change the status quo. As a discipline, health communication has traditionally been concerned with the design and effects of health messages disseminated by professionals to a community or individual. This foundational orientation parallels transactional theories of communication embodied by the modernization and development schools of thought (Waisbord and Obregon, 2012), and has resulted in a tendency to conceive of communities as in need of being sold or educated about the ‘right’ way of achieving or maintaining health, as defined by health professionals. A central weakness of this framework is that it insufficiently engages with social and political theory, resulting in a cursory theory of power relations and a lack of self-reflexivity (Lupton, 1994).

This lack of engagement with structures of power is not surprising when one considers that traditional health communication research was most often conducted under the auspices of publicly funded agencies, powerful financial institutions, or nongovernmental organizations such as the World Bank and the WHO. These institutions have particular stakes in how disease is defined and how care is provided. Because of its affinity with institutions of power, traditional health communication research has tended to reinforce already influential perspectives. Arguably, scholarship in the field has largely reflected the theoretical and ideological perspectives of its funders, engaging in limited ways with the power relations at work at multiple levels of healthcare settings, be they interpersonal, institutional, or structural (Dutta, 2010; Lupton, 1994). This has had the effect of maintaining a system of beliefs and practices that continue to, as Lupton (1994) attributes, “deflect the responsibility of health maintenance from the state to the individual” (p. 57).

Tuberculosis research conducted within the discipline of public health has had a similarly limited engagement with the ways that its definitions of ‘good’ or ‘healthy’ behavior aligns with the worldview, needs, or values of the people it is trying to influence. This has often resulted in policies that inadequately account for cultural values or that make assumptions about the meaning of behaviors, such as why people do not comply with recommendations set forth by the medical establishment.

There is, however, significant recent scholarship within the field of health communication that critically examines the structures, objects, and discourses through which prevailing meanings of health and illness are established and reinforced. Waisbord and Obregon (2012) explain that this has resulted in a theoretical and methodological rift within the field that separates “information/media effects” models from “participatory/critical” models. This divide is rooted in differences in perspective about what communication research can and should offer, including its potential to improve global health (p. 10) and the limits of a media effects model to effect change (p. 18). In his important reflection on the critical turn in health communication, “The Critical Cultural Turn in Health Communication: Reflexivity, Solidarity, and Praxis”, Dutta (2010) calls on his colleagues in the field to destabilize what he diagnoses as the universalizing preconceptions guiding traditional health communication research. In his formulation, a critical approach necessarily entails interrogating the “knowledge-producing enterprise” that sustains existing structures of power and health inequities (p. 534). His assertion is that critical health communication research has the potential to foster productive change by focusing on “redistributive justice” that gives weight to co-constructed knowledges that are inclusive of the perspectives most often excluded in “mainstream discursive spaces” (p. 535).[18]

This attention in critical health communication scholarship to the interactions among dominant and subjugated knowledges and its goal of changing conditions through the examination of dominant paradigms provides an important anchor for my project. Because my inquiry is largely focused on a public agency charged with monitoring the health of the community, it has been especially important for me to adopt a research design that can support this critical agenda. In contemporary tuberculosis control, globally disseminated protocols have proscribed attention to local contexts and knowledges. This has the effect of encouraging public health agents to speak for and about disenfranchised populations in ways that disregard a range of differences that are crucial to understanding the impact of tuberculosis on specific regions and communities. These include, but are not limited to racial, gender, class, age, and cultural differences.

From the outset I attempted to conceive and structure my work at the TCP as a form of collaborative research, although as I will discuss below, institutional limits challenged my ability to do so. Nonetheless, my objective to remain open to the

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[18] For additional work on the importance of a critical health communication, see Airhihenbuwa (1995); Dutta (2007); Ford, Crabtree, and Hubbell (2009); and Lupton (1994).

intersecting and competing knowledges at play in the arena of tuberculosis control has shaped this study's attention to the ways biomedical, public health, and traditional health communication have tended to marginalize the perspectives and bodies of people outside of the dominant white, western, and masculine norm. Analytic approaches drawn from critical health communication became all the more crucial to my analysis as I grappled with the complex ways in which discourses that shape the management of tuberculosis increasingly traverse the domain of public health, privatized medical landscape, and consumer-based model of care.

Ethnography as Theory and Method

Recent discussions of ethnographic methods have been structured by questions of epistemology that have shaped qualitative research of the past three decades. The crisis of authority, representation, and praxis that shook qualitative inquiry during the 1980s and beyond generated an array of participatory and reflexive practices as well as interdisciplinary dialogs within the social sciences.[19] In contrast to positivist research

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[19] See Lincoln & Denzin, 2003; Marcus & Fisher, 1986; others. Lincoln and Denzin (2003), for example, identify seven knots or turning points in qualitative inquiry: (a) the reintroduction of qualitative research to the fields like sociology or education that had long relied on quantitative data; (b) the opportunity for social scientists to explore neglected or difficult to answer questions; (c) an emphasis on non technical language that reintroduced art and science, social life with narrated or performed forms; (d) a focus on the ethics of knowledge production through a attention to reflexivity; (e) a shift in methodology; (f) questions of purpose which "force researchers to confront the question of whether social science, as conventionally configured, serves the purpose of improving the human lot"; and (g) changes in the domains of presentation and representation (p. 4-7).

Meanwhile, Conquergood (1991) raised intersecting issues of the body, borderlands, performance, and reflexivity in his rethinking of ethnography after the crisis of representation.

A counter to the Malinowskian model of ethnography that claims to speak objectively for the 'native' through and appropriation of their world, my work has tried to follow in the footsteps of this reimagined mode of ethnography by engaging with the politics of writing about culture and by listening to the call for ethnographers write themselves into their accounts. The similarities and differences between my understanding of events and interactions and those of tuberculosis care providers, policymakers, or patients models that aspire to objectivity, my study takes its lead from this established body of social inquiry fundamentally committed to reflexivity, inclusion, and an embrace of partial and situated knowledges. This includes a commitment to the understanding that because lived experience can only be approached through representation and interpretation, research can never be understood as an objective recounting of the world. As such, a guiding principle of my ethnographic practice is to focus attention on insights about local skills, tacit knowledges, and solutions that are often inadequately accounted for in other modes of research.

The crisis of representation can be understood as a surfacing and unraveling of contradictions that plagued the longer-term association of ethnography with the developmentalist anthropologists of the late 19th and early 20th centuries whose work aimed to make sense of a mystified and "primitive" other. The crisis was productive insofar as it generated intense debate and renewed creativity with respect to the relationship of method to theory/knowledge. This lineage is also important to consider within the context of tuberculosis research, which has its own history of engagement in post- and neocolonial settings, including institutional relationships with neocolonial projects and asymmetries of power. The lessons offered in the years since the crisis of representation, especially those related to hierarchies of power and the relationship between the researcher and the researched, have had an impact on how I have tried to carry out this inquiry.

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point to important questions about the nature of knowledge production, power and seemingly natural processes or objects within this domain. Such questions destabilize the concept of culture itself, whereby culture can be understood as "a process shaped by historical contingency as well as by a dynamic interplay between individual agency and social structure" (Cerwonka, 2007, p. 12).

Thick Description and Moving Beyond Culture as Text

With its open protocols for observing and understanding daily life within a particular social world, ethnography provides a methodological framework for following the interactions and frictions among a variety of actors that constituted my object of study. By giving emphasis to engagement with the people at the TCP, including their practices, lived experiences, and perceptions of their world, my ethnography did more than provide data. It continually pushed me to reformulate my questions and primary themes in an iterative fashion. This close link between method and theory has been a hallmark of the critical ethnographic practice that has emerged in recent decades, and it has been formative in my approach to analysis and representation.

Geertz (1973) famously proposed a version of ethnography that focuses on 'thick description', desirable for the way in which it draws out connections between individuals and their context in order to render behavior meaningful to people external to the particular situation or culture. In his effort to move culture outside of the mind and into the realm of lived experience, Geertz subscribed to a definition of culture as *public* and as *context*. If human behavior is the medium through which cultural forms are articulated, as Geertz asserted, observation then forms a crucial ethnographic tool for capturing and articulating meaning. By writing down the dynamic and ephemeral moments of cultural expression, Geertz's ethnographer transforms short-lived, observed events into formal, and permanent accounts by materializing cultural expression (p. 19). In this way, ethnographic analysis in this tradition attempts to make permanent dynamic social relationships by translating them into an appraisable form.

While the technique of ‘thick description’ forms the basis of detailed accounting of my experiences in the field, I have attempted to offer a layer of reflexive framing of my ethnographic observations by explicitly noting my own positionality as part of the context that forms the basis for the concepts, patterns or relationships that I describe and analyze. As with most ethnographic forms, my fieldwork involved paying close attention to ordinary and everyday activities, including observations of how people move through space, the shorthand enacted in regular conversations, the categories instantiated through protocol, and the explicit and unarticulated connections that underlie institutional goals. Informed by a rich tradition of ethnographic work with a focus on issues of illness, disease, and disability, my ethnographic practice concedes the ways in which knowledge is necessarily positional and partial.[20] In this respect my ethnographic practice has been guided by a conscious attempt to use thick description to attend to the linked categories of representation and reflexivity as modes for considering system-wide change. This includes an iterative assessment of the ethics and responsibilities attached to my role as an observer/researcher.

Recent scholarly reassessment of Geertz’s interpretative method at the intersection of critical anthropology and performance studies has also contributed to significantly to my approach. In *Deep Play: Notes on the Balinese Cockfight*, Geertz (1973) defines culture as “an ensemble of texts, themselves ensembles, which the

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[20] For examples of ethnographies with a focus on illness or disease that have informed my work, see: The spirit catches you and you fall down: A Hmong child, her American doctors, and the collision of two cultures (Fadiman, 1997); AIDS and accusation: Haiti and the geography of blame (Farmer, 1992); Ebola, culture, and politics: The anthropology of an emerging disease (Hewlett & Hewlett, 2008); The body multiple: Ontology in medical practice (Mol, 2002), or Righteous Dopefiend (Bourgois & Schonberg, 2009).

anthropologist strains to read over the shoulders of those to whom they properly belong" (p. 452). Dwight Conquergood (1991, 2002) offers an incisive critique of Geertz's definition as emblematic of what he characterized as an entrenched textocentrism within the academy. Conquergood calls for researchers to develop more deeply participatory knowledges through forms of engagement that are modeled on cultural interaction rather than reading. In place of culture as text, then, this perspective considers culture as performative processes (2002).

Responding to Foucault's (1980) notion of subjugated knowledges, Conquergood (1991) also argues that some knowledges and perspectives are unable to be contained within texts, particularly official or sanctioned texts. Subjugated knowledges, as Foucault describes them, are decentralized, buried kinds of knowledges. Rather than being codified within official documents or discourses, they are left out of formal modes of "systematization" and instead circulate between and within localized communities (p. 81). They are the kinds of knowledges that are silenced by dominant truth claims or those that are pushed aside, marked as insufficient or naive (p. 82). Although limited by my position as a research and volunteer for a local public heath department, Conquergood's work on excavating various forms of subjugated knowledges, helped me focus on participation and contextualization. At the same time, it formed the basis for my consideration of the kinds of voices were not included at the clinic and by extension were also largely excluded in my own field work, notably undocumented residents, the county’s homeless population, and people with substance abuse problems or serious mental health issues who lacked social supports.[21]

Subjects Who Cannot or Choose Not to Speak

Complicating both Geertz’s notion of culture-as-text and Conquergood’s resurfacing of erased forms of knowledge is the argument that the silent subject does not necessarily seek inclusion at all. Visweswaran (1994) argues that silence can be employed as a kind of resistive action; the refusal to speak serving as an assertion of agency. Rather than passive subjects who are actively excluded from dominant accounts by dominant actors, the silently resisting subject negates official discourses by refusing to participate in them at all. This tactic exposes some of the limits of the kinds of knowledge possible in official narratives or ethnographic accounts. Visweswaran’s analysis primed my attention to two kinds of silences I experienced at the TCP: the silence of people who opted not to talk to me or participate in my research about tuberculosis, and the silence of those who chose not to participate in the public health system in the first place, often because they were disenfranchised and largely untrusting of state-based institutions in general. Most often this included San Diego County’s homeless and undocumented populations among others.

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[21] Fortun (2012) similarly addresses disciplinary knowledges that resist description, theoretical and methodological silences as she calls them. She suggests that “complex conditions” create gaps in explanation, which she terms discursive risks. These gaps “emerge when there are conditions to deal with for which there is no available idiom, no way of thinking that can grasp what is at hand. [They] emerge because of a tendency to rely on established idioms and ways of thinking, nonetheless” (p. 452). And when labels or terms are applied across domains without attention to the particularities of either domain, knowledges become inarticulable. She explains, “What is Other to the dominant idiom is colonized by it” (p. 452).

Identity and Subjectivity

My orientation to ethnography is also informed by recent ethnographies that form the basis of analysis the ways that identities are formed and re-formed in the context of widespread shifts in orienting concepts such as nationality, security, or the development of new medical technologies.[22] An influential example of such work is Biehl's (2005) ethnography, Vita: Life in a Zone of Social Abandonment, which examines the lives and social context of mentally ill people in Brazil who have been left behind by their families, communities, and government. With these many layers of abandonment, the people Biehl studies have been excluded into what he terms "zones of social abandonment." Biehl focuses on the structural factors and the circulation of discourses that contribute to how families, communities and governments care for people marked as deviant – most often the nation's poorest and most mentally ill inhabitants.

Following this model my work aims to account for dynamic and competing discourses and policies of the state, the medical community, and the family, particularly their impact on the people who are called to interact with them. Biehl centers his ethnographic study on the life of a single person in order to explore in depth the ways that individual and social discourses of exclusion make and unmake subjects in multiple ways. In a similar manner, my study focuses on a limited number of people, following their stories across various intersecting planes of experience.

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[22] For example, see the entire *Ethnographic Studies in Subjectivity* book series by the University of California Press, particularly Biehl, Good, and Kleinman's (2007) edited volume, *Subjectivity: Ethnographic Investigations*.

Research Design and Methodology

A core objective of this study is to consider local context in a manner that provides insight into the uneven effects of universally mandated protocols of global tuberculosis control. This involves consideration of how broadly disseminated agendas obscure and foreclose opportunities for addressing the varied impacts of tuberculosis on disenfranchised communities and distinct demographics (characterized by racial, gender, class, and regional differences). On a discursive level, mandated protocols become a mechanism through which centralized health authorities speak for and about the populations they are charged with protecting. The ethnographic orientation of my research was important for my focus on how we give cultural meaning to objects, processes, and relationships, including the dominant knowledges that come to represent hegemonic norms that are sometimes at odds with the intersecting facets of lived experience.

My research design and fieldwork were crucial to situating the particularities and commonalities of local tuberculosis control efforts within national and international contexts. Although I conducted my fieldwork in the United States, my study engages with documents and literature that articulate my site with historical and contemporary power imbalances that have shaped global relationships and landscapes of health. My field site itself is situated at the cusp of the North/South global divide, both ideologically and geographically. San Diego County's status as a border region has had important ramifications for the mandates and practices of the TCP. In addition, local constituents like the TCP and broader public health logics in the United States have been shaped by a history of American nativism that has regularly positioned the body as a site upon which society constructs the boundaries of its model subjects (and by extension of those who are not included in that definition). In this construction, illness is often linked to foreignness, augmenting an existing local culture of fear and distrust of difference.[23] Taking cues from the ways self-reflexive and situated critical research has aimed to uproot existing power imbalances, my study cast a critical eye to the practices, people, objects and discourses that shape experience with tuberculosis in Southern California and beyond. Included in this assemblage is how, as researcher, I am implicated in these practices through the ways I interact with my participants to produce information (Charmaz, 1995).

Research Design

Because my research aims were directed across a range of institutional interactants, I developed a qualitative mixed-methods framework that iteratively employed document review, observation, and in-depth, open-ended interviews. This array of methods provided tools for drawing connections and comparisons among discussions within and across the fields of critical health communication, public health, and cultural studies. This approach offered significant insight into the TCP as a local program that responds to regional needs, state and national standards, and global patterns of tuberculosis prevalence. Inextricably linked to a particular time and social setting, the primary data I present here was collected over a two-year period beginning in early 2012, with the bulk of my fieldwork occurring within an 11-month window between February 2013 and December 2013.

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[23] For examples about tuberculosis see Reitmanova and Gustafson (2012) or Ott (1996). For work specific to Southern California, see Abel (2007), Molina (2006b), or Nevins (2010), among many. I also discuss this in more detail in Chapter Four.

The ethnographic details in this dissertation are drawn from field notes of direct observation, audio recordings of meetings, semi-structured interviews with participants, and email communications. The examples I discuss provide a sketch of my involvement with the tuberculosis community in San Diego, most notably my time at the TCP, and are meant to open a window onto complex discursive and institutional practices that I can only claim to grasp in a partial manner. This study is not intended to be a representative sample. Rather, close interaction with a small number of participants with key roles or interactions with the TCP allowed me to highlight issues specific to San Diego and contributed to a more complex and nuanced understanding of how discourses about tuberculosis and practices related to its control interact with (complement, contradict, compete) one another.

Document Review

To better gain a better understanding of contemporary medical and cultural discourses about tuberculosis in San Diego County and globally, I reviewed a range of documents before and during my site-based phases of research. This process helped me glean salient issues and trends, become familiar with language use, and garner an initial grasp of the social context of the TCP. The documents I reviewed can be divided into four primary categories. The first includes historical documents, such as research findings related to tuberculosis care, news stories, and policy statements released by public health organizations, notably including the WHO and the Centers for Disease Control and Prevention (CDC). A comparative content analysis of these documents helped me situate the current constellations of tuberculosis control best practices within broader historical, institutional and political undercurrents.

The second category of document review included a content and discourse analysis of contemporary news coverage and media campaigns related to tuberculosis at local, national, and international levels. Local news coverage often included stories about tuberculosis at site-specific locations such as schools or entertainment venues. It also included surveying health campaigns produced by public health and advocacy organizations, such as a recent awareness campaign about links between tuberculosis and unpasteurized queso fresco for example. National media coverage often focused on the tuberculosis in the United States in comparison or contrast to other countries, and more recently it drew comparisons between tuberculosis and the 2014 Ebola pandemic. International news coverage tended to focus on policy and funding needs, regions with high prevalence, and public awareness campaigns, such as the news and media event before and after World Tuberculosis Day each year in March. This step was important for tracking official discourses, anxieties, and language use around tuberculosis.

A third important category comprised the internal TCP documents to which I had access via my status as an Health and Human Services Agency of San Diego County (HHSA) vetted researcher and volunteer. These included forms, questionnaires, manuals and policy statements that guided care. In addition, I received an email address from the County of San Diego, and was included in countywide emails to health department employees and volunteers as well as general TCP emails. This email account offered me insight into the administrative culture of San Diego's HHSA as an organization and the

TCP as a department within it. Further, it offered me some credibility among TCP staff, who recognized my email address as a mark of legitimacy.

The last category of documents that were essential to my study were external to the TCP and related to the San Diego border region more generally, and in some cases to the State of California. They included reports released by researchers or community coalitions and activists, advocacy statements and community assessments. Notable among in this group were contributions by Mario Vega, a community-based tuberculosis activist, and publications by the San Diego Community Foundation, a local organization that gathers and distributes donations and assists in generating grants with the purpose of improving the lives of people living within the San Diego County region.

Taken together, these archival and contemporary textual resources provided a valuable window onto a diverse set of perspectives and practices related to tuberculosis care. They were also crucial in my effort to better understand relationships among TCP staff and their patients and served as a tool for analyzing the forms of public and professional discourses enacted on a daily basis at the institutional, community, and individual levels.

Direct Observation

My fieldwork, involving extended direct observation and limited participant observation provided me with the core data for this study. During the concentrated 11 months of fieldwork at the TCP, I spent an average of 3 days at the main clinic and administrative offices, although I also spent time at the TCP's satellite clinics and one public elementary school. Very occasionally patients invited me into their homes in conjunction with their regularly scheduled visits by their Public Health Nurse. This was complimented by less regular visits to the TCP in the year leading up to the intensive stage of fieldwork, including quarterly visits with TCP director, Dr. Erin Walter and three 4-hour visits shadowing the staff physician who had retired from the position by the time I began my intensive fieldwork.[24]

My observations within the administrative offices were mainly scheduled around meetings that focused on the organizational mission of the TCP or the management of cases. A web of cubicles defined the administrative space, and since my visits were often directly coordinated with meetings, my time and movement within that space tended to be more planned than serendipitous. In the clinic, however, a relatively open floor plan meant that I could spend long stretches of unstructured time engaged in self-directed observation. A great variety of interrelated tasks were carried out in that shared space. I most often positioned myself near the nurse's station, which served as a major hub of activity in the clinic. With time, I developed a sense of how situating myself in in different areas of the clinic at particular times of day could yield distinct insights into the quotidian workings of the clinic. The relative ease of mobility within the clinic afforded to me by Dr. Walter helped me develop closer relationships with its regular employees and primary interactants. As a result, the clinic acted as a conduit not just to patients but also to TCP employees housed in the administrative wing with whom I had less regular interaction.

At the beginning of my observation at the TCP I was cautious about my role as a researcher. Because of the generosity of the staff in letting me 'hang out' in their space

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[24] I am using pseudonyms to refer to all participants in my study.

for hours at a time, I was reluctant to intrude and perhaps overly cautious about ruffling feathers. I would spend hours mentally rehearsing a description of my project that I thought TCP employees might find valuable or relevant to their work, and I spent even longer rehearsing questions that I worried might appear critical of their hard and sincere work. With time however I opened up, and my questions began to form more of a dialogue with the people and environment in which I was enmeshed rather than a rote recitation of what I thought appropriate to say. So too did my questions about their work and experiences. As TCP employees became more familiar with my presence they began regularly checking that I was able to collect enough data or inviting me to meetings that I had not previously had access to. This opening up, by my participants and myself, transformed my direct observation experience, positioning it as one of the most vital components of my research.

My method of observation and note taking shifted over time. Early on in my fieldwork, I was focused on orienting myself to the space. Working from generalized knowledge about my subject, I did not have concrete sets of categories or patterns that I was looking for. I focused on recording highly detailed and holistic descriptions of context, behavior, dialogue, and events. I was broadly interested in interactions and movements, including who was or was not talking to whom, how decisions were made, or how people moved through space.[25] I tried not to prematurely ascribe categories or patterns to what I was seeing, but took note of key words, potential themes, or questions to raise in later conversations and interviews. As patterns, behaviors and relationships

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[25] This iterative process of data collection with refinement of categories/terms/themes for analysis reflects a modified version of Adele Clarke's (2005) approach to situational analysis.

began to emerge, I made note of them, tailoring my notes to primarily describe them, while offering as much detail as I could about the context in which they appeared.

During the second phase, I was focused on how themes and patterns were situated within a sociohistorical context that extended beyond the walls of the TCP. In this later phase, at the suggestion of one of the clinic's two part-time doctors, I arranged meetings with the doctors to discuss my observations, clarify points of confusion, and solicit their reactions to my initial interpretations. These exchanges helped forge open channels of exchange with them, while the structure and hierarchies of the clinic contributed to shaping and strengthening these conduits of communication. In this space, the doctors largely held the authority to dictate the pace of the day. Further, IRB and HHSA ethics protocols required doctors, nurses, or high-ranking TCP administrators to initially approach patients for participation in my study. Because of this and the doctors' topmost authority in the clinic, a large part of my field site experience was mediated by their activity and schedules.

While direct observation is never unmediated, ethnographic work in healthcare settings involves additional, unique layers of institutional regulation, organizational culture, and interpersonal relations that place stresses and limits on observational practices. One practical challenge that resulted from these was the difficulty of being an unobtrusive observer in the context of the clinic or administrative offices. In a setting where the majority of activities and behaviors are highly delimited and monitored, my lack of a clearly defined role as employee or patient sometimes served to impede or derail communication. In the administrative offices, I stood out as a wanderer amongst a group of employees who spent much of their day at their desks in cubicles or in meetings, gathered around the desks of their colleagues. In the clinic, however, I was often the only still body as people stayed busy around me, completing the tasks at hand. Workflow often slowed as one of the TCP employees, most often a doctor, stopped to introduce me to new visitors or employees, pausing to let me explain my study and ask if I could observe. Once TCP employees became more comfortable with my presence, these introductions went more smoothly and became better incorporated into the organizational flow, reflecting my better integration into their world.

In a converse way, observation was mediated by factors that fundamentally shape my own perception: my formation as an academic researcher, my cultural background, and my experiences with illness and disease. And undoubtedly, the very act of observation itself shaped or changed the interactions and unfolding of events at the TCP. Rather than circumscribe the effects of these subjective and experiential dimensions of observation as unwanted artifacts within my inquiry, I have done my best to embrace them as potentially productive forces in the construction of the forms of knowledge that results from immersion with human experiences and behaviors in context. The embedded nature of my observational work along with my place as a relative outsider (both to the care providers and the tuberculosis patients) had a balance of challenges and affordances. As an outsider and non-expert, I missed some of the nuances of behaviors, actions, and relationships. At the same time, most people I encountered granted me extra leeway. Exceedingly tolerant of my blind spots, TCP staff and community-based advocates became actively engaged in teaching me about their world.

Participant Observation

The institutional protocols of my field site and my position as an outsider significantly restricted me from engaging in participatory observation. Although it was not my preferred mode, my initial work at the clinic was almost entirely limited to direct observation. Institutional constraints also placed restrictions on my access to activities and information particularly because I was an independent graduate student researcher rather than a professor affiliated with a major university department or grant funded researcher for the CDC or a similar agency. However, as time passed and I became better integrated into the flow of the TCP, Dr. Walter began inviting me to some of the meetings that I had previously been excluded from. These included regular case management meetings or periodic meetings with the regional clinics to discuss goals, successes, and shortcomings. During this time, Dr. Walter also began introducing me to the group and often asked me to say a few words about my work. Implicit in this exchange was Dr. Walter's acknowledgement to the group that I was a vetted researcher.

Gradually, Dr. Walter and others asked me to participate when they felt it was appropriate. I helped edit letters and media releases, and I collaborated as the editor, voice, and face for an outreach video for doctors in Mexico and Central America, explaining the services offered by the County's CureTB referral program that helps provide referrals and continuity of care for tuberculosis patients and their contacts who travel between the United States, Mexico, and Central America. I also assisted a group of Communicable Disease Investigators (CDIs) as they traveled to a local elementary school to test students for tuberculosis after a student with active tuberculosis disease was reported. Here, I helped teachers organize students and assisted students with the necessary paperwork.

Although limited, these moments of participant observation permitted me access to forms of embodied and situated understanding that was not possible with direct observation. The collective nature of participant observation can open up aspects of the social context that are usually only available to insiders. These represented the early stages of intersubjective intellectual collaboration that placed me closer to the center of the lived experience of the workers at the TCP and have informed my thoughts about possibilities for extending or building upon this inquiry in the future.

Interviewing TCP Employees and Other Community Supports

After approximately four months of intensive direct observation, I began conducting formal interviews of staff and other professional/community affiliates of the clinic. By the time of the interviews, most of the employees at the main TCP branch were familiar with me, and I had met many of the employees at the satellite branches at least once. In total, I conducted formal interviews with 20 TCP employees, including administrators, nurses, doctors, and disease investigators. For community supports and patient advocates, I was most often introduced by word of mouth through employees at the TCP. We communicated largely though email, although interviews were conducted in person or on the telephone. I interviewed 5 community supports, including local and national tuberculosis advocates and two former TCP employees who now serve on tuberculosis advocacy and oversight committees.

I recorded and transcribed all interviews, with the exception of a few participants who declined to be recorded and two people who preferred to communicate via email correspondence. In the instances when a person did not want to be recorded, I took detailed notes during interviews. I have kept all digital materials, including transcripts, audio recordings, and email communications on a password-protected computer, and I have stored all physical materials, such as field notes and interview notes, in locked file cabinets.

I began my interview process with employees of the TCP and other community supports or activists, who were relatively accessible and overwhelmingly willing to talk to me about their jobs, their perspectives on tuberculosis in the community, and their perspectives on the strengths and limits of current models of tuberculosis care. These in-depth, open-ended interviews provided a distinct form of access that in turn helped to guide my ongoing direct observation. In these interviews, I was interested in better understanding aspects of the organizational structure and flow of the TCP that I could not ascertain from observations or document review. I was also interested in identifying a range of perspectives on tuberculosis and its treatment, including the strengths and challenges of current best practices, how TCP employees characterized tuberculosis and its control, their perspective on the individuals and communities they served, and how the disease affects the community and the everyday lives of individuals.

To help establish relationships with TCP staff early on, Dr. Walter formally introduced me at a department-wide staff meeting. With this introduction, Dr. Walter framed my research and gave permission for TCP employees to talk with me while they were at work. This was an important step for my research and for better explaining my work to a wide-range of TCP staff. Most people, including Dr. Walter, initially presumed that, as a doctoral candidate in a Communication Department, I would be most interested in the ways patients interfaced with various clinical and administrative components of the TCP. While this was indeed a productive focus of my work, my interviews with TCP employees offered a chance for sustained dialogue about additional facets of my research that positively informed subsequent interactions at my field site.

My regular and extensive contact with Dr. Walter may have heightened the sense of vulnerability of TCP employees to my research insofar as many were aware of my regular interactions with their supervisor. At the same time, some TCP employees also seemed to perceive my affiliation with Dr. Walter as something of an opportunity. At various times they approached me of their own volition to point to aspects of their job that they were unhappy with or perceived as a hindrance of some sort. They offered suggestions that I perceived as being indirectly pointed at Dr. Walter's ears or inclusion in my findings: adding additional signage to help direct patients where to talk in the clinic and lobby; reestablishing funds to stock items to occupy children who were passing through the TCP; or investing in a phone service to aid in the appointment scheduling and reminders, for example.

Interviewing TCP Patients

IRB protocol and the rules governing researchers at the San Diego County HHSA required a more formal process for the recruitment of patients for interviews than TCP staff. Consequently, I used purposive sampling to identify patients. Most often a doctor at the TCP clinic performed the initial recruitment, although sometimes nurses and other administrators engaged in recruitment as well. Potential patients were first assessed by the TCP doctors, nurses or administrators as meeting the criteria outlined by my study and stipulated by HHSA in terms of age, command of the English language, and willingness to participate in a research project concerning disclosure of sensitive information about their health status and experiences. The doctors or other TCP staff then invited interested patients to contact me, or the patients gave their permission for me to contact them. When I made my first contact with a patient I provided further details about my study. If the patient was comfortable with participation, I arranged an interview. By the choice of the patients, interviews most often occurred at the TCP itself, although occasionally interviews happened by phone or email and even less frequently in the home of the patient as part of an already existing appointment with one of the TCP staff who regularly visited. In total, I interviewed seven patients and one family member.

The act of recruiting people to share their experiences, opinions and feelings in the context of research is never without ethical challenges, and the process of recruitment in a healthcare setting raised important questions related to the nature of qualitative communication research, principles of voluntary participation, informed consent, confidentiality, and reciprocity. Importantly, my research at the TCP highlighted power differentials and the vulnerability associated with medical encounters. Most people visited the TCP because they had been compelled for employment reasons, immigrations requirements, or because they had contact with a person with tuberculosis disease during their infectious period. Others received treatment at the TCP because they were under- or uninsured or because they had a complex case that required specialized attention for treatment. Because of this, participation in this study posed a potential additional burden to the experience of being a patient with tuberculosis. With these issues in mind, I strove to be respectful of a patient’s time, energy, and any emotional burden my interview might confer. I tried to reduce the risk of potential distress, exploitation, and identification.

Ultimately I interviewed fewer patients than initially intended, and my sense is that the difficulty I faced in recruiting patients as participants can be attributed to various reasons, many of them linked to questions of power and my relationship to the institutional setting in which I was embedded. I asked all participants –TCP employees, community supports, and patients and their families– to share, to whatever degree they felt comfortable, potentially sensitive information, emotions and experiences. However, TCP patients were in a more vulnerable position than the TCP staff or community supports and patient advocates who often felt strongly about being vocal for the needs of the tuberculosis community in the San Diego County and surrounding border region. As a researcher it is likely that the way that patients perceived me was closely aligned with the doctors and other positions of power within the TCP. I wore an identification badge, dressed in professional clothing, and was formally introduced to patients as a TCP vetted researcher. This alignment with the official organizational framework manifested itself positively in the willingness of the doctors and other TCP staff to be candid with me. But it manifested as a power differential that further separated me from patients, presumably adding to the reluctance of many to participate in my research.

An extension of this was my status as a member of largely privileged, dominant social groups. My position as a white, highly educated women working as a researcher often served to further separate me from the patients who came into the clinic. Their own identities were often substantively different from my own in terms of class, ethnicity, cultural background, or citizenship status. My awareness of my alignment with the TCP, in addition to my sociocultural privilege, became a central factor in my consideration of how to engage patients in my study. I was especially aware of the possibility that how I was perceived might create implicit incentives for them to perform the role of the 'good' or compliant patient. My formal affiliation with the TCP raised many such questions, most without immediate answers but with important implications for my future research. I began to wonder about ways I had been complicit in maintaining hegemonic norms of the state and in what ways health is always a negotiated status.

Beyond limiting the scope of my study alone, however, the challenges I faced with regards to patient recruitment became significant as sparks that ignited important themes in my research, and they have helped direct me towards future inquiry. My difficulty in patient recruitment points to the stigma and sometimes alienating process of being screened or treated for tuberculosis. Further, my relationship to power highlighted the stressors and strengths of the current system of control.

Chapter Conclusions

Recognizing that concepts are contingent and historical, shaped by the social processes and forces from which they emerge, my theoretical orientation informs my methodological design in an effort to better understand how tuberculosis is understood both as a contemporary international pandemic and as a localized condition within San Diego County. This includes an interrogation of the ways this local region is situated within larger national and international contexts that influence the discourses and practices surrounding the control of diseases and treatment of illness. In the following chapter, I situate my theoretical and methodological approach more concretely in relation to my activity at my field site, the TCP housed at the HHSA of San Diego County. In it, I describe the TCP's broad organizational structure and present a vignette drawn from my time at the site that gestures towards the local context of global tuberculosis control efforts and introduces some of the people and themes carried through this dissertation.

CHAPTER TWO: SITUATING TUBERCULOSIS CONTROL IN SAN DIEGO COUNTY

To frame my research at the Tuberculosis Control and Refugee Health Program (TCP) at the Health and Human Services Agency of San Diego County (HHSA), I use this chapter to discuss the legacy of public health efforts aimed at tuberculosis control and to situate the TCP's functions as they articulate national and international public health policies at a local and regional level. I begin with a brief outline of the history of public health in order to locate tuberculosis control's place within that lineage. I trace public health's roots in projects of nation building through its current iteration that has, to some extent, internalized the management of health as a project and responsibility of self. Next, I introduce the TCP as a site of study and describe its organizational structure, primary tasks and goals, and my place within it as an ethnographer and volunteer. Finally, I present a vignette from an important morning at the TCP that helped shape my research. I offer this vignette as an introduction to some of the central participants and themes that were foundational to my work, particularly my focus on the interface between centralized tuberculosis control protocols and localized needs as well as the power and resistances that are formative of practices of disease management in local contexts.

A Brief Survey of Public Health and its Links to Tuberculosis Control

In his lectures on the history of what is now known as public health, Foucault (2000 [1974]) tracked a broad shift to social medicine in Western Europe that began in the 18th century and lasted through the mid 19th century. Foucault diagnosed modern medicine as a social medicine that was unique for its vested interest in the social body (p. 136). The shift to social medicine was characterized by increasing individuation across public and private medical care. By extension, social control of the individual began to occur within and through the human body out of concern for the productivity of individuals as forces of labor, objects, and sites of production (p. 136). The changes were productive of the medical subject and the biomedical body as a "productive force, of labor power" (p. 137).

Foucault identified three organizing stages that characterized the shift to social medicine. First was the development of a formalized and standardized form of *state medicine* in Germany at the beginning of the 18th century, which was concerned with the bodies of individuals only "insofar as they combined to constitute the state" and thus state power (p. 141). In this regime, the health of the whole equated to the health of the state. Next was the development of an *urban medicine* as characterized by 18th century France. Rooted in the "politico-medical ideal" of sanitary organization (p. 145), this logic of care worked by individualizing and observing ill patients in order to protect the healthy public by controlling the circulation of elements such as water or air (p. 148).

Finally, according to Foucault's schema, 19th century Britain saw the development of *labor force medicine*, which aimed to keep the workforce healthy by managing "the needy social classes" and thereby protecting wealthier classes (p. 154-155). This happened through (1) mandated vaccination, (2) required reporting of certain diseases, and (3) finding – and destroying when necessary – local spaces identified as breeders of disease. During this phase, the bodies of the poor became increasingly politically important as resources of the state. Foucault suggests that labor force medicine was structured by three overlaid medical systems: a welfare system designed for people without socioeconomic means; an administrative system responsible for broad, population-based tasks such as vaccinations or responding to epidemics; and a private system serving people who could afford its fees (p. 155-156).

Taking up and modifying Foucault's (2000 [1974]) account, Armstrong (1993) offers a historical mapping of changes in public health management over the 19th and 20th centuries. Like Foucault, Armstrong focuses on the discourses and practices of public health institutions and the interrelationships among factors such as space, location, and identity in the construction of the modern subject.[26] Armstrong charts four regimes of public health: quarantine, sanitary science, interpersonal hygiene, and finally what he terms the 'new' public health. Though overlapping, these four regimes each posed new solutions to public health problems and were based in changing understandings of disease as disease management strategies broadly moved from a focus on land/space to an emphasis on individual action.

Quarantine and Sanitary Science

For the first half of the 19th century, Armstrong argues that the dominant regime of public health was *quarantine*, which controlled disease by controlling space. Because

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[26] Despite my focus on Armstrong (1993) in this part of the chapter, it is important to note that there are a number of additional important works on the history of public health. For example, see *A History of Public Health* (Rosen, 1993 [1958]), *A History of education in public health: Health that mocks the doctors' rules* (Fee & Acheson, 1991), *The unfulfilled promise of public health: Déjà vu all over again* (Fee & Brown, 2002); *Public health: The development of a discipline, from the age of Hippocrates to the Progressive Era* (Schneider & Lilienfeld, 2008); *Public health: The development of a discipline, twentieth century challenges* (Schneider & Lilienfeld, 2011); or *The private side of public health: sanitary science, domestic hygiene, and the germ theory, 1870-1900* (Tomes, 1989) as examples among many.

illness and disease were thought to inhabit space, quarantine worked by parsing healthy space from ill space and restricting passage between the two domains (p. 394-395). A shift to the regime of *sanitary science* in the mid-19th century focused attention to the relationship between individual bodies and the spaces in which they lived and acted. Population shifts from rural areas to urban centers with the industrial revolution helped bring the focus on sanitary science into relief because such large-scale movement challenged existing public water supplies and systems for waste disposal and contributed to a dramatic increase in overcrowding and inadequate housing (Ward & Warren, 2007).

While quarantine focused on protecting the safety of the state, the regime of sanitary science focused on building a healthy state by preventing disease and extending life expectancy within its populace. In the regime of sanitary science, the human body was understood as an object separate from its environmental space. Public health worked by controlling the passage of entities between the two zones, for example, by regulating the quality of the air that entered the human body or better managing the movement of excrement back into the environment (Armstrong, 1993, p. 397-398). This was a productive strategy rather than a restrictive one, an approach to aid industrialism rather than a limiting technique driven largely by safety concerns.

Interpersonal Hygiene

By the turn of the 20th century, germ theory had become more widely accepted and concerns about the relationship between hygiene and disease intensified. After Koch's 1882 discovery of the bacterial cause of tuberculosis, scientific experimentation proved that the bacillus was resistant to many of the prevailing forms of disinfection

(Stanford, 1970). These developments had major implications on scientific and social understandings of hygiene and its relationship to the spread of disease. The new emphasis on bacteriology began to change how medical care was practiced, including the separation of public health from medicine and the professionalization that occurred within public health as a distinct discipline (Coker, 2000; Lupton, 1995).

The tuberculosis work of American public health pioneer Hermann Biggs is relevant as one of the first people to apply discoveries in bacteriology to the world of infectious disease control (Frieden, Lerner and Rutherford, 2000; Starr, 1982). Biggs was instrumental in setting up a tuberculosis control plan that relied on the mandatory notification of tuberculosis cases, free examinations and sputum testing for all patients, nurse follow-up and reporting, tuberculosis awareness through public education campaigns, and a commitment to increasing political commitment to tuberculosis at city, state and federal levels (Frieden, Lerner and Rutherford, 2000, p. 1088).[27]

Collectively, these changes mark beginning of the third regime of public health outlined by Armstrong (1993), when the rules governing how hygiene was understood and managed changed at the turn of the 20th century. Rather than operating via a central legislative framework that managed the relationship between bodies and their environment (rules governing disposal of dead bodies, maintaining a healthy water

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[27] In addition to contributing to a theory of infectious disease control, Biggs' work was also important to establishing public health as a legitimate field. In 1904, Herman Biggs and his colleagues Edward Trudeau and William Osler formed an interest group of professionals and laypersons called the National Association for the Study and Prevention of Tuberculosis. Later, the organization developed into the National Tuberculosis Association, and today it is well known as the American Lung Association (Murray, 2004). Another major development establishing the field of public health in the United States came in 1912, when the United States Public Health Service (PHS) was formally established and tasked with the coordination of infectious disease control at the national level. Today, PHS is the umbrella organization for the Centers for Disease Control and Prevention (CDC), the National Institutes of Health, and the Food and Drug Administration (Ward & Warren, 2007).

supply, or ventilation within buildings, for example), public health began to focus more on *interpersonal hygiene* – the relationships and boundaries that separated individual bodies.[28] In the regime of interpersonal hygiene, public health called on individuals to perform more and more surveillance and maintenance work. For example, schools taught children to avoid putting objects other than food or drink into their mouths, to wash their hands, or to sneeze away from others (Armstrong, 1993, p. 401). Laws that prevented spitting in public were reinforced socially through the public education campaigns that were launched by public health interest groups and individuals such as the Women's Health Protective Association, editors in health journals, and by public figures such as Lawrence Flick, physician and founder of the National Association for the Study and Prevention of Tuberculosis (now the American Lung Association). These individuals and groups linked spitting not only to the spread of disease but also to other behaviors deemed as immoral, such as sex or gambling (Ott, 1996, p. 117-120).

Often, embedded into the discourses of dirt and standards of cleanliness was an intensified focus on the perceived/projected poor hygiene of immigrants, African Americans, and working-class Americans (Ott, 1996, p. 122-124). In the emerging battle against dirt and germs, public health agencies emphasized the role of education about personal hygiene and the individual's responsibility to follow hygienic guidelines. Tomes (2000) proposes that the new bacteriology became the basis for public health campaigns that aimed to make Americans aware of the hidden dangers of germs lurking in everyday life, focusing on germs, their links to disease, and what behaviors to practice to avoid

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[28] This shift parallels scientific understanding of pathogens and vectors of contagion. While the science of microscopic biology offered more detailed observations of the localized mechanism of infection and transmission, the earlier causal model of miasma rightly pointed to environmental conditions even if it misconceived causal agents and processes.

them (p. 192). He writes, “The anti-TB movement played a particularly important role in transmitting the new lessons of germ awareness. Through their numerous leaflets, parades, exhibits, and Christmas seal campaigns, TB workers made themselves and the disease a prominent feature of American life in the early 1900s” (p. 192). In addition, research in bacteriology, a field that had only recently emerged in the last quarter of the 19th century, demonstrated that large swaths of people were infected with tuberculosis in its latent form. This knowledge contributed to the focus on the prevention of infection through individual hygiene rather than through social reform efforts (Starr, 1982, p. 191).[29]

Whereas previous regimes of public health were based on the establishment of boundaries that separated spaces from spaces or people from environments, the newer focus on interpersonal hygiene by civic leaders and public health policymakers at the turn of the 20th century concentrated on the borders that existed between people. This transformed the meaning of hygiene itself, which came to be understood as a psychosocial space as well as a marker of “individual difference” (Armstrong, 1993, p. 404). Linked to the growing attention on the boundaries between people was an increased surveillance/monitoring of the movement individual bodies by agents of public health, which was founded upon the implementation of practices of observation of populations by epidemiologists in tandem with the ascendency of conceptual understanding of disease

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[29] Tomes (2000) points out that antiseptic consciousness ironically reached its peak during the early 20th century when deaths caused by infectious diseases were on a steep decline. He writes, “TB became the ‘master disease’ of Progressive Era reformers not because it was on the rise but because it served other compelling agendas: to popularize the new germ theory of disease, to respond to the presence of new immigrant and racial groups in American cities, and to advocate for a broad range of social welfare measures” (192-193).

linked to a bacteriological etiology.[30] Together, the mapping of affected populations and expanded understanding of the micro-processes that comprised the trajectory of disease within individual bodies formed the basis of a new approach to medicine that helped translate individual trends into statistical health estimates and influence how governments knew and managed their inhabitants. Population-level data in turn formed a feedback loop with implications at level of the individual or group by establishing a 'normal' range of variation against which individuals could be compared (Lupton, 1995). In addition to its links to governmentality, this "hegemony of normalcy", as Davis (1997) has called it, has been critical in shaping personal expectations for our own bodies as well as those around us, particularly in relation to health and illness (p. 26).

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[30] As the primary discipline of public health, epidemiology measures the impact of disease by examining "the distribution, frequency and determinants of health problems and disease in human populations" (Vaughan & Morrow, 1989, p. 9). Using health information to try to reduce disease, epidemiological research work focuses on assessing populations at risk as a crucial tool for health planning, programming and evaluation (Vaughan & Morrow, 1989, p. 10). Much of this work is done by weighing risks of exposure against projected susceptibilities or resistances thereby creating associations between specific categories and specific diseases. For example, epidemiology associates old age with increased risk of heart disease and cigarette use with lung cancer.

Race and ethnicity are two often-cited epidemiological categories —along with other categories such as age, gender or socioeconomic status— that are used as indicators of risk or protective factors related to illness and health. While such linkages can have the benefit of raising institutional awareness for issues or populations that do not typically receive enough attention or funds, this practice is also problematic because of the tendency to flatten or outright ignore intersectional factors that are important to understanding relationships between patterns of disease.

Ho (2004) argues that the epidemiological approach to tuberculosis has most often focused on "only one factor (either cultural, environmental, or politico-economic) without illustrating the complex inter-relationships among different factors" (p. 759). This limitation is not endemic to epidemiology per se, as Ho praises "multifactorial epidemiological models that take into account biological, cultural, ecological, and politico-economic factors" because they help explain why not everyone who is infected with *Mycobacterium tuberculosis* becomes sick with active disease (p. 759).

Interpersonal Hygiene: Dispensary Gaze

As a technique of discipline, the increased attention paid to interpersonal hygiene by public health leaders and policymakers helped shape personal subjectivities and individual boundaries with others, marking the emergence of the belief that health is located within the individual and can be determined by his or her behaviors and decisions. These changes also had a major impact on the organization of care for tuberculosis treatment and control. In particular, as Starr (1982) and Armstrong (1993) point out, the emerging institution of tuberculosis dispensaries in late 19th century Britain and in the United States during the early 20th century reflected this shift in discourses of public health in which interpersonal hygiene took on a more central role. Tuberculosis dispensaries fulfilled multiple functions in service of patients, public health officials and state governance. In the United States, dispensaries served an important role for treating patients who could not otherwise afford private care. But they also fulfilled other related functions, notably providing a forum for medical students to gain training (Starr, 1982).

Although dispensaries had been in use for centuries, Armstrong (1993) suggests that the tuberculosis dispensaries of the early 20th century were different in both form and ideology. Both flexible and mobile, the updated dispensary model introduced ways of seeing illness that are still in use today. Because medical authorities had come to see disease as thriving in the intersections between people, the new dispensary extended itself into the community (p. 10). Its physical building served as a point of coordination rather than a locus of cure, and its organizational structure was designed to survey and monitor the whole community through an examination of the patient's life, relationships, and networks (p. 8). The crucial activity of tuberculosis dispensaries were the home visits performed by nurses whose job it was to learn about the needs of their patients, report on their living situations, help patients connect with aid organizations, report contacts, and educate patients about healthy living. While the clinical gaze localized illness within a bounded body, the *dispensary gaze*, as Armstrong (1993) coins it, extended the watchful eye of public health into the community to monitor patients and to surveil the normal in an effort to detect the not-yet-ill (p. 10), a legacy that has resonances even today (See Chapter Three).[31]

Interpersonal Hygiene: Sanatoria

At the turn of the 20th century, home care and dispensaries were the predominant forms of tuberculosis management in the United States. However, a boom in the building of tuberculosis sanatoria during the early 20th century meant that sanatoria began offering an additional solution for patients with long-term or intensive needs, and their popularity continued to grow over the next several decades (Frieden, Lerner & Rutherford, 2000). For example, at the cusp of a growing sanatoria movement in the United States, the founding members of the National Association for the Study and Prevention of Tuberculosis formed the American Sanatorium Association. When this organization was established in 1905, the United States was home to 106 sanatoria, which could house

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[31] See also Foucault's (2003 [1963]) work in *The Birth of the Clinic* in which he argues that new technological capacities to spatialize disease within human bodies helped transform them as entities separate from selves. In this epistemic change in medical practice, as disease became highly individuated, the patient became an "external fact" (p. 8) that could be subtracted from the illness during diagnosis (p. 14). Beyond its role as a physical space where medical practice was enacted, the clinic also began functioning as a discursive and material practice that produces truth claims about health and disease. In this sense, medical practice creates a set of knowledges about the body, which are communicated to social domains outside of the clinic.

9,107 patients. Fifty years later, at the peak of the United States sanatoria movement, sanatoria had 108,457 beds (Murray, 2004).

Predicated upon the idea of "absolute rest" (Mera, 1935), which was managed through a strictly-controlled regime that guided patents' every move, breath, or bite of food (Ott, 1996), the average stay at a tuberculosis sanitarium lasted between one and two years, though many people stayed far longer (Snider, 1997). Upon arrival, patients were most often restricted to complete bed rest, 24-hours a day. Gradually, as their stay increased, patients were allowed some time for movement (Snider, 1997). Ott (1996) maintains that the tuberculosis sanatoria movement in the United States was "perceived as the most important tool in the management of the disease" (p. 147), despite actually housing less than 10% of the overall population at need (p. 149). Although most people with tuberculosis were treated outside of sanatoria, sanatoria nonetheless remain an iconic cultural symbol of the ethical logic of establishing spatial boundaries in the treatment of people with tuberculosis (Ott, 1996). Their physical exclusion meant that diagnosis, treatment and rehabilitation could happen under a single roof, and as Ott (1996) has argued, they had the added benefit of offering a means for removing the ill from society (thereby protecting those who were ill) in a manner that was seen as humane and sometimes even luxurious (p. 150).

Along with sanatoria, legislation became an important tool in tuberculosis control and was often legitimated in terms of the concept use of "just force." The line between justice and outright coercion was, however, flexible, particularly in poor or urban communities (Ott, 1996, p. 120). For example, the federal government enacted legislative prohibitions against marriage for people with "eugenic defects", of which tuberculosis was added to the list (p. 115). Many communities passed “removal laws” allowing public health workers to use force when confining people with tuberculosis who were deemed irresponsible or uncontrollable in relation to spreading the disease (p. 120). By in large, these restrictive measures were not uniformly applied. Rather, they were targeted, most often, to patients with lower socioeconomic status or racial or ethnic difference (Coker, 2000; Ott, 1996). For people of means, tuberculosis was generally treated in a manner that reflected more concern for personal and familial propriety, while people with less social and financial capital more often faced coercive or extreme control measures (Coker, 2000).

As rates of tuberculosis continued to decline into the mid-20th century, the labor- and resource-intensive strategy of monitoring and isolating patients with tuberculosis waned (Coker, 2000). In fact, the strategy of controlling the disease through the containment of the individual has waxed and waned through time. After the introduction of antibiotics in the mid 1950s, tuberculosis sanatoria began to close their doors, a process that began in the mid-1950s and continued through the end of the 1960s (Snider, 1997). Dispensaries were also closing their doors, having been folded into existing hospital and outpatient infrastructures after the restructuring of medical education curtailed the free labor that dispensaries relied on for operation (Starr, 1982). During this time, tuberculosis prevalence and mortality continued its downward trend, and the United States government began decreasing public health budgets for tuberculosis control (Snider, 1997), reflecting a broad shift away from an emphasis on the social causes of the disease in medicine, public health, and national policy (Starr, 1982). By the 1970s, there was another refocusing on the individual with the identification of multidrug-resistant tuberculosis as a serious problem (Coker, 2000). Finally, the World Health Organization’s (WHO) unveiling of their universal containment platform, Directly Observed Therapy, Short-course (DOTS) in the mid-1990s constitutes the most recent wave of attention to individual [non]compliance.

The ‘New’ Public Health and Public Health Promotion

Armstrong (1993) pinpoints the emergence of the current regime of public health, what he terms a *‘new’ public health*, during the 1970s. A major feature of the current public health paradigm is its emphasis on health promotion, which formed as a response to the critique that health education’s focus on the individual excludes an examination of sociopolitical conditions in assessments of health (Lupton, 1995; Petersen and Lupton, 1996). One of the core principles of health promotion is the perspective that environmental conditions are as important to achieving and maintaining a healthy population as curative technologies. Armstrong (1993) suggests that the definition of environmental conditions has expanded from an attention to the living conditions of individuals and groups to also include an examination of the ways human interventions into nature have resulted in environmental effects drastic enough to impact human health.

Despite a focus outward on environmental factors, the personal responsibility of individuals has remained a central strategy of health promotion efforts, particularly since the rise of epidemiological research that has linked lifestyle traits with health and illness, replacing older explanations rooted in religion (Guttman & Ressler, 2001). Within prevailing discourses of promotion, healthiness itself is constructed as a tenuous category. One reason for this is that health promotion focuses on ‘care of self’ as a primary means for becoming and staying healthy. In addition, the introduction of the concept of risk as a key tool for health promotion has meant that people are cast in terms of their potential to fall ill (Petersen, 1996), although it is worth noting that as a regulating mechanism, the discourse of risk is not applied to all individuals equally. Nonetheless, this discourse has the effect of enforcing certain standards of health at the level of individuals and groups. In essence, the actions and desires that make up the "codes of conduct" that act as indicators of health are consistently monitored by self and others (p. 44). In this way, an important part of health in the current regime is the performance of healthiness. Its indicators are externally evaluable by self, friends, family, and other community stakeholders, and it is made measurable through research agendas, public health legislation and global policy. Performing healthiness signals that a person is fulfilling their obligation to self and nation by acting as a rational and responsible citizen.

Critiques from the fields of public health and critical health communication have argued that the distinction between health promotion and health education is insufficiently articulated and under theorized (Tones, 1986), partially given the overlapping aims of the two approaches (Holman, 1992). For these reasons, scholars have suggested that the focus on health promotion has not changed the field as dramatically as the discourse might suggest. Lupton (1995) further argues that there are significant tensions embedded within the guiding logics of health promotion and the 'new' public health. Notable among these is the opposition between the ideal of participatory care and its sometimes-paternalistic operationalization. As a result, Lupton worries that it becomes too easy to blame 'lifestyle decisions' by individuals and groups for the illnesses or diseases they face.

The critiques of health promotion signal important contradictions that have arisen from its formulation as a response to the perceived paternalism of previous approaches to public health. The contradictions between goals and operationalization allow for the emergence of coexistent and often incommensurate interpretations of health promotion to be taken up by researchers and public health practitioners at different poles of the political spectrum (Lupton, 1995). Those at the conservative end argue for health promotion strategies that guide individuals, well and ill, to take responsibility for their health thereby reducing the financial burden on public and private health systems. More progressive interpretations of health promotion argue for increased focus to be placed on governmental policies and programs as a way to better mitigate social inequity and develop health plans and systems that empower individuals and communities to shape how the public health system itself functions (Lupton, 1995, p. 51-52).

The tensions over interpretations of health promotion point to important underlying conflicts (as well as alignments) within the conceptualization and delivery of care that have concrete, if varied, implications for how public health leaders and policymakers define and solve health issues at the population level. What these diverse political orientations share is a view of the individual as rational actor and a fundamental belief that individual health behaviors mediate health status. From its most individually-oriented practitioners to advocates of community development models that seek to embed health promotion in all levels of social life, health promotion looks to individual and group attitudes as a point of intervention to change behaviors and ultimately improve health (Lupton, 1995, p. 55-58).

The ‘new’ public health was conceived amidst large-scale political changes that began to limit social sector expansion in favor of smaller government, privatization and deregulation. One discursive formulation that undergirded this movement was the rhetoric of patient-as-consumer, which emerged as part of the shift to the new public health in the 1970s and the rise of neoliberal economic liberalization of the 1980s.[32] With the increasing privatization of the healthcare and service sectors, the patient-as-consumer metaphor and the rhetoric of personal responsibility for individual health have now become a central part of health policy and popular discourse.[33] Underlying health messages across multiple domains, from media to medicine and education to the rhetoric of healthcare reform is the rational, self-interested actor. Contemporary public discourse

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[32] As a social and political philosophy that has been in ascendancy for the last 30 years, neoliberalism is marked by a rejection of Keynesian economics and its association with competition, free trade and economic deregulation, all of which is supported by socioeconomic policies that are favorable to business and boost the position of the private sector in all facets of society. In his Lectures at the College de France, Foucault (2008) notes that despite this deregulation, neoliberalism is actually marked by a new belief that “One must govern for the market rather than because of the market” (p. 121). According to this logic, the market is rejected as natural and instead seen as something that must be carefully managed. That is, the juridical gives form to the economic in the sense that the economy is the effect of a legal order. Brown (2005) elucidates, “The neoliberal formulation of the state and especially specific legal arrangements and decisions as the precondition and ongoing condition of the market does not mean that the market is controlled by the state but precisely the opposite. The market is the organizing and regulative principle of the state and society…” (p. 41).

Because of this, neoliberalism is more than just an economic worldview. It is also a political rationality that extends beyond the market to the social sphere and the realm of everyday life. A technology of government that changes relationships between governments and constituents, neoliberalism does not have a singular, monolithic framework that organizes social and political experience in the same way everywhere. The commonality, however, is a shift in rationalities and organizational logic that compels individuals to organize themselves vis-à-vis an internalization of market principles and by taking over responsibilities previously help by the state (Ong, 2006). As such, it marks the emergence of a new kind of governmentality.

[33] In her dissertation, Nancy Stark Lee (2007) traces the roots of the patient as consumer metaphor to the 1930s, during which time the over-the-counter self-care industry was more fully developed and supported by advertising (p. 55). It was not until the 1960s and 1970s, however, that the patient as consumer metaphor fully came into use. She explains, “various rights groups used the term to signify the rejection of medical paternalism through the empowerment of patients. And just as activists appropriated the term consumer from market vocabulary, in the 1980s the healthcare industry started co-opting the patients’ rights movement’s message of the empowered consumer to sell the public on the merits of consumer choice in a competitive, open-market health system” (p. 4-5).

serves as a continuous reminder that individuals are in charge of their own health and responsible for their medical destiny. The self-care practices expected of healthy citizens comprise a long list that includes monitoring the ways we eat, move, or seek pleasure. We are enlisted to pay attention to how much we weigh, manage our stress, engage in risky behaviors, or seek medical maintenance and care. The list goes on, but the implication is that much of the work of maintaining a healthy community is an amalgam of the individual choices made by that community's citizens.

The consumer-as-patient model that drives the current corporatized healthcare model in the United States casts citizens as necessarily health-seeking subjects. Reeder (1972) has linked the growth of consumerism in the context of healthcare to structural changes in society and in the healthcare field. Central among these is the shift to privatized, prepaid healthcare programs offered through bureaucratic institutions. The widespread rise of consumerism in the 1960s that likened people to consumers first and foremost was foundational in the reconceptualization of recipients of health care as medical consumers rather than patients.

A shared perspective that crosscuts differences of opinion in the 'new' public health is that the delivery of effective information empowers the patient-cum-consumer to take an active role in his or her own health. These changes reflect what Rose (2007) has characterized as a reorganization of state powers in advanced liberal societies that has decentralized the responsibility for the health and reproduction of populations from the government across a number of entities. These include regulatory commissions, private companies, professional groups, and indeed individuals themselves (p. 3). Clarke et al. (2010) point to the ways that patient groups today are "inside research activities" and not just working to improve political processes (p. 13). Established in 2000, the TB Alliance is a public/private partnership comprised of academics, non-governmental organizations, patients and members of industry that offers a clear example of the form of reorganization that Rose (2007) and Clarke et al. (2010) discuss. Members of the TB Alliance, who span heterogeneous positions in the patient/care equation, advocate the development of new tuberculosis medication options.

Armstrong (1993) argues that one of the most important features ushered in with the new public health management model is the extension of surveillance throughout the "body politic," which has occurred by embedding an awareness of health across social, political, and economic activity (p. 405-406). An updated extension of the disciplinary gaze, in the new public health surveillance is both external and internal to individuals. According to the logic of this paradigm, public health authorities must be alert to the threats posed by the potential dangers lurking everywhere. And so too must individuals – beginning with themselves. Petersen (1996) adds that the focus by the new public health on preemptive interventions, in particular on the dictate of self-care, "represents a subtle and sophisticated form of individualism that involves everyone in the task of tracking down and controlling or eliminating sources of risk from their own lives" (p. 45). In other words, this logic of care is reflected in and constitutive of a social system that imagines individuals as private enterprises tasked with managing personal risk. Petersen (1996) further argues that individuals produce their own rationality by maintaining a "contrived style of conduct" that draws upon a rhetoric of the individual as entrepreneur (p. 48). As such, health promotion has been said to have contributed to the privatization of health through its focus on the distribution of risk management throughout the body politic (Armstrong, 1993) and within the industrious, self-regulating individual (Petersen, 1996).

Introducing the TCP

The TCP functions with the logics and contradictions of the ‘new’ public health and faces intersecting challenges related to infectious disease control at the level of the individual and the community. These include tensions that arise between individual health as private responsibility, the protection from illness as public right, and the government’s stake in establishing and maintaining the parameters of infectious disease control, while maintaining international standards and protocols of tuberculosis control as monitored by state and federal entities.

San Diego County’s HHSA, which houses the TCP, is one of sixty-one county public health departments in California, and serves the county’s three million residents (“San Diego County”, 2014). The aim of the TCP, like other local tuberculosis programs, is to provide a centralized hub for the control and prevention of tuberculosis within their geographical jurisdiction in service of larger state and national authorities. Tuberculosis programs are evaluated based on performance targets established at national, regional, and local levels. In this regard, the TCP’s location is notable insofar as the nationwide treatment and control objectives put in place by the Centers for Disease Control and Prevention (CDC) were largely based on the California Health Department’s program evaluation platform. This implies that while having to conform to national goals and standards, the TCP is physically and politically situated in a position of potential impact upon national policy. The CDC’s treatment and control objectives are designed to measure of how well programs throughout the nation conduct a wide array of agency functions that map onto the logics of health promotion and the new public health including: managing policy development and planning; identifying and treating people with active tuberculosis disease; conducting contact investigations to identify and test people who have had contact with someone with active tuberculosis; screening people who are considered high-risk for infection; conducting patient education related to the transmission, treatment, and prevention of tuberculosis; maintaining laboratory and diagnostic services; conducting data collection and analysis; and providing training and education opportunities for the community.[34] These state and national targets address a program's outcomes across goals including detection, investigation, and treatment completion rates in order to standardize how local programs are monitored and evaluated.

The TCP interfaces considerably with the private sector, assuming a degree of council as the overseer of all active tuberculosis treatment countywide and as an advisor to cross-border coordination of care for mobile patients, families, or contacts. Under TCP director Dr. Erin Walter's supervision, TCP staff counsel private doctors about how to diagnose, treat, and report tuberculosis. In addition to such direct relationships with the private sector, the TCP interacts with other aspects of the private and public sectors that expand beyond medical care of patients. For example, during the contact investigations that are designed to identify people who have been exposed to a person with active tuberculosis, public health workers engage with the community at a number of levels, most often in the form of site visits for testing and education. These formal and informal

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[34] See, for example, the CDC (1995) document, Recommendations and Reports: Essential Components of a Tuberculosis Prevention and Control Program and the California Department of Health's (2014) Tuberculosis Program Assessment Tool.

public/private interactions reflect a system of tuberculosis control that relies on relationships with its local community by largely centralized protocols, even if such relationships are not fully supported as a result of insufficient funding (See Chapter Four) or are largely built on informal and distributed models of communication and advocacy (See Chapters Three and Four).

While much of the tuberculosis control work performed by the TCP is enacted at the administrative nexus of individual and community behaviors, a portion is constituted through legal intervention, which comes in many forms including mandatory testing and treatment, ordered isolation, monitoring patients as they take their medications, and reporting vital statistics designed to track population trends. A crucial turning point in the United States that established a legal basis for the relationship between public health goals and the governmental exercise of power came with the 1905 Supreme Court case, *Jacobson v. Massachusetts* (Jacobson v. Massachusetts, 197 US 11, 1905). In this case, Swedish immigrant Henning Jacobson challenged the legal authority of compulsory vaccination, in this instance for smallpox. Ultimately Jacobson lost his case. Consonant with the *harm principle*, the court established a legal precedent that allowed the state to limit the rights of individuals if those rights put the safety of the general public at risk.[35]

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[35] Classical liberal theory has argued that as rational beings, individuals should be free to organize their own thoughts, opinions, and bodies in any manner they wish, as long as their actions do not impede on the rights of other individuals. A classic example of this logic, with implications for contemporary public health policy, is John Stewart Mill (2004 [1859]) who argued that the individual is sovereign “over himself, over his own body and mind” (p. 10) and distinguished this form of sovereignty as separate from the political power of government. In *On Liberty*, Mill separates a social sphere of activity from an individual sphere in order to assert that society may only have an indirect interest in the actions of an individual or consensual group. In this case, society or government may not encroach upon the part of a person’s life that only affects him or herself, or in the case of a group, actions that affect only those who have freely consented to participate.

The ruling also limited this provision with a clause that barred such intervention should it be cruel, unjust or inhuman, although did not offer clear guidelines for establishing or operationalizing what appropriate reach might look like. Although it has been challenged and fine-tuned over time, the acquiescence to state power represented by *Jacobson v. Massachusetts* has remained the prevailing orthodox in infectious disease control.

Even before the 1905 ruling establishing legal precedent for state intervention into the authority of self-determination in private citizens, the United States employed a range of measures in the name of tuberculosis control, particularly during the last decade of the 19th century after the discovery of *Mycobacterium tuberculosis* and the expansion of germ theory. Examples of such measures included the establishment of rules regulating public spitting, mandatory reporting of known cases, the sanctioned destruction of 'contaminated' homes (Ott, 1996), and the detention and treatment of infectious and noninfectious individuals (Coker, 2000). Nonetheless, the main strategy of control in the late 19th and early 20th century was centered on public information and a reliance on individual initiative to seek care. However, the development of effective antibiotics in the mid-1940s marked the beginning of a significant expansion of control strategies that engaged the legal enforcement of individual responsibility. Because the education campaigns that were central to tuberculosis control during the first part of the 20th century

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Although Mill places sanctity in the sovereignty of the individual, he also argues that the *actions* of individuals may not obstruct the *rights* of other individuals. Widely known as the *harm principle*, this is a crucial component to understanding the limits of free will and the role of the state as they have been expressed in classical liberal theory. According to this logic, there is a dual appeal to the power centralized in the state: first, to protect individual and societal freedom, and second to legitimate the government's power to limit those rights if individual freedom of mind and body comes at the expense or endangerment of others. Specifically, the state may limit individual freedom if and only if an individual's personal exercise of freedom encroaches on the rights or wellbeing of another person or group, as is the case with much public health and infectious disease policy.

did not have the kind of impact that public health officials were seeking, health departments changed their strategies. Armed with scientific data, as health departments emphasized the dangers of tuberculosis, they gained more legal authority they gained to “regulate the behavior of the sick” (Gostin, 1995, p. 220-221).

Beyond legal interventions, the TCP engages in a number of other non-clinical activities related to tuberculosis control. For example, managing public perception of tuberculosis risks and promoting knowledge of appropriate preventative and treatment responses are important components to the work done at the TCP. This work happens at multiple levels, including managing local media, schools, patient family members, actions and perceptions of the potentially ill and offers an example of the way public health control and surveillance extends beyond the clinic into the “body politic” as Armstrong (1993) argues (p. 405-406).

Another realm of non-clinical activity conducted by the TCP that extends the performance and surveillance of risk management beyond the walls of the health clinic are contact investigations, which try to determine if people with active tuberculosis have infected others. During contact investigations, public health workers interview patients with active tuberculosis disease to obtain the names of people who the patient had contact with and therefore may have been exposed to tuberculosis. This is also an important component in identifying venues in which an exposure may have taken place. Although contact investigations are a highly effective narrative tool, they cannot always account for all potential tuberculosis patients, in part because patients are often reluctant or unable to recreate a complete list of names and places.

Another significant portion of the non-clinical work done at the TCP is what is known in the public health world as surveillance, which involves the systematic collection and analysis of data about a health category or event (Hall, Correa, Yoon & Braden, 2012). For the TCP, this means collecting and reporting data in three primary areas: (1) reporting tuberculosis cases via the state of California to the CDC using the national tuberculosis surveillance form called the Report of Verified Case of Tuberculosis that collects demographic, clinical, and outcome information on individual patients; (2) managing data on immigrants who are applying to be permanent residents in the United States or to carry refugee status who have been reported to the TCP through the CDC's Electronic Disease Notification system as being a "suspect case" for tuberculosis via an abnormal x-ray on their oversees exam or all minors between the ages of 2 and 14 with a positive skin test; and (3) collecting aggregate data to evaluate performance on how well the program finds, tests and treats, when necessary, contacts of people with active, pulmonary tuberculosis. A CDC grant-funded Medical Officer, Mary Clarke, who functions as the TCP's epidemiologist, assists TCP Dr. Walter by managing surveillance data. Beyond required surveillance reporting, Dr. Clarke also uses the data collected at the TCP to conduct program-level evaluation and descriptive epidemiology. This includes producing statistics for the county and state, facts sheets, and reports that are important tools in guiding policy and the focus of researchers.

A related question is whether certain strains of tuberculosis are linked genetically to any other cases in San Diego. To address this question, Dr. Clarke tracks the results of genetic sequencing, which helps detect, map and link various strains of tuberculosis. Genotyping is valuable for its ability to offer data on the genetic differences between various strains of tuberculosis,[36] thereby helping to track whether strains have impacted more than one person or alerting the program to potential clusters or outbreaks. This database does not show names, biological relationships among people in the database, or other identifiable information. One result of this measure is that smaller clusters of individuals with the same tuberculosis strain are more difficult to map than the larger clusters. According to Dr. Walter, when using the information in this database, small clusters are not obvious but instead require determined and focused effort to uncover. As a result of this limited affordance of the genetic database, staff members at the TCP actively engage in other forms of detective work, often embedded in the task of contact investigations, which are not driven by initial genetic information. TCP disease investigators comb a patient's narrative clues in order to uncover relationships between tuberculosis cases. However, the task of linking established cases often requires TCP staff to make connections among information located in distinct knowledge bases distributed across the clinic and administrative branches, including information contained in a patient's case file, electronic clinic notes, or working knowledge in the heads of clinical and administrative staff.

The TCP's Location

The site of the main HHSA complex, which is home to the TCP's headquarters, can be described as a community-less space. Located in a nonresidential area, it exists in a largely commercial neighborhood that is marked by its lack of publicly accessible or

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[36] A laboratory-based approach that analyzes the genetic patterns for individual strains of *M. tuberculosis*, genotyping is most often used to help with contact investigations by allowing cluster mapping, which is the matching of two or more *M. tuberculosis* samples (National Tuberculosis Controllers Association & Centers for Disease Control and Prevention Advisory Group on Tuberculosis Genotyping, 2004).

inviting spaces for people to gather. It is situated just off of a main thoroughfare between a highway underpass and a discount chain auto repair shop, northwest of downtown San Diego at the edge of a neighborhood known as the Midway district. The HHSA building is accessible to a range of clients, located close to the intersection of two major interstate highways and within walking distance of San Diego's Old Town neighborhood, which is also a hub serviced by many public and private transportation options.

Lacking many of the characteristics associated with San Diego as a vacation destination, Midway is comprised largely of retail and commercial strip malls that house low-end retail shops, fast food chain restaurants, strip clubs, and motels. Its character is, in part, linked to its proximity to San Diego's former naval base. Today it is close to the site of the Marine Corps recruitment depot, current naval facilities, and a local police department storefront location. With a majority of the property designated for commercial use, many people pass through the area as either customers or workers.

Although I spent much of my time at the TCP's main clinic and administrative offices, the TCP also offers services at six regional public health centers countywide. Accumulating many miles on my car during my fieldwork, I became an expert on the complex freeway system that defines southern California. In addition to its main branch, there are three centers serving San Diego's expansive, though less densely populated north county region, one serving its east county region, another serving its south county region, and the final satellite serving central San Diego County. Together this network of public health centers serves residents across the 4,500 square miles that comprise San Diego County (Public Health Services, Community Health Statistics Unit, 2014).

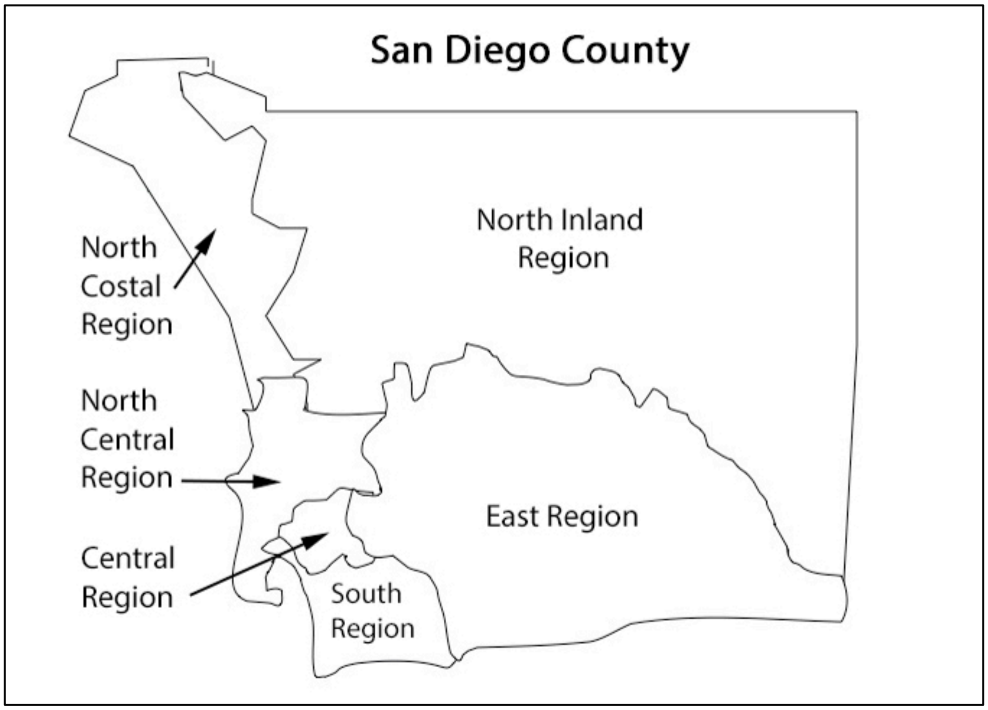

Figure 2.1: San Diego County TCP Jurisdictional Map, developed from materials provided by the TCP.

Physical Layout of the TCP

The physical space of the TCP's main branch offers an indication of its internal logics. Any time I visited the patient waiting area, the room was full. For the most part visitors were quiet as they waited to be called, milling around the open space in the back or taking a seat in one of the plastic chairs that were positioned towards a small television mounted to the ceiling with programing too soft to hear. The waiting room was anchored with windowed clerk desks along the sidewall, where visitors first checked in or made payments at the conclusion of their visit.

Although both forms of entry were highly controlled, entering the TCP as an employee was a remarkably different experience than entering as a patient. While patients entered through heavy double doors that opened directly into the small waiting room, TCP employees and official visitors most often entered through the automatic glass doors lead into HHSA’s main foyer. The guard’s station immediately to the left served as reception and a check-in point for visitors to departmental offices. Staff and pre-verified visitors with an identification badge proceeded with ease by flashing their badge at the security guard to indicate belonging and using the same badge as the entry key to their respective department offices.

From the perspective of an employee, the patient waiting area does not figure prominently in daily work. Rather, the TCP functions as two nearly distinct zones situated next to one another. In this arrangement, the clinic is separate from the administrative offices. Divided by a series of two locked doors with a short breezeway in between, the clinic and administrative offices share a single, long wall. With uncarpeted floors, the sound of people’s shoes hitting the floors pierces the space of the clinic. In the background a radio at the nurse’s station can usually be heard, often tuned softly to a contemporary pop hits station. The sounds of the clinic are dampened as a person moves through the breezeway and into the administrative offices. In this transition, the unlocking door brings with it the warmer air of the office space, while thick carpet underfoot absorbs the sound of soles walking through the corridors. Fingers striking keyboards, phones ringing, and conversations between employees in the passages created by the empty spaces between cubicles generate a non-distinct white noise that fills the space.

As an ethnographer embedded within this space, I had a privilege of moving fluidly between the two sides. During the initial stages of my research, I moved across the divide as a practical matter of trying to understand people's roles and how various positions were linked. Later I found myself passing from side to side in order to follow people, information, or hunches. After I had been at the TCP long enough to feel comfortable moving freely between the administrative offices and clinic, I had a growing curiosity about the significance of this boundary and what it meant for those who traverse it.

I learned that the tasks, responsibilities, and experiential dimensions of either side offer some insight into the physical division of clinical and administrative tasks. More importantly, it is reflective of the internal logics guiding this tuberculosis control program. The tuberculosis clinic is responsible for skin and blood-testing, chest x-rays, sputum collection, initial patient education, advising of community doctors, and the treatment of latent and active tuberculosis and affiliated care. The administrative division meanwhile largely focuses on case management, press interface, media projects, reporting and statistics, cross-border collaboration, community education, and contact investigations. Although some TCP employees pass back and forth between the two zones several times each day, many never venture from one side to the other, reflecting the overlapping yet separate aims of either side and staff members' relative position within the division. Notably, the conceptual categories reflect a control platform that figures the individual as largely separate from their community. In this physical configuration, treatment of the individual, as symbolized by the clinic, is generally separate from how that person is embedded in a community, which is handled in large part by the administrative offices.

Leadership and Organizational Structure of the TCP

The individual with the broadest understanding of the various functions of the TCP is Dr. Walter, who has served as the TCP's Program Director/Tuberculosis Controller of San Diego County since 1989. As the director of the TCP, Dr. Walter is responsible for overseeing all tuberculosis-related events and decisions that occur within San Diego County and managing all 62 TCP employees.[37]

Also indispensible to the functioning of the TCP is Dawn Jackson, a trained Public Health Nurse who serves as the TCP's Program Manager. Dawn, who reports to Dr. Walter, directly oversees most of the TCP's divisions, whose broad range of tuberculosis-related services and programing include the department's fiscal unit, administrative support staff, disease investigation and housing units, the North and South San Diego intake and clinic services teams, and certain aspects of clinic services. In particular, the Clinic Supervisor, staff nurses, x-ray technicians, admissions clerks, and the community living aide report to Dawn. Alternately, Dr. Walter directly oversees her administrative secretary, the TCP's Community Health Promotion Specialist, the staff for CureTB, a binational referral program spearheaded by the TCP, and a specialized group of clinic employees (an epidemiologist, two part-time physicians, the clinic's radiologist, a Community Health Specialist for Refugee Health).

Another key figure at the TCP is Sonya Hernandez. In her role as Clinic Supervisor, Sonya has a comprehensive perspective on all of the services the clinic offers. Although Sonya's office is located in the clinic and she spends most of her time

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[37] This total reflects employment as of September 2013. At that time there were vacancies for one Public Health Nurse position, one Registered Nurse position, and one Communicable Disease Investigator position.

there, she is one of the TCP staff members who regularly traverses the boundary between the two sides. As an employee who frequently moves between clinic and administrative offices, Sonya offers clinic doctors and nurses a fuller understanding of the social and legal contexts of particular patients, and she updates administrative staff on narrative details and other findings from the clinic that might help with their work and that might otherwise not be included in the medical history recorded by the doctors. Along with the more formalized process of reviewing patient files and attending regular staff meetings, the movement of staff between the two spaces represented of the primary, though informal, ways knowledge is transferred among key actors at the TCP.

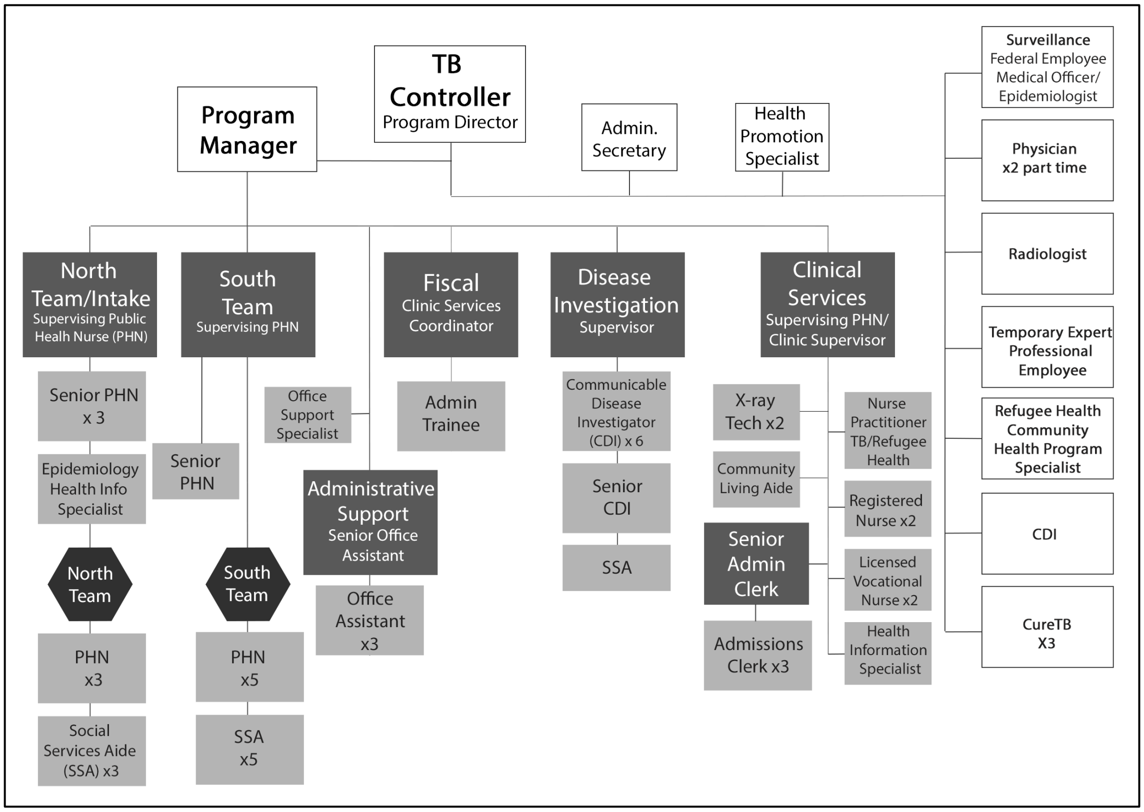

Figure 2.2: TCP Organizational Structure, developed from materials provided by the TCP.

Daily Activities at the TCP Clinic

Because the clinic served as my avenue for meeting tuberculosis patients and because of its relatively open floor plan, I spent much of my unstructured observation time there. The clinic is a space of constant movement, perhaps even more so because it was chronically understaffed during my time at the TCP. When I began the intensive 11-month phase of my fieldwork, only two out of four nurse positions were filled, adding to the busy energy of the space. The nurses multitask all day long. In addition to their duties with patients, the nurses act as covert stage managers. They direct the doctors by reminding (and re-reminding) them about patients who are waiting to be seen in examination rooms and gently teasing them if their initial reminders do not work. They also help manage patients who are agitated about wait times or nervous about treatment, and they mitigate miscommunications or misunderstandings with the doctors or other TCP employees. In addition to these formal and informal duties, nurses also conduct patient follow-up, help with patient education, and are responsible for patient reminders and rescheduling missed appointments.

Because the clinic was understaffed during my time observing, there was a palpable and persistent tension between the nurses and any TCP employee they perceived as not ‘pulling their weight’ or asking too much of them unnecessarily. Frequently it was the clinic’s doctors that fell into this category. From my perspective, the nurses often seemed aggravated by the working pace of Dr. Davies, perhaps because her working demeanor is unapologetically deliberate and methodical and by extension her pace is slower than many of the other kinds of clinic activity, which tend to be fast-paced and co-occurring (calling patients, answering phones, checking patients in, patient education, communicating with administrative staff, etc.). Dr. Davies also had the challenge of being the first physician hired at the TCP after the retirement of the clinic's long-time and beloved full-time doctor. With her arrival, Dr. Davies instituted changes to protocol and documentation. Nurses expressed to me multiple times during formal interviews and informal conversations that this change felt taxing given their overstretched responsibilities. It was not clear to me whether these frictions arose from decisions made by Dr. Davies to change the operations, or if she was merely taking the blame for carrying out policy changes and solutions determined by her superiors.

Working in the field of tuberculosis since 1987, Dr. Davies was an early advocate for the establishment of dedicated tuberculosis protocol after reading an early journal article explaining the links between tuberculosis and HIV/AIDS and identifying its prevalence in prison populations. Working as a doctor in a State Prison in Central California at the time, Dr. Davies developed a dedicated tuberculosis-screening program for the prison inmates and began forging a career at the intersection of tuberculosis and HIV/AIDS.

Dr. Davies' colleague and the TCP's second part-time physician is Dr. Hall, who is quiet and focused. She is a comparatively new doctor, particularly to the field of tuberculosis. The nurses expressed a great deal of respect for her work style, in part I learned, because of her efficiency. In addition, as a new doctor, she tended to be more apologetic about the decisions she made. As a result, her initial requests were often ignored; she regularly asked questions or assigning tasks more than once before the nurses took notice.

Like the nurses, the doctors remained extraordinarily busy throughout the day. Rarely taking a full lunch break, both doctors often skipped it all together, preferring to sip on a coffee or soda while they caught up on paperwork. They remained focused and actively engaged for almost the entire time they were at the clinic. When they were not seeing patients, they answered email and telephone questions from private doctors, reviewed files, followed new tuberculosis literature and news, responded to questions from nurses and other HHSA staff about patients and protocols, or signed prescriptions. Because they were each part-time employees at the clinic, the doctors only overlapped coverage on Thursdays. By design, their intersection occurred as a way to coordinate care, patients, and protocol for clinic staff.

Orienting Vignette

The following vignette from my fieldwork offers a glimpse into TCP culture and introduces two important patients, whose stories I follow at various points throughout this dissertation. Through this sketch, I hope to introduce some of the tensions and contradictions that surface within the current system of tuberculosis control.

As my research at the TCP took shape, my observations began to follow from the basic routines of TCP employees. I tended to arrive at 8:00am, when many other staff members were also arriving. In the clinic, patients were not typically scheduled until 9:00am, giving the doctors and nurses a chance to review charts, follow up on phone calls, or address complex cases with each other or other TCP staff. I would often use this time to check in with people in the clinic and administrative offices and then position myself near the nurse’s station to get a sense of the day’s schedule.

At 9:30am one morning in early October 2013, I arrived to the clinic later than usual and was surprised to walk into a nearly empty space. A fast-moving cold front with bouts of heavy rain was moving across San Diego. Many more people than the standard 25% were missing their appointments. Some called. Others just did not show up, leaving the clinic empty except for its staff, who were hoping the rest of the day followed this slower pace. They welcomed the extra time to catch up on files and other paperwork. This morning was a particularly important moment for my research since the slower pace meant that people had more time to talk about their work in context. As they were adjusting schedules, reading ex-rays, or discussing the needs of particular patients, the clinic staff and a few administrative employees who regularly passed through the clinic spent more time than usual explaining their actions or answering the questions I had about the working of the TCP, including the intricacies of some of the complex cases I was following.

When the first patient finally arrived at nearly 10:00am, I moved from the central area where I had been reviewing the day's schedule into the office shared by the doctors where I encountered Dr. Davies working. Out of habit, I positioned myself across the desk from Dr. Davies, who would usually tell me some of the basic details of a patient's history as she reviewed the files so that we could discuss whether the patient might be a good fit for my study. While Dr. Davies was engrossed in the patient's file, I took the opportunity to glance at my HHSA email inbox, which usually remained empty. That morning, however, I saw an email memo relaying to TCP staff and volunteers that the CDC's "Find TB Resources" newsletter had been suspended. Being a year into my fieldwork and having regularly observed activity at the TCP for eight months, this email immediately registered to me an additional if minor example of the ways in which tightened budgets were impacting tuberculosis care at the system level.

After we talked about the general details of the patient she was seeing, I followed Dr. Davies out or her office – she went to visit the patient and I returned to my “post” near the nurse’s station. As Dr. Davies passed by, one of the nurses remarked that this should be an “easy patient”. The term “easy patient” was clinic shorthand for a person without tuberculosis or with a latent infection that was straightforward to treat and a patient who was (easily) willing to accept treatment. Dr. Davies laughed, telling the entire group that the nurse was probably right, but that she had learned that just when she thinks a case is normal, the opposite is often true. This comment provoked a small chorus of chuckles from the nurses, although Dr. Davies’ speedy exit from the examination room indicated that the nurse’s prediction was accurate.

The remainder of the morning unfolded at this slower pace, and I continued to spend much of my time situated near the nurses’ station, listening to and occasionally participating in the conversations that unfolded around me. Angelica, one of the nurses who had been with the TCP for the longest, was always the first to address me directly, breaking the ice for the others. Gazing toward the empty path left by a patient who had just exited one of the examination rooms, she remarked to me and anyone else within earshot, “It helps sometimes to just have someone here with you.” The patient who just left, she explained, had come in alone and thanked the nurses multiple times for taking the time to comfort her. During these slower moments in the clinic, the nurses often talked amongst themselves and with other employees about the patients who had recently visited and other aspects of their jobs. Although unstructured, this type of clinic talk was not wasted time. Rather, these moments served as rich sources of on-site education for new nurses and a chance to fill in gaps related to a patient’s needs, including details of their backgrounds or current context that might help identify potential needs or constraints. Today they discussed clinically and/or interpersonally difficult cases from recent weeks and shared status updates on individual patients.

As Dr. Davies reentered the hallway, Angelica approached her with some details about patients with complex needs, clinically and personally. Among these cases, they discussed a young man whose story had already become central to my research. Adrian Alarcon was a patient with active tuberculosis disease whose experience stood out to me for a number of reasons. I learned many of the details about Adrian’s story long before I met him in person, in part because the complex nature of his situation meant that his case was discussed frequently within the clinic. In addition, it was one of the few cases that regularly navigated the clinic/administrative boundary, as TCP employees from either side frequently moved to the opposite space to discuss intricacies of his treatment or social situation.

In many respects, his profile as an American-born college student of Guatemalan descent in his early 20s was atypical of the patients seen at the TCP. With some variation, the TCP serves three primary populations: people who need to be screened or treated for immigration purposes, those who require screening for employment or volunteer opportunities, and those who are referred for screening or treatment by private physicians. This last group is generally underinsured or dealing with a complex social or medical situation. Traditional-age college students often fall outside of this set because their socioeconomic status is one that frequently affords health insurance and is also often suggestive of conditions that minimize exposure to tuberculosis in the first place. But Adrian was uninsured at the time he arrived at the TCP, and we later learned that he had spent time traveling in Guatemala to visit family, which is considered significant for Guatemala's high rates of tuberculosis. His treatment unfolded with a number of complications such as an allergic reaction to his medications, problems maintaining consistent treatment, and questions about whether and how his case was linked to other people.

Another person with a complicated case who had become important to my research was Isko Cruz, a 70-year-old man from the Philippines who regularly traveled to San Diego with his wife to visit family living in the area. By contrast to Adrian, Mr. Cruz's case received almost no attention within the TCP, not because his circumstances were any less complex but because he was a relatively more straightforward patient to treat. I accompanied Emma Martel, a Public Health Nurse (PHN), on a home visit one morning to see Mr. Cruz and his wife. We visited the Cruzes in their temporary living space, a mobile home that their children rented because they worried about the health and safety of their daughter. They were so shaken by the tuberculosis diagnosis that they asked that Mr. and Mrs. Cruz remained in this alternate living space long after Mr. Cruz's disease stopped carrying a risk on infection and after Mrs. Cruz's test revealed that she has latent tuberculosis infection and was therefore not infectious in the first place.

When I first met them at the end of Mr. Cruz's infectious period, the couple wanted nothing more than to comply with the treatment guidelines recommended by their care providers at the TCP, even in the face of difficult personal circumstances, health issues, and a deep desire to return to their permanent home in the Philippines to attend to personal matters that had escalated during their time in San Diego. Being diagnosed with tuberculosis had changed their plans for a short visit completely. Although San Diego County only required Mr. Cruz to stay in the jurisdiction until he was no longer at risk of transmitting the disease to others, his daughter urged the couple to remain in San Diego for the entire duration of the treatment, even while asking that the couple remain in the temporary living space.

My experiences at the TCP have offered an entry point into a variety of discussions about the multiple and often competing discourses about tuberculosis in local contexts like San Diego County, including how they inform the ways that we know and understand tuberculosis as global pandemic. For example, the Cruzes' experience has prompted an examination of the many deliberations about the intersections of health and geography, particularly when read alongside Adrian's experiences and in light of the discussions about the new public health that focus on risk and individual patients as vectors of disease described by Armstrong (1993), Lupton (1995), and others. In particular, both stories brush up against the understanding of San Diego as a border region primarily impacted by migration from Mexico. It is true that both Southern California and Baja California experience rates of tuberculosis incidence comparatively higher than the national rates of their respective countries, with the incidence of tuberculosis in San Diego at double of the United States national average and the incidence of tuberculosis in Tijuana more twice that of Mexico's national average (International Community Foundation, 2010). As a result, research has tended to focus on the complicated nature of case management in an area of high mobility and migration in which people cross the border for employment, health services, commerce, recreation and relocation (Villa & Moya, 2008). Such mobility –languages and traditions, desires and apprehensions, humans and diseases– demonstrates that the United States and Mexico are closely intertwined, joined by binational concerns and bicultural communities.

However, it is important to consider how a focus on the Mexican immigrant as a potential carrier of disease rather than on the complexities of mobility more generally obscure particular economic, environmental and social conditions that also facilitate the spread of infection and impede treatment efforts in the region. Rather than framing the border region as a site in which an epidemic passes from an infectious source to a previously uninfected population, it is essential to consider the particular socioeconomic and structural factors of this region that create the conditions for the disease to flourish. Furthermore, it is also important to consider the kinds of mobility and displacement that occur beyond United States/Mexico exchange alone. The experiences of the Cruzes and Adrian demonstrate in concrete ways that San Diego is a site of heightened exchange with various transnational flows among diverse mobile communities with varying needs and motivations.

Adrian and the Cruzes also became important figures in my research because of the converging and diverging details of their experiences being treated for tuberculosis, particularly the differing interactions between the socioeconomic, systemic, and discursive elements that helped constitute their experiences of tuberculosis. In particular, each of them was aware of and impacted by public discourses that highlight the status of tuberculosis as an infectious disease, including its associations with poverty, homelessness, and HIV/AIDS. For the Cruzes, associations with tuberculosis' social position as a stigmatized disease contributed to how decisions about care were handled by them and their family and was reflected in the reluctance of their children to house them. For Adrian, stigma played an important role in his relationships with his peers at his university and in some ways in his ultimate inability to adhere to the requirements of treatment that the TCP set forth for him. Like Adrian and the Cruzes, the fear for many undergoing treatment for tuberculosis extends beyond worries of physical deterioration alone. Individual fear also reflects shared anxieties about social and familial castigation in which gender, immigration, workplace, or other power differentials that can help inform decisions related to screening, treatment or disclosure.

In addition, Adrian and the Cruzes responded very differently to their requirements for treatment, which raised many questions that I take up in the chapters to come. For example, in what ways is the government responsible for helping to create and sustain the environmental/social conditions conducive to the responsibilities of healthy living required of its citizens? That is, how can healthy decisions be made if healthy living is not an affordable reality or if the requirements of the system pose too much of a burden to the individual it intends to help? In the case of tuberculosis, this takes many forms. It relates to a patient’s inability to take time off from work to seek medical care at HHSA, which runs during regular business hours, or a patient’s difficulty managing diabetes without private insurance, for example. In addition, in what ways does tuberculosis and its obligation for care challenge the rhetoric and practice of today’s mandates for the proactive healthy individual? How do patients indirectly and directly critique or comply with a rhetoric of individual empowerment/choice, and how are normative discourses rearticulated?

My fieldwork at the TCP provided a unique position that aided my assessment of the needs and strengths of a local public health system alongside the broader sociopolitical context that helps shape it. As I contend throughout this dissertation, it is time to understand tuberculosis as a location and context specific disease that is always positioned within this wider framework. Tuberculosis works as a lens, refracting underlying social, economic, and structural inequalities. It offers a frame for understanding the material impacts of broad, intersectional social forces such as globalization or growing poverty at the level of local communities and individual lives. Within this framework, the body –particularly when marked as different or othered– reveals its profound intersubjectivity and interculturality in the ways that it is constructed, reinforced, and even contested by means of sociopolitical conventions, public health interventions, and the practices of daily life.

CHAPTER THREE: CURE AS PREVENTION – CONSIDERING DOTS AS A STRATEGY FOR TUBERCULOSIS CONTROL

The number of active tuberculosis cases worldwide rose steadily during the late 1980s and early 1990s, prompting an increasing fear of the disease's spread through Western Europe and North America. In response, public health leaders at the World Health Organization (WHO) declared tuberculosis a global health emergency in 1993 and formally recognized a need to redesign strategies for tuberculosis control. In the first page of its 1994 *Report on the TB Epidemic* (World Health Organization, 1994a), the WHO states, "It is no longer possible to eliminate an infectious disease in one corner of the world and allow it to run rampant in another." The newly global plan of action that the WHO outlined involved a coordinated set of strategies aimed at broadly expanding detection and treatment programs globally, which the WHO promoted with the tag of "cure is the best prevention" (World Health Organization, 1994a; World Health Organization, 1994b).[38]

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[38] As the United Nations agency that concentrates on improving international public health, the WHO focuses on disease control, setting and evaluating global health standards, developing evidence-based policy-level interventions, and providing technical support to member nations (World Health Organization, 2006). It functions as an international, non-state body without direct legal authority, though its policy and programming recommendations have a wide-reaching impact on the global health landscape.

Many factors have shaped the goals and interests of the WHO since its establishment in 1948. Notable among them was the World Bank's entrance into health sector lending during the 1980s, which increased its voice in global health decision making in part because its global spending on health eclipsed that of the WHO. In addition to the World Bank, the creation of other health related organizations with a global voice, such as the Global Fund to Fight AIDS or the United Nations Programme on HIV/AIDS, have diluted the WHO's role as the preeminent voice guiding global health debates and initiatives (Clift, 2013). Another pivotal factor has been an increased dependence on voluntary donations from government, non-governmental and private organizations. The WHO is funded through sliding scale contributions from its 194 member countries, which accounts for just 20% of its budget. The balance must be raised through

In an inversion of the popular public health adage that prevention functions as the best cure, and in the context of a report that an estimated 30 million tuberculosis-related fatalities would result in the coming decade if decisive action was not taken, the WHO argued that tuberculosis is best controlled by intercepting the spread of infection through the treatment of individual patients with active tuberculosis disease. The "Tuberculosis Programme Framework" that the WHO released in 1994 laid out the elements of the new strategy, although it does not explicitly describe why preventative measures are not a predominant part of its endorsed approach (World Health Organization, 1994b). The focus on cure was arguably driven both by the vast numbers of already infected individuals and by the limited impact that the WHO believed it could affect in relation to reducing vulnerability to tuberculosis by addressing vectors of contagion and conditions that reduce immune response.

The WHO standardized its treatment-focused strategy during the mid 1990s in the form of Directly Observed Therapy, Short-course (DOTS), a universal containment platform and branded mechanism of control predicated in large part on the treatment and surveillance of individuals with active tuberculosis disease. Rooted in research that was conducted across local contexts in the global south before its transformation into international policy, a central feature of DOTS is its requirement that health workers watch as patients take their medications in order to account for the quantity of antibiotics consumed and the duration of treatment a patient receives. Many public health leaders praised this feature of DOTS for providing a cost-effective solution to the

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voluntary contributions from nations and non-governmental actors. These changes notwithstanding, the WHO remains an important voice in the global health landscape.

conundrum of cure and prevention. Although it is most widely known for its direct observation component, in part because its acronym foregrounds it, the DOTS strategy is actually based on five interrelated principles: (1) a political commitment by national governments to maintain strong public health systems and to sustain support for tuberculosis programming; (2) a strong network of laboratories; (3) standardized treatment, including the direct observation of treatment; (4) a consistent and effective drug supply; and (5) a system for monitoring and evaluation. Embedded in this model is an increased emphasis on individual actors, yielding a generalized patient who is treated within a global framework largely devoid of locally based solutions for control.

Through a discourse of international containment, the uptake of DOTS was swift and wide-reaching, due in part to the publicity afforded by the surge of tuberculosis prevalence in wealthy and previously low-endemic regions across Western Europe and North America. Since its establishment, DOTS has become the preeminent tool embraced by public health policy and programming in hundreds of countries worldwide.[39] It also continues to be regarded by many public health policymakers as the

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[39] In the time since the launch of DOTS, there have been a few additions and changes to the framework supporting international tuberculosis control efforts. In particular, in 2001, the WHO developed the Global DOTS Expansion Plan that focused on developing additional support for the 22 countries with the highest rates of tuberculosis (World Health Organization, 2001). In 2006, the WHO launched the Global Plan to Stop Tuberculosis to increase DOTS coverage and strengthen with program goals to meet by 2015 (Stop TB Partnership, 2006; Stop TB Partnership, 2007; World Health Organization, 2007).

In 2011, the CDC’s Division of Tuberculosis Elimination released a strategic plan for the elimination of tuberculosis, which was intended to work in tandem with DOTS to reduce the burden of tuberculosis by focusing on six goals based on Institute of Medicine recommendations: (1) prioritizing timely diagnosis and treatment of tuberculosis patients and their contacts; (2) focusing on targeted testing and treatment of people with latent tuberculosis infection; (3) developing new tools for the diagnosis, treatment and prevention of tuberculosis; (4) increasing involvement by the United States in global tuberculosis control; (5) actively engaging key stakeholders such as policymakers, healthcare providers, and communities; and (6) sustaining a commitment to tracking “progress toward the goal of TB elimination” (Centers for Disease Control and Prevention, 2011).

central tool in the prevention of drug-resistant tuberculosis, a link that was crucial to its uptake in the United States (Coker, 2000).[40] Notwithstanding important reductions in tuberculosis worldwide, rates of decline have been slower than anticipated since the uptake of DOTS, even while DOTS continues to be the global standard upon which funding and other forms of support are measured and distributed.[41]

This chapter introduces the "cure as prevention" paradigm and interrogates its central product, DOTS, under which cure of the individual acts as a public health intervention for the global community as a whole. I raise questions related to why this universal approach to tuberculosis control has prevailed over multipronged or regionally situated measures. The first part of the chapter locates tuberculosis and DOTS within its social and historic context. I discuss the sociopolitical environment that fostered the

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These goals reflect intersecting priorities in tuberculosis control across public health service delivery, research, and development. In theory they bolster existing DOTS efforts. But amid shrinking budgets, several TCP administrators and local activists worry no amount of policy directives can combat the diminished attention and urgency given to infectious disease control. See the next chapter for a more detailed discussion of the local impact of divestments in global tuberculosis control.

The changes by the WHO and the CDC were designed to solve the problem of slower- than- expected gains in the elimination of tuberculosis. I have chosen to focus on DOTS because it remains largely unchanged and the central signpost of each of these subsequent iterations.

[40] Drug resistance continues to be a major challenge in the control of tuberculosis. The WHO (2014b) assesses multidrug-resistant tuberculosis at 5% of all tuberculosis cases worldwide. This figure is much higher, about 20.5%, for people who have previously been treated for tuberculosis (p. 4). In 2013 alone, 480,000 people developed multidrug-resistant tuberculosis (p. 6). In addition to its human toll, drug resistance is more financially intensive to treat than non-resistant tuberculosis. A 6-month supply of first-line tuberculosis antibiotics for non-resistant pulmonary tuberculosis costs between $10 and $20. Second-line medications used to treat multidrug-resistant tuberculosis are 100 times more expensive, in part because treatment itself lasts for two years (Selgelid, 2008, p. 12). See the next chapter for an additional discussion of the links between drug resistances, the shortage of new tuberculosis medications, and a failure of current tuberculosis control efforts at the systemic rather than individual level.

[41] Since 1990 the tuberculosis mortality rate has been reduced by 45%, close to 2015 targets of 50%. However, while the rate of new tuberculosis cases has continued to fall, this has occurred at a slower pace than first anticipated. While the global prevalence of active disease has fallen by 37% since 1990, this is not rapid enough to achieve the 2015 target of 50% (World Health Organization, 2014b).

WHO's strategic focus on eliminating tuberculosis at the end of the 20th century, including the development and marketing of DOTS and the ethical and operational challenges posed by its critics.

Next, I consider how DOTS functions within the context of a local public health department drawing from my ethnographic fieldwork at the Tuberculosis Control and Refugee Health Program (TCP) at the Health and Human Services Agency of San Diego County (HHSA). A central focus that emerges here is how the TCP's work is entwined with a broad range of institutions and sites beyond the clinic itself, a situation that resonates in significant ways with Foucault's (1977) analysis of the broadly distributed nature of discipline within modern society. The distribution experienced at the TCP presents both opportunities and challenges for management of tuberculosis. While it adds additional institutional resources to the management of tuberculosis, it also places the disciplining of health and compliance in tension with other disciplinary institutions of civil society. In this section I also address how discipline, including moments of resistance, begin to articulate some of the limits of the current system.

Finally, I make the case that a universalized "cure as prevention" approach to tuberculosis control collapses understanding of numerous dimensions of tuberculosis disease in its effort to solve the conundrum of how best to manage it. "Cure as prevention" locates causality within the body of the infected individual rather than in the social, political, or environmental mechanisms of transmission. In so doing, it reflects a perspective that foregrounds medical heroics and pharmaceutical-driven interventions, while deemphasizing social, political and economic factors such as the relationships among increased susceptibility, malnutrition, high population density, lack of adequate health care, or infrastructure that supports preventative treatment –many of which are tied to poverty and lack of public infrastructure. As such, focus is narrowly cast on the biomedical variables in the etiology of tuberculosis, thereby limiting the field of possible solutions available for understanding and managing this disease. This particular feature of the current paradigm represents an overall narrowing of understanding and an inability to account for the multifaceted contributors to the cause and spread of tuberculosis that might actually open up many more opportunities for intervention if consistently addressed.

Situating DOTS Historically

Although tuberculosis was at one time the leading cause of death in the world, by the 1950s prevalence had been steadily declining in the United States and Europe for the 150 years that their governments had systematically collected vital statistics on causes of death (Gandy & Zumla, 2003). This decline preceded the advent of antibiotics and can be attributed more to sweeping improvements in standards of living and nutrition than to the scientific breakthroughs by a handful of ‘heroes’ (Barnes, 1995; Coker, 2000; Eisenberg, 1999). Less-crowded living conditions, increasingly reliable access to purified water, and the development of sewage disposal systems greatly reduced human exposure to many of the causes of infection. In addition, improved nutrition and a focus on personal hygiene contributed to a reduction in deaths caused by infectious diseases. With this positive impact of improved living standards on reducing tuberculosis prevalence, the discovery of the tuberculosis bacillus in 1882, highly funded public health campaigns during the 20th century, and the development of effective antibiotics in the 1940s were additional important technological and social interventions that further accelerated rates of decline.

Despite the persistent presence of tuberculosis outside of the United States and Europe, by the 1950s, consensus among key public health leaders regionally and internationally was that infectious disease, including tuberculosis, was under control. Some even anticipated that effective global health interventions along with the promise of new antibiotics meant that tuberculosis was on a path to complete eradication (Murray, 2004; Daniel, 2006; Dormandy, 2000; Gandy & Zumla, 2003). But the optimism expressed by public health leaders was short-lived. Although tuberculosis incidence dropped at an average rate of 5.8% each year between 1953 and 1984 (Navin, McNabb & Crawford, 2002), rates of tuberculosis in the United States and other low-endemic nations inverted in the mid 1980s, to the surprise of many leading public health figures at the time (Gandy & Zumla, 2003).

The 1994 WHO report, *TB: A Global Emergency* (1994a), reflects a focus on the dramatic increases in infection in United States and Western Europe during a time when public opinion held that tuberculosis had been all but eradicated in wealthy, industrialized nations. The number of tuberculosis cases in the United States grew by an average of 20% between 1985 and 1992 (WHO, 1994a), although this figure was far greater in several higher-endemic regions, most notably New York, Florida, Texas and California (Cantwell, Snider, Cauthen & Onorato, 1994). Certain nations in Western Europe experienced even higher increases. Tuberculosis increased by 27% between 1988 and 1992 in Italy. Spain saw rates climb 28% between 1990 and 1992 alone, while Denmark experienced an increase of 40% between 1986 and 1992 (World Health

Organization, 1994a). As a result of this increase in previously lower-endemic nations, by April of 1993 public health leaders at the WHO declared tuberculosis to be a global emergency and worked quickly to mobilize resources and develop a strategy for an international response for global control (World Health Organization, 1993; World Health Organization, 1994a).

It is important to note that the WHO's framing of tuberculosis as a re-emergent threat exposes the organization's alignment with the privileged vantage point of the global north (Farmer 2000; Ott, 1996). As Farmer (2000) reminds, "Tuberculosis has been with us all along" (p. 184). Indeed, during the mid 20th century when the United States and Europe were celebrating successes in infectious disease control, tuberculosis remained a leading cause of death in many other parts of the world, as well as in small pockets across the United States and Europe where infrastructure, poverty rates, and general health conditions most resemble underdeveloped nations. This history helps define tuberculosis as a condition that not only changes across time but also across geo-political locations and in relation to perceptions of risk.

This history also points to a power structure that prioritizes the interests and concerns of wealthy nations. Bayer and Wilkinson (1995), for example, attribute the sudden attention paid to tuberculosis in the early 1990s to a growing fear "that what had been a treatable disease might become an untreatable danger to middle-class populations that had in recent years been spared the threat of tuberculosis" (p. 1547). Because countries outside of the United States and Europe faced persistently high rates of tuberculosis, the label of re-emergence might better be understood as the re-emergence of tuberculosis as a priority on the global health agenda precipitated by its renewed presence in non-impoverished populations in the global north, thus a problem no longer primarily impacting the lives of the poor or disenfranchised. This perspective helps to situate the design of DOTS into a historical and ideological framework, revealing a series of discontinuities that call into question its largely universal approach. While components of the DOTS strategies were developed and applied in high-endemic countries outside of the United States and Europe in the years leading to the resurgence in the global north, in many ways DOTS as a branded global approach is reflective of the risk perceived for middle class populations.

In the years since the WHO declared tuberculosis to be a top priority, historians, policymakers and public health figures have identified a range of factors that contributed to the escalation of tuberculosis prevalence at the end of the 20th century.[42] Among them, the most frequently cited factors include the emergence of multiple antibiotic-resistant forms of tuberculosis, less funding given to tuberculosis control programs during the 1970s and 1980s when the disease was thought to be under control, and deepening and widening economic disparities and accompanying lack of public resources that increased the vulnerability of poor and disenfranchised populations. In addition, researchers and public health leaders also point to the emergence of HIV in the global north during the 1980s as a major contributor to the rise of tuberculosis, a fact

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[42] For more information on the rise of tuberculosis in previously low-endemic regions, see Farmer (1999), Farmer (1997), Frank (1993), Gandy & Zumla (2003), or Ott (1996) as examples among many.

that should underscore the relationship of endemic tuberculosis to all factors that compromise immunity (malnutrition, comorbidity with other diseases, etc.).[43]

Compounding these factors, Gandy and Zumla (2003) argue that political and public health leaders put faith in a theory of political economy that predicted that global development would necessarily yield widely distributed global prosperity. This oversimplification, argue Gandy and Zumla, ultimately underestimated complex power balances among nations and, by extension, the uneven prevalence and burden of tuberculosis. Raviglione and Pio (2002) meanwhile suggest the WHO and other health organizations simply lost interest in tuberculosis. This is evidenced by what they describe as the integration of the managerial aspects of tuberculosis programs into the broader global public health system. Integration meant that the specialized knowledges and expertise particular to tuberculosis control were subsumed, which happened at a time when the economic crises of the 1980s had already weakened public-health infrastructure, sweeping health sector reform was just beginning, and the HIV/AIDS pandemic had begun to spread. As a result, a great deal of institutional memory and tuberculosis-specific expertise was lost.

In addition to the sociopolitical factors affecting prevalence, it is important to consider how disease organisms respond to human attempts to intercept them. For tuberculosis, this occurs most noticeably in the form of antibiotic resistance. Dr. Walter, medical doctor and director of the TCP, describes antibiotic resistance as the evolution

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[43] The risk of activating latent tuberculosis is much higher for people with HIV and others who are immunocompromised. Meanwhile, tuberculosis negatively impacts the course of HIV by encouraging the production of stimulatory cytokines that impact the functioning of the immune system and by reducing white blood cells that help fight infection (Fätkenheuer, Taelman, Lepage, Schwenk & Wenzel, 1999). Together, both diseases are far more destructive than either is alone.

of the germ. When antibiotics were first introduced, all tuberculosis was susceptible to drugs. But as treatment protocols changed and began to incorporate a combination of medications into treatment design, the bacillus shifted in response. First mono-resistant tuberculosis emerged as a problem, followed by multidrug-resistant tuberculosis during the late 1980s. Most recently, extensively drug-resistant tuberculosis, which is resistant to all antibiotics available today, has emerged as a problem. With every human intervention, tuberculosis bacteria respond, mutating to survive exposure to medications.

While incomplete treatment is often pointed to as one of the most significant factors in the development of drug resistance, it is important to note that drug resistance is a highly complex subject with a range of potential contributors that work in concert. Resistance can happen when too little medication is given, a patient stops taking medication too soon, or inconsistencies in the drug supply limit a health agency's ability to deliver medications to a patient. It is not simply coincidence that an increase in drug resistance is also traced to communities with infrastructure problems, poorly stocked drug supplies, insufficient resources on the part of public health agencies, or local markets saturated with old or counterfeit drugs (Selgelid, 2008). Further, despite recommendations by researchers and public health advocates for global priority to be placed on the development of new tuberculosis drugs and vaccines, tuberculosis has remained a relatively low priority issue for publically funded research initiatives and for the global pharmaceutical industry whose focus is on more lucrative markets, which has yielded very few pharmaceutical responses to the problem of drug resistance (see the next chapter for an extended discussion of this issue).

Programmatic Links to Surveillance and a Global Platform

The very diversity of the factors cited in the rise of tuberculosis during the late 20th century suggests that no singular or unified understanding of causality exists. Instead its rise has been amorphous, articulating differently to distinct localized conditions. Despite this, the resulting DOTS platform rested on a universal strategy of breaking the cycle of transmission through treatment of the generalized patient, reflecting the WHO's emphasis on prevention through cure.

The tactic of intercepting the transmission of disease is not new. It has roots in classical public health strategies, but it has been conceived and operationalized in a variety of ways. Frieden, Lerner, and Rutherford (2000) pinpoint particular conceptual continuities and discontinuities between DOTS and the public health interventions pioneered by Herman Biggs, a physician and public health pioneer in New York at the turn of the 20th century. Biggs first served as chief inspector in the newly created division of bacteriology in New York City from 1892 to 1901, later taking post as the General Medical Officer of New York State followed by his time as State Commissioner of Health for New York from 1901 to 1920. Central to Biggs' work on tuberculosis control was an embrace of surveillance and the isolation of tuberculosis patients in private homes, hospitals, and sanatoria.

In particular, because no antibiotic treatment existed at the time, his philosophy positioned surveillance as a crucial component to better account for the number of tuberculosis cases in a given location. It was also considered essential to curtailing the spread of disease. Much like the WHO's DOTS strategy, Biggs adopted measures that worked to control the disease through a focus on individual cure, which in the time before the advent of antibiotics was defined by how well the lesions caused by the disease could heal (p. 1089). But Biggs' platform was not international in scope. This meant that his interventions, far from being generalized across regional and national differences, were more closely articulated to the needs and challenges of his local jurisdiction.

During the late 1940s, tuberculosis control was taken up as a global issue for the first time. With the promises of bacteriology, existing vaccination campaigns, and the development of effective antibiotic interventions, the WHO invested developing a vertical approach to international tuberculosis control (Raviglione & Pio, 2002). This approach was characterized by the development of highly specialized tuberculosis programming with dedicated hospitals, laboratories, and clinics. While this model was largely effective in industrialized nations, its impact was not nearly as significant in other parts of the world where the cost-intensive, specialized infrastructure was difficult to implement and maintain. With the failures of the vertical model in controlling tuberculosis worldwide, public health leaders shifted their approach in the mid-1960s. During this time, attention was placed on the integration of tuberculosis with general health services. As Raviglione and Pio suggest, this strategy was heavily promoted in less-industrialized counties in which the vertical approach had been ineffective.

A direct conceptual link to DOTS was established in the research that developed from the broad move to integrate tuberculosis services. Specifically, DOTS has its antecedents in colonial and neocolonial tuberculosis research conducted during this time. Key research was carried out by the British Research Medical Council in Madras, India (Fox, 1958), and by public health tuberculosis specialist A.S. Moodie in Hong

Kong (Moodie, 1967). Developed in the context of the decentralization of tuberculosis services, this research began to standardize what we know today as direct observation strategies. The findings from both research agendas recommended observing treatments for nearly all tuberculosis patients as a means to ensure treatment compliance. Fox's research in Madras was particularly influential. Modeled after research demonstrating successes with the direct observation of treatment for patients with leprosy and other parasitic and infectious diseases in Africa, Fox's findings informed a report published in 1974 by the WHO Expert Committee on Tuberculosis, which heavily influenced current WHO strategies for tuberculosis control (Raviglione & Pio, 2002).[44]

The DOTS strategy is further linked to research conducted by the International Union Against Tuberculosis and Lung Disease during the 1970s (Kim et. al, 2005; Lienhardt, Ogden, & Sow, 2003; Raviglione & Pio, 2002). This research was conducted in high-endemic, less-industrialized nations, and served as the formal basis of what became the core principles of the DOTS approach. The emerging principles (the importance of ensuring a political commitment at the level of national governments, developing a secure and reliable antibiotic supply, observing patients taking their medications, establishing a network of laboratories, and adopting a systematic way to record tuberculosis cases) bear a striking resemblance to the core tenets of DOTS.[45]

Momentum for adopting the observation of patients taking medications as a crucial component of tuberculosis control accelerated during the late 1980s. Even

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[44] See the WHO's Expert Committee on Tuberculosis, Ninth Report (1974).

[45] See The Mutual Assistance Programme of the IUATLD [International Union Against Tuberculosis and Lung Disease] (Rouillon, 1991) and Principles of IUATLD Collaborative Tuberculosis Progammes (Enarson, 1991).

before the WHO codified the observation of patients into its formal strategy, the Centers for Disease Control and Prevention (CDC) published *A Strategic Plan for the Elimination of Tuberculosis in the United States*, which positioned the direct observation of patients as a central, though not required, component to their recommendations (Dowdle, 1989). Following the CDC's recommendation, the Advisory Council for the Elimination of Tuberculosis (ACET) of the CDC made direct observation of patients a matter of federal policy in 1993. As the new standard of care for tuberculosis control in the United States, ACET stipulated the implementation of the direct observation of all individuals with active tuberculosis disease in communities whose completion rates for the treatment of active tuberculosis disease were below 90% and encouraged the implementation of DOTS in all other communities (Centers for Disease Control and Prevention, 1993).

The Establishment of DOTS as a Protocol and as a Branded Approach

Contemporary concern for the [non]compliant individual became a formal global best practice in 1995 when the WHO implemented DOTS as the predominant control strategy in its campaign to respond to the dramatic increase in tuberculosis rates worldwide. More than protocol alone, DOTS functions as a branded approach. In 1993 and 1994, the WHO developed the DOTS platform from the perspective of system design rather than clinical breakthroughs (Ogden, Walt & Lush, 2003). Condensed from its earlier iterations, the new approach was heavily marketed by the WHO and the World Bank.

According to Keshavjee and Farmer (2012), during the late 1980s and early 1990s when the DOTS platform was developed bilateral assistance for public health and disease control had all but vanished and resource-poor nations had become increasingly reliant on international financial institutions like the World Bank. In the context of the tuberculosis control, the relationship between the WHO and the World Bank was complex. The WHO became increasingly dependent on the World Bank because of its growing presence in the healthcare sector. Meanwhile, amidst a wide-reaching debt crisis, the World Bank prioritized funding the treatment interventions it deemed cost-effective and that proposed concrete objectives with measurable outcomes. At the time, no such control measure existed for tuberculosis. The WHO designed DOTS and promoted it to the World Bank as a strategy that was “simple to treat, algorithmic, and requiring no expensive inputs” (Keshavjee & Farmer, 2012, p. 933). In effect, the DOTS brand was conceived as much as an economic agenda as a medical protocol.

With the new platform designed, the WHO partnered with the World Bank to enact a two-part strategy designed to aid in the international uptake of DOTS (Ogden, Walt & Lush, 2003). The first part of the strategy was to generate international awareness as a means of securing legitimacy for the plight of global tuberculosis control. This was accomplished with the WHO’s formal declaration of tuberculosis as a global emergency, which corresponded with targeted media campaigns designed to disseminate the message. Another important moment in legitimizing the increased attention to global tuberculosis control was a report published by the World Bank (1993) that named the antibiotic treatment of tuberculosis as one of the most cost-effective interventions in existence. This declaration established the World Bank’s investment in tuberculosis control and, by extension, influenced financial and health policy decisions internationally (Raviglione, 2003). It also enforced a perspective that promoted individual pharmaceutical interventions rather than social, political or environmental solutions.

Once the message of global urgency had been distributed, the second step was to introduce and market DOTS as *the* new policy for tuberculosis control. First and foremost, DOTS was created as a product with a simplified message in hopes that it would help assemble and mobilize a diverse array of participants in the international community, each with varying goals and needs. The message was disseminated through a heavy media, editorial, and press release campaign designed to lobby powerful policymakers in strategic regions and to raise money for global tuberculosis control (Ogden, Walt & Lush, 2003).

The fast-paced uptake of DOTS at a global level represents a culmination of a unique set of factors that ranged from shifting leadership and priorities in global health lending to a surge of tuberculosis cases in previously low-endemic areas. Key leaders at the WHO and World Bank recognized this moment as an opportunity to shape the agenda of tuberculosis control into the future. As Ogden, Walt and Lush (2003) point out, “Branding and marketing may only be successful where there are external focusing events that an internal media campaign can build on” (p. 187). The authors argue that the foresight demonstrated by key players in the DOTS branding campaign to recognize the leverage afforded by tragic events such as the multidrug-resistant tuberculosis outbreak in New York and the impact of the global HIV/AIDS crisis may ultimately have been one of the most significant reasons the campaign celebrated such successes.

Challenges to DOTS

Critiques of the DOTS Design

Despite its quick uptake internationally, there have been conceptual, operational and ethical challenges to the implementation of DOTS as the prevailing standard of care. Conceptually, some researchers and clinicians have critiqued DOTS for being developed based on limited research, despite its intended universal application across different sociocultural contexts (Coker, 2003; Lienhardt & Ogden, 2004; Ogden, Walt & Lush, 2003). Ogden, Walt and Lush (2003) suggest that this simplification was strategic. To promote DOTS to international constituents with diverse needs and to quickly mobilize resources, the WHO responded by developing a broadly targeted communication and control strategy with a simplified message. The public health leaders and scholars who expressed concern that the strategy was oversimplified worried that it could compromise tuberculosis control itself since differences across local contexts could not be represented adequately by its five key elements. An additional conceptual worry was that the early research crucial to the uptake of DOTS was retrospective and did not parse the impact of direct observation from other programmatic components such as its links to increased funding and expertise (Pasipanodya & Gumbo, 2013).

Operationally, researchers and public health experts have noted that a lack of clear guidelines for implementation contributed to challenges in carrying out the DOTS program. In particular, the vastly differing needs and resources available to individuals, communities and governments across the world have lead to inconsistencies in the implementation and effectiveness of DOTS (Lienhardt & Ogden, 2004; Lienhardt, Ogden & Sow, 2003). In addition, the issue of resources raised further operational challenges. Researchers and policymakers were concerned with the sustainability of DOTS at the level of national governments because the costs of carrying out such a labor- and resource-intensive program were much higher than treatment models that focused on self-administered strategies (Selgelid, Kelly & Sleigh, 2008; Volmink & Garner, 2007; Zwarenstein, Schoeman, Vundule, Lombard & Tatley, 1998). At the local levels, some health departments believed that their programming functioned well without DOTS and expressed concern that implementation of the program would require considerable unnecessary increases to the resources necessary to run their programs (Bayer and Wilkinson, 1995). Finally, compounding questions about implementation and operating costs, others worried that DOTS did not place enough emphasis on the importance of research and development in effecting change in the lives of tuberculosis patients. The fear was that already-stretched budgets would divert even more funding away from causes such as drug and vaccine development (Volmink & Garner, 2007).

Other DOTS detractors worried about how best to balance the rights of individual patients within a framework that also protected the public's health (Hurtig, Porter & Ogden, 1999; Pronyk & Porter, 1999; Selgelid, Kelly & Sleigh, 2008). Often framed as an ethical concern, one dominant area of discussion has focused on the potential threats to privacy posed by DOTS and the ways breaches in privacy can lead to stigmatization in local contexts where DOTS practices are perceptible to the community (Selgelid, Kelly & Sleigh, 2008, p. 241). Such stigma can lead to a range of behaviors that impede attempts to control tuberculosis such as reticence to seek diagnosis or treatment and limitation of disclosure.

Perhaps the most unified ethical critique of DOTS, however, came from pockets of researchers and policy experts who argued that the platform imposed unilateral limitations to the freedom and self-determination of patients based on generic criteria. The concern was that the compulsory monitoring of all individuals with active disease is unable to consider variations in individual situations. This perspective argues that treatment decisions should always be decided based on the principle of employing the least invasive measure available in order to reach the health outcome desired. As Coker (2000) advocates, the idea of 'least restrictive' should mean that people are "allowed to fail before being condemned for that failure" (p. 118). Coker extends this critique to suggest that a focus on universal DOTS has shifted focus away from the original aims of reducing the global tuberculosis burden and minimizing drug resistance. He is concerned that the current system is instead creating an environment where the policing of compliance has become the new end. He contends, "Although this may be only a subtle change, it has major civil liberties consequences that are enhanced by the assumption that DOT [direct observation] is the best approach. And this may not be so" (p. 11).

Questions of Efficacy

Alongside these conceptual, operational, and ethical concerns, questions remain about the effectiveness of DOTS. A review by Pym and Cole (1999) released a few years after the launch of DOTS positioned the strategy as "an important short-term objective" but warned that it would likely be longitudinally ineffective (p. 1005). The authors cited the slower and less extensive than anticipated impact of DOTS. They instead advocated for increased attention and resources to be committed to the development of new treatments and vaccines. They coupled this biotechnical solution with a call for a frank look at the shortcomings of DOTS in order to trigger "the political will needed to swiftly develop a new generation of tuberculosis-control strategies" (p. 1005).

Other studies have troubled the notion that direct observation is always the most effective protocol. Volmink and Garner (2007), for example, conducted a review of 11 randomized and quasi-randomized controlled trials that compared directly observed therapy with self-administered treatment. Their findings suggest that there is not statistically significant evidence that demonstrates that direct observation results in higher rates of cure than self-administered treatment without observation. They suggest that the direct observation intervention is expensive to implement and therefore recommend developing strategies that focus on "reducing social and health system barriers" instead (p. 7).

Pasipanodya and Gumbo (2013) also reviewed studies that compared direct observation to self-administered treatment in order to evaluate their impact on drug resistance. The authors were looking for information on microbiologic outcomes (drug resistance) as opposed to programmatic data (whether patients completed their prescribed treatment, for example). They found that while direct observation may help reduce patient noncompliance, it has no impact on drug resistance or patient relapse. In their discussion, the authors do not critique the DOTS program overall, but ultimately suggest that direct observation is a costly technique that consumes too many resources.

Certainly, however, a strong critique of directly observed therapy is also by extension a critique of DOTS because of how prominently this component figures in the strategy overall.

In their conclusions, Pasipanodya and Gumbo (2013) propose that future research should focus on identifying and examining factors beyond adherence that may impact drug resistance and tuberculosis relapse. The implication is that there may be limited applicability for the generalized results from studies that attempt to compare direct observation to self-administered treatment since the success of either strategy is necessarily linked to local conditions and contexts. While the study was most interested in the physiological effects of drugs, its biochemical focus offers a clear example of the limits of making patient compliance the default mode of operation. It presents a counter to the narrative that equates direct observation with the elimination of drug resistance, thus pointing to the ideological nature of the tendency to fault non-compliant patients.[46]

Despite studies that question the efficacy and negative economic impact of DOTS, there is a large body of research that recommends DOTS for it clinical successes, cost effectiveness, and ethical high ground, particularly in the case of its direct observation component.[47] DOTS supporters remain adamant that the program is "the health breakthrough of the 1990s" (Kochi, 1997) and engage in heated debates

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[46] For additional examples, see Cox, Morrow & Deutschmann (2008); Garner, 1998; Keshavjee & Farmer, 2012; Kimerling et al., 1999; Migliori et al., 2002; Zumla, Mwaba, Squire & Grange, 1999; Zwarenstein, Schoeman, Vundule, Lombard, & Tatley, 1998.

[47] For examples of support see: Booker (1996); Frieden and Driver (2003); Kochi (1997); Smith (1999); and Yew (1999).

For examples of location specific DOTS successes see: China Tuberculosis Control Collaboration (1996); Jacquet et al. (2006); Oxlade et al. (2006); Suárez et al. (2001); and Xianyi et al. (2002).

about the value of direct observation, citing that endorsements for self-administered treatment are in direct conflict with the current recommendations by top public health organizations that was developed directly from research.[48]

DOTS proponents have also argued that it is impossible for care providers to know who will comply and who will not, nor is it possible to verify self-reported compliance. The underlying ideology of DOTS, then, is that *all* patients have the potential to be noncompliant, and therefore all patients must be monitored. Booker (1996), for example, suggests that arguments against DOTS are often rooted in a language of rights that is limited by its own ideology. He argues that any other framing of tuberculosis control would ultimately privilege the individuals who can be identified over those who cannot (the public), writing, "The greatest kindness that we can offer tuberculosis patients is to do everything reasonable to see to it that there are as few of them as possible. When we are making public policy decisions, we must treat statistical individuals as seriously as we treat actual individuals." (p. 98). For Booker, direct observation is necessarily folded into his a definition of reasonable intervention. While there are certainly some merits to this position, its emphasis on the efficacy of action upon the individual in the name of public good shifts attention away from the role of structural failures, social constraints, and institutional limitations in the spread of tuberculosis.

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[48] For an example of this kind of debate, the "Correspondence" section of the January 9, 1999 volume of *The Lancet* is particularly informative. It includes heated opposition to and strong support for a research study that advocated that the direct observation component of DOTS should be reconsidered (see, Frieden, 1999; Harries, Salaniponi, & Kwanjana, 1999; Kochi, 1999; Lienhardt, Rowley, & Manneh, 1999; Uplekar, Walley, & Newell, 1999; Zwarenstein, 1999).

A Continued Embrace of DOTS

Despite conflicting research with regards to the effectiveness of DOTS conceptually, operationally, and ethically, this strategy remains the gold standard of tuberculosis control. There are a number of factors contributing to the continued embrace of DOTS. First, measuring and interpreting the impact of changes in policy or practice is a difficult task, and Khan and Coker (2014) suggest that much of the research on the positive impact of DOTS is limited in scope and applicability despite being cited across multiple contexts. Some studies, for example, have not built an assessment of multifactorial variables that account for economic progress or political change into their research design. In addition, studies often fail to establish enough of a historical perspective as a basis for comparing current successes or shortcomings (p. 646). These limitations have the potential to skew and therefore overvalue positive findings.

In addition, a look at global economics and power relations offers insight. McConnell (1999) argues that while “the best tuberculosis-control strategy is undoubtedly elimination of poverty” (p. 946), he points to a cycle of international lending and debt patterns in which resource-poor nations are increasingly repaying as much or more than they received in aid in the first place. This observation is important to consider in light of the World Bank’s heavy investment into DOTS. Specifically, the funding and control measures established during the period that DOTS was first created were invested in heavily by the World Bank, which has resulted in a continued investment in ensuring DOTS remain the focal point.

Finally, Ogden, Walt, and Lush (2003) explain that the WHO increasingly relies on external donors such as the World Bank and other private and non-governmental organizations for two main reasons. First, the WHO's core budget has continued to wane since the 1980s, which in turn increases dependency on funding sources above and beyond their smaller-than-feasible core budget. Furthermore, in order to secure buy-in from governments, the WHO is reliant on collaboration with the agencies that fund countries directly, such as the World Bank, thus limiting the range of alternatives that are possible. Compounding this, Khan and Coker (2014) argue that current tuberculosis-control efforts rely on a model that encourages programs to obscure challenges rather than bring them to light. The authors suggest that this model incentivizes highlighting successes by linking grant funding and jobs to uniform targets. This impedes efforts to uncover and overcome issues within tuberculosis-control programs and deemphasizes problems related to diversity and complexity within a program or the region it serves.

San Diego's TCP: Implementing Global Tuberculosis Control at the Local Level

As it stands today, DOTS is a five-point strategy designed to protect the public against infection through a political commitment to sustain funding, maintain a network of laboratories, ensure the availability of antibacterial drugs, monitor and evaluate clinical and programmatic outcomes, and administer standardized medications through intensive monitoring of patient treatment. In practice, however, the branding of DOTS as a strategy of 'cure as prevention' reflects an increasing preoccupation with the monitoring and control of individual bodies rather than with environmental issues such as improving ventilation systems, or sociopolitical conditions such as underemployment, poverty, or intersecting health conditions resulting from limited access to healthcare. In particular, an intense focus on the individual body is manifested as a fixation on whether patients begin and complete their treatment regimens as prescribed. The implication of this is that failure to control tuberculosis is largely the consequence of the uncooperative or defiant behavior of 'non-compliant' patients.

Much of the scientific literature tacitly supports the focus on individual compliance through a research agenda that concentrates on antibiotic interventions into disease as the singular or most important source of control and cure. This work has further reinforced the importance of completing tuberculosis treatments exactly as prescribed as a means to ensure a patient's disease is no longer communicable and to prevent bacterial resistance to antibiotics. But as Ho (2004) argues, antibiotic treatment is necessary but not sufficient to the control of tuberculosis. She writes, "Antibiotics can be viewed as treating the relatively *proximate* cause of tuberculosis whereas addressing the social conditions giving rise to tuberculosis targets the more *distal* links in the long causal chain" (p. 759, emphasis in original). From this perspective, it is vital to consider the particular ecologies in which drug resistance has expanded instead of positioning it as a matter of patient non-compliance alone. Further, decentering patient noncompliance involves looking beyond lack of available drugs or other components of transmission. Perhaps equally important is developing an understanding of the cultural, discursive and material factors that might limit compliance. Finally, decentering compliance also entails interrogating the construct itself, including the ways communities, doctors, governments, and health organizations might also be noncompliant.

Adrian Alarcon

The accounts of TCP staff regarding their patient, Adrian Alarcon, offer a starting point for thinking about these issues as they play out in the context of a local public health clinic, providing a provocative example of the contingencies that arise within the current constellation of global best practices for tuberculosis control. As the clinic staff explained it to me, Adrian's mother suspected her college-age son's condition was tuberculosis. After feeling ill for weeks and seeing multiple doctors without finding a solution, Adrian and his frustrated mother appeared at the TCP without an appointment, convinced that Adrian had tuberculosis. Adrian's journey to treatment had in some ways become a tale of larger-than-life proportions in the context of the daily routines at this county public health clinic. At the clinic, people rarely voluntarily appear and present clinic workers with a compelling case for why they believe they need to be treated for tuberculosis. Rather, they most often come to fulfill a requirement.

That this narrative account of Adrian's arrival at the clinic was repeated so frequently among its staff reflects the tensions that clinic staff sometimes feel in treating a disease as highly stigmatized and with as many rigorous treatment criteria as tuberculosis. Clinic staff members often engage in procedures that require invasive and sometimes unwelcome measures, and they often encounter patients who are reluctant to be tested or treated. For example, people who have been identified as contacts of patients with active tuberculosis are asked and sometimes ordered by the court to be tested for tuberculosis. Even outside of such extreme instances, most people arrive at the TCP clinic in order to fulfill a compulsory screening that is not of their own volition. This is in part attributable to the public health function that the TCP serves for the community and also because within the United States, it is less likely that people who have regular medical care would have tuberculosis in the first place.

For the clinic staff, managing the reluctance of patients and their families is as large a part of the screening process as the diagnosis itself, which is another reason that Adrian’s voluntary appearance at the clinic seemed so peculiar. The fact that clinic staff so frequently repeated the story of his arrival at the TCP indicates that his story represented a kind of institutional lore in an environment where people do not often voluntarily present for treatment. For the clinic staff involved in this particular mode of storytelling, the story itself recounted the tale of a voluntary patient with severe disease who was willing rather than reluctant to enter into such a rigorous treatment regime. It became a kind of management work of the staff themselves by offering a counterpoint to the kinds of resistances they encountered on a regular basis.

Adrian’s story was special for the clinic staff because in it he fulfilled the role of a self-regulating, self-interested, and rational actor – a responsibility required (though not always achieved) by the logics of DOTS and a value that clinic staff often lamented as missing from many patients. This particular version of Adrian’s story serves as a frame that reveals the ways knowledge about patients at the TCP is often fragmented and can reflect variation between the goals and duties of administrative leadership and clinical staff. This became clear to me towards the end of my ethnographic work at the TCP, when Dr. Walter recalled the details of Adrian’s arrival. These details revealed subtleties and complexities of the situated knowledges that map onto employees’ assigned roles and the distribution of access and activity across the physical spaces at the TCP.

By Dr. Walter's account, this fourth-year natural sciences college student was actually sent to the TCP by the most recent doctor he had seen. The doctor suspected tuberculosis but because Adrian was uninsured at the time she referred him to the TCP for testing. The doctor failed to notify the TCP about Adrian's referral, despite being standard protocol required by the State of California. Dr. Walter was relieved, even grateful, that Adrian and his mother followed through with the doctor's referral because, as she explained it, this kind of inconsistency is one of the ways people "fall through the cracks." Although there were gaps between experiencing symptoms and beginning treatment, Dr. Walter believed that the risk of Adrian remaining untreated and potentially infecting more people or facing grave illness himself had luckily been intercepted and hopefully mitigated to some extent, particularly once the disease investigators began identifying and reaching out to his contacts.

The lapse in protocol on the part of Adrian's original doctor helps to shed light on the frequent disconnect between the ways tuberculosis control is articulated within the medico-administrative DOTS platform that assumes patients must be watched and doles out harsh penalties when they do not comply, but fails to do the same for other actors in the situation, in this case private doctors. According to Dr. Walter, the perception by the community overall, including many of its doctors, is that tuberculosis is no longer an issue in San Diego. One of the TCP's roles is consulting with and educating the community's doctors about tuberculosis infection and disease. This most often happens in response to a situation like Adrian's where a doctor fails to follow state or federal mandated rules guiding notification, although Dr. Walter wishes this kind of education could be preemptive rather than reactive. She attributes the reactive nature of much of this community education work to an overarching lack of emphasis on prevention. The current orientation towards ‘cure as prevention’ makes it harder for the TCP to reach out to private practitioners and community clinics because budgets are often tied to objectives set by local, national and private funders that do not prioritize using resources on such preventative measures, which points to another factor that complicates the cure as prevention model of tuberculosis control that focuses primarily on the actions of individual patients.

As further details of Adrian’s narrative were revealed to me, his story provided insights into other limitations of the cure as prevention model of tuberculosis control that relate to its primary focus on the behaviors of individual patients in isolation from their communities. One of the primary questions that arose in Adrian’s case was whether he infected others before he was diagnosed with tuberculosis or received treatment. Age, geographic location and racial/ethnic identity are among the most significant factors that the TCP takes note of in their initial efforts to establish potential links among cases through contact investigations, which are carried out by dedicated staff trained in this area. These investigations are viewed as important since they correlate to the likelihood of social interaction between patients. As it happened, when Adrian first appeared at the TCP, the clinic had recently begun treating Felipe Monterroso, a man in his mid 50s also living in San Diego’s North County region who, like Adrian, was of Guatemalan descent. However, no other intersection between the lives of Adrian and Felipe appeared in their case narratives. Further, the fact Adrian and

Filipe were not biologically related, lived in different cities in North County, and were separated by a generation seemed to indicate to TCP staff that their social circles did not likely overlap.

A few weeks into Felipe's treatment, contact investigators had identified at least a dozen other individuals who had come into contact with Filipe, many of them with active tuberculosis disease. At this juncture, Dr. Walter decided to intensify contact investigations in order to uncover links beyond the information that patients provided in their initial interviews. Dr. Walter noted that their shared Guatemalan descent was a potential lead and asked the office's outreach workers and contact investigators to re-interview all identified patients, even people who were being seen by private care providers. She hoped this series of expanded interviews would help the team discover other people who had come into contact with this particular strain and, by extension, might give the TCP staff a clearer picture regarding how this cluster was linked. In addition, Dr. Walter also charged the staff epidemiologist with the task of strain identification and cluster mapping. This would serve as the genetic counterpart to the interviews, hopefully helping to identify the scale of people impacted by this particular strain of tuberculosis.

One morning, as some of Filipe's contacts were arriving at the clinic to be screened for tuberculosis, clinic supervisor Sonya Adams and I crossed from the clinic to the administrative suite where Dr. Walter's office was housed. As Dr. Walter and Sonya talked, the two wondered aloud if any connections to Adrian had been unearthed, despite Felipe's claim that he did not know the young man. During their conversation, one of the office's Communicable Disease Investigators (CDIs) approached our small group to inform Dr. Walter that Adrian had not been at home when TCP staff tried to contact him to set up a follow up interview. The CDI had since learned that Adrian had continued to attend band rehearsals and performances at his church in northern San Diego County. This was an urgent issue because Adrian was still infectious. In accordance with San Diego County's Home Isolation Program (HIP), Adrian had been asked to remain at home during the infectious period of his illness. HIP required Adrian to stop attending all university classes and all extracurricular activities, including participation at church, and to remain at home except for his scheduled, chauffeured visits to the clinic. Initially, HIP's home isolation requirement is requested without a legal order. The patient's commitment to quarantine is established through a doctor's recommendation and bound with a signature from the patient indicating an understanding of and agreement with the terms. This option for quarantine is considered less restrictive for the patient and less costly for the government than administering quarantine in a hospital or other clinical setting.

To begin the process of patient placement on HIP, the TCP Intake Nurse or the Public Health Nurse Case Manager assesses the patient's home environment to determine whether there is access to appropriate support networks and resources to maintain home isolation. This includes a system of family or very close friends who can help the person carry on the necessary functions of everyday life that extend beyond the private space of the home itself, such as shopping for food and other necessities or washing laundry. If support at home is considered inadequate, which tends to be the exception, TCP staff makes arrangements for housing at a living facility managed by the county during a patient's infectious period. If home supports are deemed adequate, an assigned CDI monitors the patient through random phone calls and home visits, with additional assistance provided by the outreach worker responsible for administering all directly observed medications and the Public Health Nurse case manager who oversees the patient's file and helps to coordinate care.

Until this point, the TCP thought of Adrian as a compliant patient because he was always home when they checked in and he was willing to take his medications without question. Perhaps the powerful TCP staff narrative that Adrian had arrived voluntarily seeking treatment also influenced this perception. However, in part because the direct observation of medication is not carried out over the weekend, the TCP did not suspect that Adrian remained active in his church. Ironically, it was Adrian's breech of his HIP contract that led the TCP to recognize the link between him and the older patient, Filipe. The church at which Adrian continued attending band rehearsals and performances was the same as the one that Filipe and his family attended. Despite the numerous TCP staff helping to monitor Adrian's HIP status, it was ultimately one TCP contact investigator's attempt to contact Adrian that alerted them to both his transgression and the unifying link between cases.

Responding to Noncompliance

In the task of containing and preventing the spread of tuberculosis disease, adherence by patients to prescribed tuberculosis treatment regimens is a requirement in the United States and elsewhere. Non-adherence is taken seriously, and its definition is multifaceted. Not only limited to whether a patient takes prescribed medications, adherence also extends to examination, testing, and medical recommendations such as isolation (Centers for Law and the Public's Health, 2009). When a patient is noncompliant, local health departments employ legal measures in phases. For public health officials and policymakers, the law is regarded as one of the best tool for controlling tuberculosis even if it is reserved as a measure of last resort.

In the State of California, the law generally makes stipulations to intervene in three ways: the prevention of cases, the identification of cases, and the management of cases (Cabrera, Hodge, & Gostin, 2009). Included in this framework is the mandatory treatment of people with active tuberculosis, if and when it will make the person non-infectious or significantly reduce their period of isolation. In addition, the law supports the mandatory medical examination of a person suspected of having or confirmed to have tuberculosis. While the CDC recommends tuberculosis screening for specific populations –particularly for people with autoimmune deficiencies, people dependent upon drugs and alcohol, or people with crowded living conditions– state law actually requires many different population groups to be screened, including immigrants, childcare providers, correctional facility employees, medical facility employees, county and state volunteers, and long-term care residents and employees (Cabrera, Hodge, & Gostin, 2009).[49] By extension, United States law requires the reporting of active tuberculosis cases to local health departments, who in turn report verified tuberculosis cases to the CDC. These reports contain the patient's county of residence, country of origin, self-identified race and ethnicity, drug-susceptibility test results, HIV status, and

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[49] The Americans with Disabilities Act authorizes employers to require medical examinations once an offer has been made. All employees must be asked to take the same set of tests, all medical information must remain confidential, and the employer cannot withdraw an offer based on the detection of a disability. A positive tuberculosis test falls within this category.

information on excessive alcohol use, homelessness, and detention at a correctional facility (Miramontes, Pratt, Price, & Navin, 2013).

Another form of legal intervention is the mandatory isolation of a person with active communicable disease through a court-issued Order of Isolation, which requires the recipient remain at the home or hospital or face confinement via incarceration. This injunction is used in situations like Adrian's, when a voluntary HIP contract has failed. The TCP issues an average of 20 legal orders per year. Of these, the vast majority of people comply with the terms of the order. When a patient is unable or unwilling to follow through with the requirements of the Order of Isolation, local health departments, in concert with local law enforcement, issue warrants of arrest. The patient in this instance is charged with committing a misdemeanor (Centers for Law and the Public's Health, 2009). Each year only a few warrants are issued for arrest, and most warrants never result in arrest. Dr. Walter explained that people with an "escape valve" often leave the jurisdiction or the country. On the other hand, when people know they cannot leave, they usually opt to take their medications as prescribed after receiving the legal Order of Isolation. It is a small cohort who is arrested for noncompliance, just one to two each year in San Diego County. "I guess I look at it like every time we serve someone a legal order, certainly every time have finally have to put someone in jail…it is our failure," Dr. Walter explained to me. She continued, "You know you are going to have failures. People who are deep into their drugs or whatever it is, but it is a failure to find some way to make it work for that person … And we don't have that many. But avoiding that moment and that consequence and that big expense for them and hassle for everyone would be good."

Reflecting on Noncompliance and Discipline

Public health regulations that stipulate legal penalties for noncompliance represent some of the most severe health interventions conducted in the name of the public good. Although this mechanism for control serves an important function, its deployment in the face of patient non-compliance raises questions about a model of care that is organized first and foremost around monitoring the actions of individual patients. This is not just because of the limits to self-governance built into this model but more important because of what such instances might reveal about the limits or contradictions of the system itself.

While Adrian's story provides a compelling example of how legal interventions are integral to the formal strategies for managing patient compliance, it also helps illuminate the intersecting practices, discourses, and spaces of tuberculosis control at the TCP in which the disciplining of health is a distributed activity that also occurs outside of legal intervention. In his investigation of the production of truth that creates self-disciplining subjects, Foucault (1977) outlines the move to a disciplinary regime during the 18th century that aimed to cure criminals rather than kill them. In this shift, the power over death yielded to a control over life, which occurs through a series of micro-technologies that inscribe bodies through disciplinary techniques that are more productive than they are repressive. Discipline functions not just through "enclosed institutions" but instead as "centers of observation disseminated throughout society," and is effective because it permeates both the self *and* the social. (p. 212).[50]

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[50] See also Armstrong's (1993) discussion of the dispensary gaze, also discussed in Chapter Two, which he argues has extended the gaze of public health into the community as a way to look after patients and

This diffusion is reflected in current best practices of tuberculosis control, although it is not formally codified into the DOTS platform. The TCP's control function lies largely beyond its legal authority, and it is not wholly contained within its formation as an administrative institution. Rather, a significant portion of tuberculosis management materializes within and between the private spaces beyond the TCP itself. Largely indirect, this technique of management occurs through the networks and actions of people outside of the direct and actionable reach of the state.

For example, while the TCP directly monitored Adrian's case, allocated his medications, and procured the legal documents necessary to compel him to stay at home, many other entities were involved in monitoring and supporting his care. His university assisted in the identification, testing, and education of potential contacts. Later, the university helped by administering Adrian's directly observed therapy after he was released from HIP and able to return to campus. Once the leadership of his church understood the implications of tuberculosis disease and its existence in their community, they also aided in identifying other potential contacts. In addition, the church began more closely monitoring its participants to ensure that those who had been implicated in this tuberculosis incident were not exposing others. Adrian's family provided a place to live and the material means to maintain the activities necessary to

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manage risk (p. 10). Likewise, a feature of the 'new' public health, the health management model he argues is in place today, is the continued expansion of surveillance throughout the "body politic" in which health becomes an important variable within and across social, political, and economic domains (p. 405-406).

sustaining life. They also stayed in regular contact with nurses at the TCP clinic and caseworkers in the administrative offices.[51]

The TCP lacks the legal authority to sanction any of these extra-agency entities. In fact, the only entity that the TCP can compel to action through legal injunction is Adrian. The distributed nature of case management, then, contradicts dominant conceptions of the ways medical authority operates because (public) health in this example is most often enacted through non-legal means and is dependent on distributed networks of surveillance and support. It is forged within and between dynamic conjunctions (and sometimes contradictions) between formal institutions of health and other institutions of society, distributed across governmental, private, and community actors. In fact, once the institutional structures more effectively connected with Adrian's social networks, such as his church, their role in managing his care and the care of others became more prominent. In this way, the distributed nature of case management is profoundly local, occurring in schools, places of worship, places of work, private homes, and internalized at the level of subject formation. It constitutes a collaborative, though not always reciprocal, relationship between public health employees, community members, and patients, even if collaboration is sometimes invisible or tacit. Because of this, many aspects central to the disciplining of health are

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[51] See Foucault (1980), who suggested that the changes in medical politics that occurred in Western Europe during the 1800s represented one of the first times that the family became a vital unit in the medicalization of life. He wrote: "The family is assigned a linking role between general objectives regarding the good health of the social body and individuals' desire or need for care. This enables a 'private' ethic of good health as the reciprocal duty of parents and children to be articulated on to a collective system of hygiene and scientific technique of cure made available to individual and family demand by a professional corps of doctors qualified and, as it were, recommended by the State" (p. 174).

currently unrecognized within formal assessments or descriptions of the public health system.

Introducing the Cruzes and Self-Regulated Patients

While Adrian provides a clear example of what medical practice terms noncompliance, by and large most patients comply with the rules and guidelines for treatment established by national and international directives and carried out via local public health entities like the TCP. In these instances, the current system works, even in the face of challenging personal circumstances, which begs the question of why. My observations of the TCP's treatment of the Cruzes, an older Philippine couple, provide some answers and allow us to consider what the "work" of the system comprises. On paper the Cruzes might have been predicted to be a difficult case to treat because of the many personal struggles associated with their case and because of co-occurring diabetes. Not residents of the United States, the Cruzes were only in San Diego County to visit their daughter and her family when a trip to the doctor's office revealed that Mr. Cruz had active disease and needed to begin immediate treatment. Because Mrs. Cruz had latent tuberculosis infection, the doctor urged her to undergo preventative treatment. Unable to return to their home in the Philippines until Mr. Cruz's condition ceased to be infectious, the Cruzes had to remain in San Diego County for the first portion of treatment. Facing a fear that they would infect people in the family's household, the Cruz's daughter moved them to a temporary housing situation. Mrs. Cruz acted as her husband's primary caretaker, doing all of the shopping, cleaning, cooking, an organization of medications and appointments. Further complicating their situation was that the couple acts as the primary caretaker of their adult son who is mentally disabled and living in the Philippines. Although their other children were taking care of their brother while their parents were away, the Cruzes worried that their son was not receiving the care and attention he needed and were anxious to return home.

One afternoon the Cruzes invited me to accompany their Public Health Nurse, Emma Martel, on a home visit. When we first arrived at their home, we spent several minutes with the pleasantries of friendly conversation. The Cruzes seemed genuinely thrilled to see Emma, and treated her visit as if a friend had arrived. Likewise, Emma greeted the Cruzes with a kind of warmth that comes with familiarity. Behind us in the living room, a television set played a Philippine satellite broadcast of a game show. Before the television's arrival the week before, their only access to news or entertainment was a radio that broadcast local stations in English that were by extension focused on local politics and entertainment. Although the Cruzes speak English, their community in San Diego was limited to their daughter's family, and they were grateful to finally have some news and entertainment relevant to their interests and language needs after many months without.

After Emma checked with Mr. Cruz about symptoms he had been experiencing (itching and high blood sugar), she began administering his tuberculosis medications, passing each one across the table once she counted and rechecked the number of pills remaining in the bottles. Mr. Cruz swallowed the pills one at a time, each with a small sip from the plastic bottle he had been holding from the time of our arrival. Afterward, without prompting, he commented that he has no problem taking his medicines. As if to remind or reassure us that he is a cooperative patient, he continued that he did not mind because he knew the medicines were good for his body. After Mr. Cruz swallowed all of the pills, Mrs. Cruz lamented in passing that 6 months of treatment was too long for them to stay in the United States, and Mr. Cruz agreed, emphasizing again and again that he and his wife had not expected to stay in San Diego for more than a few weeks. Upon hearing this Emma announced that she had good news for them: (1) Mr. Cruz had three negative sputum tests and received clearance from the Health Department's doctors allowing him to return to his normal activities, which meant that (2) he was no longer part of the mandatory home isolation program (HIP), which his wife has been off for several weeks, once her latent tuberculosis infection diagnosis was confirmed. In an instant, his face transformed from worry into an expression of joy. “That means I get to go back to the Philippines?” he asked.

This reaction, I later came to understand, pointed to some of the ways this family's story is important to understanding the complex relationships between treatment, public health policy and individual burden. At this point there was nothing legally requiring Mr. Cruz and his wife to stay in the United States. No longer infectious, they both needed to finish their course of treatment, her for latent tuberculosis infection and him for active tuberculosis disease. But, with some paperwork, this treatment could happen either in the United States or in the Philippines. They were eager to return, and although the Cruzes could theoretically leave San Diego, they also had to negotiate a family dynamic that highly discouraged it. In The Cruzes children living in San Diego Country were adamant that the couple remains in the United States until they completed their treatment, in part, Emma speculated, because the family poorly understood tuberculosis and did not fully trust that Mr. Cruz was no longer infectious.

Discipline and Compliance

The Cruzes are compliant despite the big burden they are enduring. DOTS alone, however, does not seem to be what accounts for their compliance. In addition to the ways the disciplining of health is distributed throughout the community and its institutions, it is also manifested institutionally vis-à-vis the organization and prioritization of knowledge and power. Foucault (1977) identifies three techniques of control that are central to this formulation of power: hierarchical observation, normalizing judgment, and examination. The examination links to the state's role in intervening at the level of individual lives and formation of selves. Examination turns individuals into a case. The transformation from person to case is an important step in justifying the state's control at the level of individual bodies and lives by extending the reach of medical examination to include hierarchical observation and [dis]normalizing judgment. In this example, the clinic extends beyond the walls that house the examination rooms. Clinical authority justifies state intervention into life domains that are not always explicitly medical by creating such a link as unequivocal. This in turn helps to manufacture a state of bodily exception in which the contagious patient is separated from life as usual and the not-yet-infected are identified and screened.

In this ideology of the delinquent, it is possible to "join under the authority of medicine, psychology or criminology, an individual in whom the offender of the law and the object of a scientific technique are superimposed – or almost – one upon the other" (Foucault, 1977, p. 256). In this shift from spectacle to surveillance there is a move towards a system of continuous documentation linking the center and the periphery. This is the creation of the abnormal individual – the "Other," the disabled, the foreign, the diseased. This is the person "we" fear, who simultaneously offers a justification for drawing lines and enforcing limits.

Disciplinary power, then, establishes a minimum threshold that measures and hierarchizes according to ability. Ultimately, this threshold sets standards "that will define difference in relation to all other differences, the external frontier of the abnormal" (Foucault, 1977, p. 182-183). The key marker of this kind of control is the production of subjects, like the Cruzes and other compliant patients, who conform to standards of normality without question, who for the most part *want* to conform without question. As a set of practices carried out through the body, the disciplinary modality of power produces limits, instills self-regulation. Disciplinary power thus guides life, even gives it. In this way, it renders people legible as productive sites for the working of power, while containment and cure work to differentiate individuals and groups on the basis of regulatory norms. In the context of the clinic, this is materialized in the patients themselves, who often come to internalize their own surveillance, such as the Cruzes who would have likely taken their medicine even if a health worker was not present every day.[52]

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[52] It is important to consider, also, the nuance of Cruzes' performance of compliance. That is, we cant fully know if their compliance was a matter of the couple having internalized the surveillance or whether they were eager to perform compliance before the representative of medical authority. This raises important questions about whether their performance is defined in part by the embodied interaction that confers their interpellation.

Discipline and Resistances

Because power is not centralized within a particular place or entity, be it the government or the economy, it is multiple and often contradictory. So, too, are subjects. This includes the ways individuals are never wholly compliant. While resistance is sometimes direct and purposive, it should be noted that it is not always conscious or carried out with forethought in direct response to a concrete object or entity. In her analysis of Foucauldian power and resistance in the context of public health, Lupton (1995) explains:

> While the governmental tactics of health promotion and public health may have much to offer those who possess the appropriate economic, cultural or symbolic capital, for others their inducements will go unheeded or will be actively transformed or actively contested. If people do not find themselves interpellated by governmental discourses…they will not respond accordingly. (p. 131)

While individual desires and actions are formed through multiple subject positions and through intersecting relations of power, people must in turn "be willing to exist as subjects" and conform to the norms or expectations of a given situation in the first place (p. 133). Resistance can occur when this relationship is stressed, broken or not existent in the first place.

Often resistances occur at the micro-level, within the field of everyday life. Adrian's continued participation at church, for example, represented such a resistance as materialized in his failure to follow the TCP's assigned protocol. In this sense, Adrian's oppositional attendance at church may well have been the result of a conscious frustration with the limits placed on him by the public health system. It may also represent his perception of the church as an institution that supports his well-being. But given his acts of compliance in every other domain, Adrian's failure to conform to the demands of the TCP could also be seen as a form of what Lupton (1995) calls extra-discursive resistance, propelled by an intersection of subject positions that could not wholly coalesce around the interests of and solutions offered by current tuberculosis best practices.

Adrian's resistance provided the legal and moral justification for TCP staff to invoke legal intervention in their efforts to control the disease and Adrian. His act of transgression and the TCP's handling of it raise questions related to the role of compliance and the locus of care in tuberculosis disease management. At the beginning of his care, state-sanctioned authorities exerted indirect, if intermittently enforced control over Adrian's body. He was told to stay at home, prescribed a set of medications, and told when to take them. The healthcare workers who administered his medications and monitored his recovery also reported on Adrian's treatment and movement. But as his story highlights, this method of containment does not always work. Not only can we look to Adrian's transgression as a site of resistance, but so too can we look to the absence of affordances in the DOTS design to better understand the limits of institutional power in a situation where the law requires modes of life that some perceive as unsustainable. In some ways, this inflexible system fails to account for contingency when treatment conflicts with the social life of patients. Further, it fails to recognize potential opportunities afforded within the distributed components of disease management because it cannot wholly account for extra-institutional affordances.

While the workers at the TCP seem sincerely dedicated to serving the needs of their patients and their community, the strategy they are required to employ operates as a one-size-fits-all model that approaches tuberculosis as an agent that must be controlled *in spite of* the patient and their circumstances. In fact, this model treats unmitigated compliance as essential to control. Adrian's case begins to expose some of the limits of this arrangement. For Adrian and others who have struggled with the rigid treatment protocols, the current system inadequately accounts for the economic, familial and social factors that also make up their disease. In my communication with Adrian, he indicated such frustration with the situation and all of its requirements that he was reluctant to talk about his situation beyond the required narratives asked of him by the clinic. In many ways Adrian can be figured as a crossover or boundary patient whose sense of privilege as a university student and someone with much broader social connections in San Diego (family, church, school) colored his priorities in ways that the Cruzes did not have access to.

Our email correspondence about his experience was short and occurred only after we met a handful of times at the TCP clinic. He told me that dealing with the requirements of the system often seemed more burdensome than the disease itself. As a college student, Adrian had to suspend his studies and with it any semblance of a social life in order to meet the rigorous treatment regime. Treatment is not just limited to the host of medications patients have to take daily. For Adrian, the burden of treatment also included the regular visits from the county's public health nurses and the series of interviews conducted as the CDIs tried to work out the geographic spread of his strain and if it was linked to others. He was also contending with issues of privacy and disclosure, which fueled fears that his classmates would find out why he was absent from school. His peers were already actively using social media to express anger and frustration that they had been notified of their status as potential contact and required to come to the university's clinic for a screening. This is another point at which Adrian can be inhabits as a boundary position. His immersion in the working-class community of his church is contrasted with the privileged community represented by his university and his social media community, each of which offered distinct pressures related to his experience of treatment. Moments of tension between Adrian's various subject positions point to the instants he failed to be fully interpellated by the discourses and practices of public health.

Chapter Conclusions

The universal application of DOTS can contribute to the existing structural barriers that patients must overcome in order to be compliant, such as only being able to take medications or visit the clinic during regular working hours, even if it means compromising quality of life or livelihood. Of course, any alternative to a universal application of DOTS raises questions related the problem of determining when and where an exception to the existing protocol is appropriate. In addition, while there is no way yet to address the question of the communicable phase of the disease without limiting social interaction, it is important to consider how elements of DOTS and HIP might be paired with social and clinical support strategies to better mitigate its negative impacts and better assist with patient compliance.

For Adrian, this may have included a more meaningful way for him to continue his studies. Perhaps, TCP staff could regularly connect patients and their families with online support communities and incorporate discussions about those interactions into their patient education materials. Once HIP had concluded and Adrian was enrolled in school again, he had to continue taking the medications during the day because his university took over the allocation of directly observed therapy. While this solution was considerably more convenient than coordinating his daily routines around the times that TCP staff could meet him at home, the medications left Adrian feeling weak during his crucial learning hours. If TCP staff were available to treat him in the evenings, the medication might have had less of an effect on his productivity and feelings of continued frustration at the toll it takes to interface within the system's stringent demands.

Although the experiences of Adrian and the Cruzes represent individual stories among thousands, they illustrate the ways in which the disciplining of health occurs across social institutions –beyond but inclusive of DOTS and local tuberculosis control programs. It also demonstrates the ways DOTS can fail its patients and how patients can, in turn, resist. As such, their examples pose an interesting problematic to the universal application of DOTS within local settings. Adrian's story in particular reveals a system without enough flexibility to respond to the needs of the patient with, for example, increased forms of support. DOTS focuses on the bacterial etiology of the disease as it is manifested within individual patients as the solution for tuberculosis control but is unable to account for its own shortcomings as well as its extraordinary potentials via meaningful collaborations with local communities.

While Adrian's experience highlighted how his needs exceeded the ability of DOTS or the TCP to help, current tuberculosis control best practices occasionally serve various social functions or supports family dynamics. However, this positive impact remains largely informal and almost always undocumented within the formal system, and it is often dependent on the circumstances of the patient and the relationship between the patient and public health workers. The Cruzes, for example, looked forward to their visits from TCP staff. For them, as they explained to me, these visits offered a sense of security that they were healthy or doing what they needed to become so. The visits also provided a form of human connection that the couple needed while they were so far away from their permanent home in the Philippines and unable to stay with their San Diego family and primary source of community in the region. For them, DOTS became more than a monitoring program, but the positive social roles that the TCP fulfilled for the Cruzes remain unconsidered and unstructured within the current model of tuberculosis control.

Reconsidering DOTS

This chapter has examined the ways current tuberculosis protocols aim to reduce the global burden of tuberculosis by way of the assimilating authorities of surveillance and control. In the case of DOTS, curing infected individuals (often to the detriment of important preventative measures) is framed as prophylactic for the population at large, with antibiotics representing its primary pillar. To the extent that the DOTS strategy aims to account for structural issues in the control of tuberculosis, a tendency to focus on the bacillus, cure, and the noncompliant patient ultimately offers an insufficient model for change. In this system, control happens at the level of individual bodies but without the flexibility to also address individuals in their local contexts because this form of control is generalized and lacks articulation to social and material specificities.

Further, the current system has been implemented globally without significant consideration given to what less-restrictive forms of care might be appropriate for particular communities, especially some low-endemic communities, and without the flexibility to allow local communities to test how such a policy might work or to allow for adaptations. Meanwhile, many of the positive aspects of the current system, such as companionship or advocacy, most often occur as informal byproducts of the actions of individual actors and represent potentials that remain unofficial rather than purposefully cultivated.

In discussions about the future of tuberculosis control, there are a few areas worthy of further consideration. First, tuberculosis is a responsive and hardy microorganism, morphing over time in response to its environment such that changes in medical technology modify what the disease has potential to become. Antibiotics, which provide the material basis for the DOTS protocol, are becoming increasingly ineffective, as drug resistant strains of tuberculosis have gradually emerged in response to human intervention. In many ways, tuberculosis seems to be outpacing biomedical attempts to control it. While divestment by drug companies remains a serious issue (see the next chapter for a more detailed discussion of this issue), new antibiotics alone cannot solve the problem of tuberculosis. Adding to the complexities of transnational disease management is that scientific developments, such as antibiotics, can only transcend individual patients to afford global health results in tandem with sustained consideration of the social, political, and economic dynamics that shape health outcomes (Murray, 2004).

Second, while current tuberculosis control measures are concerned with the health of a homogenous public, the formal system is designed to intervene at the opposite pole by monitoring and controlling at the level of individual bodies abstracted from their cultural and situational specificity. It is a system that is organized largely around thwarting the presumed noncompliance of generalized actors, although it does not justify action according to individual or community-based criteria. Rather, justification occurs based the perceived risk of the unidentifiable whole. Meanwhile this focus on broad, universal principles has contributed to a system that has difficulty accounting for the needs, particularities, and irregularities of the very constituency it seeks to control and aims to protect.

Third, beyond cure alone, DOTS relies on the isolation of individuals and other organizational management practices related to disease control such as the management of agencies that insure the provision of drugs, clinical resources, and expanded mechanisms of case detection. In its current configuration, then, cure is employed as a catchall phrase that flattens understanding of the broad impact of tuberculosis. The supply-and-demand orientation of the current model of control deemphasizes sociopolitical factors such as economic disparities, variability in access to care, racism, or gender inequalities (Farmer, 1997). That is, DOTS pictures the eradication of disease as primarily a clinical and infrastructural problem. As I will explore in detail in the next chapter, this forecloses the consideration of factors affecting the vulnerability of individuals and communities. And because its design lacks the reflexivity necessary to identify and respond to broad structural shortcomings within the system itself, the current model eclipses a wide variety of regionally situated strategies and resources available to manage and prevent the transmission of tuberculosis.

In addition to these weaknesses in the system's design, there continue to be structural, social, and environmental barriers that are impeding tuberculosis control efforts. Weakening infrastructures, shrinking public health budgets, less emphasis on research and development, and insufficient attention given to meaningful inclusion of local community contingents are just a few examples of many. Locally, TCP employees point to social and structural constraints that limit their own work. Notably and consistently, TCP staff cited insufficient funding as one of its most significant barriers to the design and delivery of services, outreach and prevention efforts. Further, an unequal distribution of the disease burden puts poor and disenfranchised individuals and communities at greater risk and presents larger obstacles to treatment.

Local organizational structure and treatment protocols would benefit from developing measures that can better account for the social and structural forces that have an impact on a patient's experience before, during and after treatment. For instance, certain clinic policies and procedures can be dissuading, including overcrowded waiting rooms, extreme wait times, inconvenient clinic operating hours and locations, seemingly repetitive procedures, inadequate explanation of what and why procedures are being done, indirect and direct costs, the limits on individual autonomy, and more. There is simply not enough institutional support, most palpably in the form of funding, to implement changes at the level of service design and delivery. These site-specific limitations in concert with limitations in overall system design ultimately mean that the focus remains on the behavioral aspects of individual patients. In this framing, treatment barriers are most often attributed to negative characteristics of the patient – such as lack of willingness, lack of education, age, or cultural beliefs– instead of the larger social and institutional forces that may be at work, including the barriers embedded into the design and delivery of services.

Ultimately, DOTS as a global initiative often clashes with local needs and conditions. While both poles are concerned with controlling infection and managing uncertainty, tensions often emerge in the conflict between uniformity and contingency. In its uniformity, DOTS signals an overall narrowing conception of what the disorder is and what approaches are appropriate to contain it. But the etiology of tuberculosis is complex, linking issues of drug resistance, transmission, and other individual-level factors (which are differently distributed) to larger system-level and sociopolitical constraints. The risk of complete uniformity, then, is that it can also work as a form of collapsing, a making singular of something that is multifaceted and dynamic. It can obscure the ways infectious disease control must be approached on multiple fronts.

At stake in this understanding of disease is how people like Adrian or the Cruzes are constituted as [non]compliant subjects in relation to a diverse set of institutions that work largely in concert, though also sometimes in contradiction, with one another. Important to this argument is not that public health institutions sometimes overreach or unnecessarily encroach upon the rights of individuals, which is certainly sometimes the case. Rather, what is central to this argument is that DOTS, and by extension leadership at the local level, is not aligned with how power functions broadly across institutions. That is, the agents of public health institutions are not recognizing how control functions as intra-institutional, distributed, productive forms of power. This relationship is reiterated again through research that repeatedly demonstrated very little difference in outcomes between self-administered and directly observed therapy. Many institutions are involved in the disciplining of health beyond the direct reaches of the state, the law, or the clinic. This presents many opportunities for localizing disease control that are often missed.

Along with its global implications, tuberculosis is also a local, personal, community, and systemic disorder. An extreme focus on patient compliance at once blames the individual for system-level problems, even while it misses why individuals are noncompliant in the first place. As the most predominant means for controlling tuberculosis, an acute focus on compliance establishes the limits of a system that cannot account for contingency at the level of individual need – even as it simultaneously requires intense focus on individual action and behavior. Neither can account for regional vulnerabilities or disparities in prevalence or recurrence. Decentering compliance in this context is critical. But it requires questioning the taken-for-granted subject of tuberculosis infection. Rather than the individual, perhaps it is the system itself that is in need of cure.

CHAPTER FOUR: GLOBAL PUBLIC HEALTH POLICY AND LOCAL FRICTIONS WITH THE CURE AS PREVENTION FRAMEWORK

Although the World Health Organization (WHO) launched its worldwide strategy for tuberculosis control, Directly Observed Therapy, Short-course (DOTS), in the 1990s, the core principles of the policy were based on research conducted during the 1950s and 1960s in colonial and neocolonial contexts and preliminarily formalized by the WHO during the mid-1970s.[53] It is not surprising, then, that the successes and weaknesses of this standardized and universalized platform have varied across time and place. While the last chapter examined some of the limits of the universal design and application of DOTS as they relate to its central precept that cure functions as the best form of prevention, this chapter considers the variations that happen in local contexts. Drawing from my fieldwork in San Diego County, this chapter reflects on the intricacies of local organizational efforts and the broader sociopolitical environment that influences them in order to build a case for rethinking how tuberculosis control itself is conceived of and operationalized.

As a border region with high rates of travel, changing patterns of migration, and comparatively higher rates of tuberculosis than the national average, San Diego County represents an important and politically charged example of how variation occurs in local settings. At a programmatic level, employees at the Tuberculosis Control and Refugee

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[53] Notable among the original research were studies by Fox (for example, see, 1958) and Moodie (for example, see, 1967). Fox's findings in particular informed an influential WHO report (World Health Organization, 1974) that went on to shape subsequent tuberculosis control strategies (Raviglione & Pio, 2002).

Health Program (TCP), which is housed at the Health and Human Services Agency of San Diego County (HHSA), must determine how to formulate action around DOTS as a generalized platform with few local-level protocols established by the WHO or required by the United States government outside of tuberculosis reporting requirements. Building on the previous chapter's assessment of DOTS, this chapter examines the fine lines that TCP staff must traverse daily as they negotiate the semantics and logistics of tuberculosis control in a local setting. Importantly, this highlights the need to manage tensions between the responsibility for public health and safety in a general sense, as conceptualized by DOTS, and the treatment of individuals, which is the primary way that DOTS is actualized at local levels.

By considering the interpretive challenges faced by TCP staff, this chapter examines the tensions, contradictions, and ambiguities that emerge from the dynamic global/local relationships that influence tuberculosis control efforts at the local level. I begin by examining how the ongoing problem of drug shortages places a wedge between idealized conceptions of universal treatment and existing local conditions. Shortages of key tuberculosis medications reflect shortcomings in tuberculosis control infrastructure that impact the ability of local health departments and private or non-profit community care facilities to do their job. Next, I turn to the sweeping divestments in tuberculosis research and development. The global scale of these pullbacks signals the limitations of a laissez faire approach to infectious disease research, development, and pharmaceutical production/distribution. I argue that recent drug shortages paired with the steady pullback of funds to support ongoing research and development comprise core public health concerns that receive far less attention by global policymakers than the treatment compliance of individual patients, particularly in relation to the growing problem of drug resistance.

Linked to research and development divestments is a funding structure at the national and state levels that prioritizes crisis over prevention, which has generated a pattern of reduced funding for local programs during times when tuberculosis is better under control, and renewed attention when the disease makes a comeback. Reflecting on this situation, I draw upon observations and discussions with clinicians and administrators at the TCP to examine how employees at the TCP are constrained by the current cycle of tightened budgets, particularly the ways smaller budgets have limited the scope of how the TCP is able to serve its patients and the kinds of partnerships it is able to maintain with the community. I also consider the kinds of challenges that emerge, particularly in the form of informal community connections and moments of advocacy, even amidst the restrictiveness of austere budgets.

From this focus on organizational-level factors that impact local health departments, I turn to a consideration of the role that intersecting discourses about race and nationality have played in shaping the ways local tuberculosis programs deliver treatment. The classificatory tools that emerge during a given time and place are closely associated with the social, economic, or ethical orientations of their sources, and as a disease, tuberculosis is particularly reflective of evolving relationships between anti-immigrant rhetoric and medical policy. I begin with a brief consideration of the historical entwinement of fear/hatred of difference and its justification with scientific, medical, and legal systems. Next, I then examine how the TCP strives to manage epidemiological realities of the higher burden that the tuberculosis epidemic places on certain minority groups—in particular new immigrants who face a generalized fear of outsiders and racial and ethnic communities of people born in the United States who are socioeconomically disadvantaged. I argue that the focus on immigration as a source for disease conceals the equally important role of localized social, political, and economic factors.

Finally, I conclude this chapter by considering the diverse needs of the individuals and community groups in San Diego County, paying close attention to the vulnerable populations that the TCP fails to reach and/or adequately serve. In doing so, I argue that United States policymakers must begin to incorporate the needs and strengths of specific communities into its overall tuberculosis control strategy, including a stronger commitment to support prevention efforts by developing adaptive programming that better reaches under-served community groups. Such a shift would undoubtedly require a commitment by policymakers to undertake major changes in the organizational structure and logic of the current system that uproot many precepts of the existing, largely uniform model. In spite of this need for such overarching reassessment of current policy and resource distribution, I suggest that informal acts of outreach and advocacy already being carried out at the TCP offer insight into the kind of strategies that could help build stronger, more adaptive systems of public health and tuberculosis control.

Medication Shortages

On a daily basis TCP staff negotiate and adapt to material and bureaucratic limits placed on their local agency. Foremost recent examples of these constraints have been a series of first- and second-line antibiotic shortages that have increased exponentially in recent years in the United States and worldwide (Barton, 2013; Centers for Disease Control and Prevention, 2013b; Treatment Action Group, 2014).[54] Tuberculosis drug shortages are a global challenge (Gray & Manasse, 2012; Pauwels, Huys, Casteels & Simoens, 2014), although in the United States they follow a broader trend of recurring shortages of antibiotics of all types in recent years (Griffith et al., 2012; Ventola, 2011). Shortages of key tuberculosis medications place significant pressure on local public health agencies and private care providers, contribute to service delivery limitations, and are a factor in the development of drug resistant strains of tuberculosis (Lessem, 2014). Shortages of key tuberculosis medications also have diverse negative implications that extend beyond direct treatment efforts. For example, shortages of the tuberculosis vaccine caused delays in the ability of public health programs to administer tuberculosis tests and have required local programs to postpone the hiring of new health staff. Drug shortages have also had an impact on the livestock industry, which relies on tuberculin to test and move their animals (Lessem, 2014). I observed indications of this problem emerging at the TCP in the form of an underlying worry by TCP director Dr. Walter and other administrative leaders that their supplies would disappear. There was also a noticeable increase in TCP resources directed towards advising the county's private care providers about how to modify treatments

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[54] There are five primary, or first-line, tuberculosis medications: Isoniazid, Rifampicin, Pyrazinamide, Ethambutol, and Streptomycin. These drugs are the most potent in treating tuberculosis, particularly for people with active disease who have not previously received treatment. They are also the easiest tolerated of the medications, with less-toxic side effects. All other tuberculosis medications are considered second-line drugs and used in varying combinations to treat drug-resistant tuberculosis (World Health Organization, 2010; Zhenkun, Lienhardt, McIlleron, Nunn & Wang, 2010).

when the external care providers had difficulty obtaining medications in dosages appropriate to their patients.

Shortages of tuberculosis medications have been attributed to manufacturing discontinuations, trouble obtaining raw materials, or issues with the active ingredient (Lessem, 2014). However, because the United States Food and Drug Administration (FDA) cannot not legally require manufacturers to provide reasons for shortages, determining specific and detailed causes can be difficult, if not impossible, given that the reasons offered by drug companies are often vague and sometimes nonexistent (Griffith et al., 2012). Fundamental to issues of supply and distribution are the small number of FDA approved manufacturers in the United States (Lessem, 2014; McKenna, 2013) and the FDA's lack of authority to compel companies to produce a particular drug or stipulate the amount of production a company must engage in (Griffith et al., 2012).

A related concern are the impacts of patents that prohibit generic manufacturing (Médecins Sans Frontières & International Union Against Tuberculosis and Lung Disease, 2013) and the unstable costs of medication in a fragmented market that lacks built-in protections to help regulate costs by determining a fixed uppermost price (Médecins Sans Frontières & International Union Against Tuberculosis and Lung Disease, 2012). Within the context of a largely unregulated pharmaceutical market, it has been a common practice for drug companies to raise the price of tuberculosis medications during shortages (McKenna, 2013).[55]

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[55] While medication shortages are one reason the costs of drugs to treat many forms of infectious disease, not just tuberculosis, have been increasing in recent years, other times price hikes are a result of corporate

These problems are compounded by the fact that the United States does not stockpile crucial tuberculosis medications in case of wide-scale production or distribution issues. And while the United States contributes funds to the maintenance of the Global Drug Facility, a supranational medication procurement and distribution system that maintains a quality and affordable supply, it does not participate in the program itself (Lessem, 2014).

A recent shortage in the United States of isoniazid (INH), a first-line tuberculosis medication that is widely used in the treatment of both latent infection and active disease, had widespread consequences. Beginning in late 2012 and continuing for a significant portion of 2013, the United States faced a national shortage of INH and a combined rifampin/INH medication, which was developed specifically for patients taking preventative treatment.[56] Although the Centers for Disease Control and Prevention (CDC) has acknowledged the seriousness of drug supply interruptions in the

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strategy on the part of pharmaceutical companies to raise prices for less-common “specialty” drugs. The New York Times (Pollack, 2015) recently published an in-depth article charting this trend after a recent price hike for Daraprim, a drug most commonly used to treat the parasite based infection toxoplasmosis, which saw the medication jump from $13.50 per tablet to $750 per tablet. Other medications for less common diseases have seen similar price hikes. Pollack uses Cycloserine, a drug used in the treatment of multidrug-resistant tuberculosis as an example after its price increased from $500 for 30 pills to $10,800.The general manager of the company that produces Cycloserine, Rodelis Therapeutics, said the price hike was adopted to make sure the medication remained “reliable” (Pollack, 2015, Sept. 20).

After enormous public and political response to Pollack’s article, Rodelis Therapeutics, who had only recently acquired the rights to Cycloserine, returned the drug to the Purdue University Research Foundation, who announced they plan to charge $1,050 for 30 pills. This is twice what it originally sold for, but far below the $10,800 price tag set by Rodelis Therapeutics. Despite major pushback, Turig Pharmaceuticals has refused to lower costs for Daraprim (Pollack, 2015, Sept. 21).

[56] At the beginning of the INH shortage, three pharmaceutical companies supplied the United States with the drug – Teva, Sandoz, and VersaPharm (Centers for Disease Control and Prevention, 2012). By January 2013 VersaPharm announced it would not be producing INH for at least a year, and by February 2013 the remaining two companies began resupplying a limited supply of INH, though production and supplies did not return to capacity for several months (Centers for Disease Control and Prevention, 2013a).

past, the INH shortage signaled a new level of concern for the agency as the first shortage of a first-line tuberculosis medication in the United States (Centers for Disease Control and Prevention, 2013a). Although the INH shortage did not, for the most part, significantly affect clinical operations at the TCP, they were made aware of instances in which it impacted the broader healthcare community in San Diego County and across California. Early on during the shortage, for example, a local children's hospital contacted the TCP for advice when they experienced difficulty obtaining 100 mg tablets of INH for a child who was reacting negatively to the liquid form of the drug. Fulfilling its role as overseer of all tuberculosis care in the county, the TCP was ultimately able to help the hospital find a solution to safely treat this child by offering an alternate treatment recommendation.

In order to track and potentially forestall shortages at the TCP, Dr. Walter addressed the ongoing shortage with her staff on a regular basis, adding it to her agenda for more than one of her periodic regional meetings with TCP satellite branches that I attended. In one of the meetings several months into the shortage, Dr. Walter stipulated that any staff that had difficulty obtaining *any* medications needed to notify her immediately. Following the CDC guidelines, if the TCP had a problem procuring specific drugs, Dr. Walter would have to seek assistance directly from contacts at the CDC. At that time, there was no central information hub for reporting drug shortages or availabilities. TCP administrators and staff relied on a handcrafted assortment of formal and informal notification mechanisms for information about the shortage, who was impacted, and drug availability timelines. Formal avenues included following the messages about shortages that were delivered through the FDA's electronic notification system. In addition, TCP staff could access a database maintained by the American Society of Health-System Pharmacists and the information available on the Health Alert Network, the CDC's primary delivery system for urgent health announcements. In order to piece together a bigger picture, they also relied on informal networks to acquire knowledge about breakdowns in the system. Among the informal mechanisms, TCP employees followed local and national news coverage, monitored various websites that offered information about current shortages, and initiated phone calls or email inquiries about the programmatic impact of shortages to other tuberculosis administrators at the county and state levels.

Although services were not profoundly hindered in San Diego County, Dr. Walter explained to me that a vast number public health programs across the country experienced various levels of difficulty obtaining INH and began limiting the kinds of preventative services offered in their communities. Her reflections on the situation align with statements issued by the CDC recommending local entities limit their treatment for latent tuberculosis. Issued in early 2013, these unprecedented recommendations counseled local programs to reduce or temporarily halt preventative services to all patients but those who faced the greatest likelihood of developing active tuberculosis disease, such as patients who were immunocompromised or children under the age of five. In their recommendation to postpone treatment for a majority of latent tuberculosis patients, the CDC advised local programs to develop systems for contacting these people again once the INH shortage was resolved (Centers for Disease Control and Prevention & Prevention Health Alert Network, 2013).

The CDC’s proposed emergency workaround added a multilayered burden to already taxed local health systems. First, local departments needed to assume the responsibility of devising such a notification system. They were also responsible for developing additional protocols and staff trainings to address any new medication regimens (Centers for Disease Control and Prevention, 2013a), which represents a considerable additional expense in staffing and time for programs that do not usually have surplus resources to invest. Second, local health programs faced the challenge of reenlisting latent tuberculosis patients who are among the most difficult to recruit for treatment because of the caustic nature of the medications used, long duration of treatment, and lack of noticeable symptoms of infection that are often a primary motivation for patients to seek care. Research also shows that delaying treatment or increasing the number of pills in the case of alternate medication plans ultimately means that a significant portion of patients choose to forgo preventative treatment altogether (Centers for Disease Control and Prevention, 2012). And unlike people with active disease, latent tuberculosis patients cannot be legally compelled by health departments to undergo treatment.

For these reasons, local health department staff reasonably feared that a delay in treatment for patients with latent tuberculosis would further reduce treatment completion rates. Finally, the INH shortage also presented clinicians with ethical dilemmas. In an interview with the Treatment Action Group (TAG), an HIV/AIDS activist organization with a branch dedicated to tuberculosis advocacy, the Deputy Director of Santa Barbara County’s Department of Heath explained that the INH shortage put doctors in the position of deciding who receives a particular medication and who does not (McKenna, 2013), a precarious position for any physician, not least those working for public health agencies under the framework of government, as is the case with local tuberculosis programs.

Given the centrality of mediations like INH in the DOTS strategy, one might ask how protracted shortages arise in the first place. The answer is multilayered, linked to a culture of the global pharmaceutical industry and minimal motivation for investing in low-return drugs like tuberculosis antibiotics. In the case of the INH shortage, the three drug suppliers of INH in the United States in 2012 – Teva, West-Ward (VersaPharm), and Sandoz – reported difficulties obtaining the active ingredient (Centers for Disease Control and Prevention, 2012; Centers for Disease Control and Prevention, 2013a; Lessem, 2014). In addition, the CDC pointed to a failure by the drug companies to hold to the 2011 presidential executive order that requires drug manufacturers to provide advance notice of manufacturing interruptions for drugs that are sustain life or prevent incapacitating disease, for which tuberculosis medications qualify (Centers for Disease Control and Prevention, 2013a). The purpose of such a warning system is to provide enough notice to local and state programs that they might have adequate time to consider how to modify services in advance of a crisis. However, existing circumstances offer little incentive for companies to comply with the presidential order or the 2012 FDA Safety and Innovation Act, which also stipulate the reporting of shortages. Manufacturers who fail to abide by these regulations simply receive a noncompliance letter, which is also made available to the public, but they bear no monetary fine or restriction on their operations (McKenna, 2013).

In January 2014, the National Tuberculosis Controllers Association, TAG, and PATH, a Seattle-based nonprofit global health organization, convened a working group to address the growing problem of drug shortages in the United States. With representation by members of prominent tuberculosis policy and advocacy organizations such as the CDC, FDA, and Infectious Diseases Society of America among many, the working group outlined five steps to begin implementing systemic change. A top priority was the creation of a national reserve as a short-term solution to drug shortages that could help channel needed medications to locations with shortages and no alternatives.[57] The working group also proposed that the United States centralize tuberculosis medication acquisition, distribution, and communication, which would create "pooled" demand, thus incentivizing drug manufacturers. It would also allow for a more accurate assessment of current levels of stock. Important long-term recommendations included broadening the number of suppliers in the United States by offering production incentives; encouraging United States drug manufacturers to supply to the Global Drug Facility as a way to increase their market share (an indirect incentive to continue production); and to improve communications about shortages by developing a centralized information system and database (Lessem, Wegener & Farrow, 2014).

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[57] It is important to note that any stockpiling practices must be carried out with exacting inventory and communication practices to prevent an artificial storage, which is defined as poor distribution of a medication or a reduced availability to purchase supplies when institutions or other entities purchase more than they need (Griffith et al., 2012).

Shrinking Budgets

Research and Development Divestment

The INH shortage and others like it highlight flaws in tuberculosis control infrastructure that are linked to a broad divestment in tuberculosis research and development and shrinking public health budgets. Across-the-board pullbacks in funding for tuberculosis research and development by private and public organizations have impacted the ability to maintain adaptive and strong public health systems, including the ways local systems function. Tuberculosis research is highly dependent upon a small number of donors, the majority of which are public or philanthropic organizations. The National Institute of Allergy and Infectious Diseases and the Bill and Melinda Gates Foundation, for example, were the two largest donors in 2013, contributing 45 percent of all money dedicated to tuberculosis research (Daniels, 2014). Current global research and development priorities mean that less than ten percent of medical research resources are concentrated on diseases that account for ninety percent of the global burden of illness, including tuberculosis, with disease burden assessed by bioethicists and epidemiologists as the combined measurement of a diverse number of factors related to how diseases impact individuals and communities —e.g., incidence, rate of mortality, impact on life expectancy, public health impacts, and economic impacts among others (Resnik, 2004, p. 43).

In the United States, private and public spending on tuberculosis research and development has stagnated in recent years (Daniels, 2014; Frick, 2014). In conjunction with the global pullback of tuberculosis research and development, recent cuts in the United States have had a double impact on domestic research and development initiatives.[58] While public sector and philanthropic funds comprise the bulk of funds spent on research, private sector cuts have also been drastic and wide-reaching in the last several years (Daniels, 2014) following five consecutive years of funding increases that were insufficient to mitigate growing needs and including climbing costs of research (Frick & Jimenez-Levi, 2013). Some companies reduced their financial commitment, while others retracted funding for research and development altogether. The withdrawal from the private sector adds pressure to increasingly austere public programming (Frick & Jimenez-Levi, 2013).

While popular media and public health communication almost exclusively frame failed patient compliance as the root of the drug resistance problem in the current pandemic, the role of failed pharmaceutical production, distribution, and research responses is underemphasized. This is due in part to the eclipsing of preventative tuberculosis strategies within a public health framework that favors cost-effective curative treatments based on existing pharmaceuticals. A key issue that undermines efforts to control tuberculosis within a largely privatized medical economy is that the vast majority of tuberculosis disease exists within communities that are impoverished, providing little financial motivation for continued investment by the global

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[58] Between 2009 and 2012, funds allocated to tuberculosis research at the National Institutes of Health (NIH) averaged as constant over time, while the cost of research rose 7.4% in the same time period. In 2013, cuts related to sequestration reduced NIH's budget overall, and appropriations in 2014 reduced NIH's budget is even further. Both subsequently impacted the amount of money allocated to tuberculosis.

The sequestration in 2013 also had a negative impact on the CDC's budget, including limiting funding to the crucial TB Epidemiologic Studies Consortium, which has been vital to developing shorter treatment regimes for tuberculosis patients. The United States Agency for International Development experienced brief gains in 2009 and 2010, while spending for tuberculosis remained steady in 2011. However, tuberculosis spending was significantly cut in 2012 (Frick, 2014).

pharmaceutical industry.[59], No doubt, this orientation is linked to a privatized biomedical research agenda incentivized by the profit potentials of developing drugs for health problems perceived as politically and publically important to wealthy communities. Investment is increasingly urgent since the proliferation of tuberculosis strains with drug resistance is rendering current medications less effective overall.

Within the discourses that support this policy agenda, the emergence of drug resistance is framed as crisis rather than a normal development that needs to be managed and addressed through continued research. But treating drug resistance as an acute crisis does not require policymakers or drug developers to adopt a long-term perspective that sees the responsiveness of the tuberculosis bacillus as a part of its inherent makeup. Instead, it foregrounds short-term needs, which often places the responsibility of drug resistance on the individual and justifies continued slashing of budgets since the value of the funds is not as easily seen. As such, this policy emphasis contributes to structuring the ideological orientation of medical professionals and public health policymakers that characterize ill patients as irrational actors who must be compelled into compliance, while ensuring protections for the freedoms of private enterprise and a commercialized medical landscape.

It is true that the failure of patients to complete treatment can contribute in important ways to the problem of drug resistance. However, the continual degradation of the effectiveness of medications is virtually as inevitable as the pathogens that cause

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[59] See, for example, Blanc and Nunn's report (2000) on the incentives and disincentives influencing the development of new tuberculosis drugs. See also Resnik (2004) who argues that neither pharmaceutical companies nor governmental agencies that support biomedical research are highly motivated to fund projects that most significantly impact developing nations. In the United States, public pressure incentivizes research on cancer, heart disease, diabetes, and obesity, among others (p. 48).

tuberculosis to mutate over time. As such, effectively confronting the pandemic necessitates that the development of varied and complex treatments become a core agenda of pharmaceutical research and of the public and private institutions that fund biomedical research.[60] Although still significantly limited, renewed attention to developing new tuberculosis medication in the last decade and a half has yielded some important potential options currently undergoing rigorous and time-consuming clinical trials and submission to regulatory agencies.[61] More recently, however, the overall

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[60] Although the first drug found to kill tuberculosis bacteria was discovered in 1943, tuberculosis medications are still not very advanced. Research over the last 40 years has produced very few new drugs to treat tuberculosis, which is far behind the gains of other pharmaceutical developments. Instead, most research has tended to focus on developing combination drug regimes to combat drug resistance and finding ways to shorten treatment time for drug resistant tuberculosis because the medications involved are potentially toxic to the body (Zumla, Nahid & Cole, 2013). The hope has been that shortened treatment plans would increase the number of people who start and complete their medication regimens (Lienhardt, Ogden, & Sow, 2003).

[61] In March 2012, a new tuberculosis medication named Delamanid showed some initial success in clinical trials with multidrug-resistant tuberculosis (Gler et al., 2012). This development is of enormous importance to patients with multidrug-resistant tuberculosis, but Phase III clinical trials will not be completed until 2016 (Fokazi, 2014). In November 2013, under pressure from international tuberculosis advocacy organizations, the European Medicines Agency’s Committee for Medicinal Products for Human Use responded to the increasing unmet need for treatment options for multidrug-resistant tuberculosis and authorized the conditional use of Delamanid in treatment of adults with multidrug-resistant tuberculosis for whom other established treatment regimens do not work (European Medicines Agency, 2013).

As of November 2013, Delamanid was not approved for use in the United States (Lowes, 2013). As recently as March of 2014, however, the same international tuberculosis advocacy organizations that appealed for the conditional authorized use of Delamanid were again advocating its release. This time appeals were made directly to the drug’s developers at Otsuka because advocacy groups thought the company was not responding quickly enough. They argued more could do more to make the medication available on a limited basis. In response to an open letter drafted by tuberculosis advocacy groups urging Otsuka make the drug available through a compassionate use program, Otsuka Managing Director Patrizia Carlevaro cites the establishment of a process for reviewing compassionate-use requests as an example of the company’s compliance with the requests made by advocacy groups. However, TBOnline, a web portal with information for people working to end tuberculosis, reports that as of March 2014, only one patient in Europe had been granted access to Delamanid under their compassionate use program (TBOnline, 2014).

Meanwhile, the FDA granted accelerated approval for a second drug, Bedaquiline, December 2012, based on the findings from phase IIb data, and a number of compounds are undergoing phase II and III trials. Despite this progress, it is still unclear how accessible Bedaquiline will be (Médecins Sans Frontières & International Union Against Tuberculosis and Lung Disease, 2013).

divestment in infectious disease research and development, including the complete withdrawal of three major companies (Pfizer, AstraZeneca, and Novartis) from all antibiotic research and development over the last several years, has threatened to slow or halt recent successes. The lack of new tuberculosis medications and vaccines can be attributed in part to the poor distribution of medical research and development resources for tuberculosis, a devaluation of infectious disease in private research, and a lack of global coordination or collaboration amongst existing efforts. The abandonment of research efforts by drug companies is significant not just for its impact on the production quantity of tuberculosis medications, but because potential discoveries and drug compounds owned by such companies never make it past their early stages of development nor are they shared with the public (Daniels, 2014).

Tuberculosis advocates continue to insist that research and development efforts need more attention and resources, pointing to the human justice implications of eroding funding for a devastating disease that disproportionately impacts the world's most disadvantaged populations. Resnik (2004), in particular, contends that it is the obligation of developed countries like the United States to inaugurate a "trust fund" that consistently sponsors research projects that focus on global health problems. Similarly, TAG has strongly lobbied members of United States Congress to increase multiyear funding for tuberculosis research and development conducted by federal agencies in its contention that research and development is a vital though undervalued component for tuberculosis control (Frick, 2014).

At a local level, San Diego-based public health consultant and tuberculosis advocate Mario Vega is passionate about easing the burdens associated with being diagnosed with and treated for tuberculosis. A former TCP employee, Vega links research and development shortfalls to a broader invisibility and lack of political will with regard to tuberculosis. Over the course of several interviews and email correspondences, Vega explained his feeling that tuberculosis control will never succeed unless the system as a whole shifts perspective away from the prevailing monolithic biomedical perspective and embrace a philosophy that incorporates a meaningful way to account for the psychosocial implications of being diagnosed with tuberculosis, including the needs of patients being treated for active disease or latent infection during treatment and after their treatment concludes.

For Vega, this paradigm shift would dislodge the dominant perspective that treats tuberculosis as a public health threat by shifting the focus to a human-centered approach that treats tuberculosis as a social justice issue. Vega argued that a major part of a biosocial solution to tuberculosis care must involve a renewed commitment to research in order to develop new medical tools, particularly newer, shorter, and less caustic treatments that would allow people to return to their ‘normal’ lives more quickly or become less derailed by painful or damaging medications. The other component of Vega’s vision for the future of tuberculosis care is the important job of recruiting the people who are most often beyond the reach of traditional public health frameworks, including undocumented residents, the homeless, or people with serious mental health issues. For this component, Vega argues that a renewed commitment to research and development would provide an indirect litmus that displays the political and financial commitment by governments and private organizations that is necessary to build strong and responsive public health systems that engage in more direct forms of community outreach.

Elizabeth Turner, also a former TCP employee who now sits on tuberculosis advocacy and oversight committees, spent her entire 40-year career working in public health tuberculosis control. Over the course of two formal interviews, Turner expressed to me her worry that the situation has been "getting worse," not just because drug shortages have been occurring more frequently but also because drug prices have steadily increased during a time while public health budgets continue to decline. Adding to the urgency of the situation is her sense that that there is little public awareness, paltry and diminishing funding for research, and general complacency on the part of public policymakers about to the needs of tuberculosis control programs nationwide, particularly in regions with concentrated disease burden like San Diego County. Like Vega's assessment that research and development dollars are integral to the success of tuberculosis control efforts, Turner's comments point to the ways that a shortage of public and private support for research and development initiatives inadequately contributes to the current, integrated system in which tuberculosis control itself cannot function without the wellbeing of each of its contributing elements. For Turner, the essential components are assuring a consistent and affordable drug supply, maintaining adequate research and development funding, and increasing budgets for tuberculosis control programs.

While Vega and Turner offer different impressions of the role that decreased research and development budgets have played in tuberculosis control in the United States, this particular issue seemed largely divorced from the worries expressed to me by TCP staff, who tended to focus almost exclusively on the negative impact of local budget shortfalls and to a lesser extent on the need for new drugs. Concerns over local budgets or access to medications were not typically articulated in relation to an awareness of broad divestments by government agencies and private corporations, as Vega and Turner described. Rather, TCP staff often characterized budget and medication concerns as shortcomings in the system at local, state, and federal levels or framed them as the result of decisions made by single actors rather than indicative of limitations in an interrelated web of factors that impacted global public health policy along with local programming. In this sense, although felt, research and development shortfalls went largely unnoticed by employees at the TCP.[62]

Diminishing Budgets for Tuberculosis Control Programs

Linked to global and national funding cutbacks that impact research and development have been wide sweeping budget shortfalls for local tuberculosis control programs in the United States. There are about 2,800 local health departments in the United States that serve diverse populations and needs. Some local health departments serve single cities, while others serve multiple counties. However, most are similar in structure to the TCP, operating as county-based local health jurisdictions. Public health programs are funded through a combination of federal, state and local dollars. While the

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[62] One speculation I have, which I would like to pursue in the future, is that the TCP staff members who are responsible for the day-to-day treatment of tuberculosis have a deeply felt sense of responsibility for specific patients and for their community. They also seem to have a sense of urgency about their own responsibility to provide effective tuberculosis treatment and control in San Diego. This is necessarily a more short-term view that causes them to look for immediate solutions. It would be difficult to take the more reflective, longer-term systemic view that Vega and Turner have.

majority of that funding comes from the state and local levels, federal funding remains a key source of revenue for maintaining public health programming.[63] Because public health funding is considered discretionary in most states, it is at a higher risk for cutbacks during times of economic downturn, even while remaining vital to maintaining local public health infrastructure and basic services (Levi, Segal, Laurent & Lang, 2013, p. 15). Although San Diego Public Health Services has seen modest gains of about $4.3 million since fiscal year 2011-2012 (County of San Diego Health and Human Services Agency, n.d.), these increases have not been enough to offset population growth, inflation, and cuts in other parts of the budget. One effect of budget shortfalls is that the median number of public health employees has decreased since 2010 (National Association of County and City Health Officials, 2014).

The erosion of resources further strains already taxed public health infrastructures and has clear implications for population health and disease control in the future. For example, even as newer treatments are discovered, limited resources have prevented them from becoming widely implemented. The CDC has approved a new treatment protocol for latent tuberculosis infection that dramatically reduces the

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[63] In fiscal year 2012, California received $684,468,876 in public health federal funding from the CDC. Putting this figure in perspective, although California received the largest allocated set of funds in comparison to other states in 2012, the state ranked 37th in per capita spending. California's per capita spending is $17.99, while the national average of per capita funding was $19.54 (Levi et al.,, Segal, Laurent & Lang, 2013, p. 8). In 2013, CDC funds remained steady at $17.99 in per capita spending, but by 2014 funding fell to $673,891,027 or $17.58 per person.

There is a similar pattern in public health federal funds allocated to California by the Health Resources and Services Administration (HRSA). In fiscal year 2012, California received $874,584,956 of public health funding from HRSA. California received the single largest allocation, but ranked below the average allocation of $23.18 per person. Though HRSA funding allocations for California remained steady in 2013, funding dropped to $763,247,514 in 2014, which meant a drop to $19.91 in per capita funding (Trust for America's Health, 2014).

amount of time a patient has to take medication —dropping from nine months to a 12-week treatment course. Dr. Scott, one of the TCP's two part-time physicians, is adamant that the clinic should make this option for treatment a priority. She explains, "It would be a really good bang for your buck, and I think you're going to get more people to take it. I think 9-months of self-administered medication is really tough for most people." The limiting factor for cash-strapped local tuberculosis programs is that the CDC stipulates the direct observation of patients with this shortened option. Like many programs across the United States, the TCP does not have adequate funding to hire the additional staff necessary to make home or work-based direct observation possible. In lieu of home visits, the clinic has offered to provide direct observation on-site at their main clinic in San Diego. However, Dr. Scott contends that this 'solution' has proven to be a significant disincentive for patients because it requires them to travel once a week to the central clinic, which may be less accessible than one of the satellite branches and consistently has long wait lines before being seen, even with an appointment, because of understaffing. Consequently, most patients who have been presented with this option have elected the longer treatment duration.[64]

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[64] Another development aimed at alleviating some of the burden of resource-intense, home-based direct observation is video directly observed therapy (VDOT), which is currently being piloted in certain regions across the United States, including San Diego County –see, for example: Collins, et al. (2013); Garfein et al. (2012); Krueger et al. (2010); Mirsaeidi, Hashmi, and Schraufnagel (2014); and Mirsaeidi et al. (2015).

For VDOT, care providers observe patients taking their medications remotely via video that is observed in real-time or recorded on a smart phone, cell phone, or tablet for later viewing. The goal is to eliminate the need for healthcare workers to visit a patient's home or place of employment or the requirement for a patient to travel to their regional tuberculosis branch.

Initial findings from pilot sites suggest that VDOT helps to increase treatment completion rates for most patients, while decreasing the amount of resources necessary to treat people. With clear benefits, VDOT is a promising new treatment technology to help supplement the delivery of directly observed therapy.

Current budget cuts follow historically repeated patterns in which funding for tuberculosis is reduced in response to national, regional or global assessments of reduced threat of disease. With weaker programs, tuberculosis makes a comeback, and tuberculosis programs become a priority once more. This cycle is a shared challenge for public health programs in countries with lower rates of tuberculosis, in that the small disease burden often leads to relative anonymity. Dr. Walter suggests that the diminishing allocation of resources at the TCP is reflective of a national trend and stemming largely from the fact that, in her assessment, tuberculosis is "not a very compelling story to tell." She contends that public and political awareness is waning largely because the number of active cases in the United States have dropped dramatically in the last decade and the people now most affected by the disease are "foreign born". If this is the case, it demonstrates an important way in which national policy and public perceptions impact local agencies even when the conditions they are addressing are quite distinct from national norms. In the United States, less visibility for tuberculosis has meant that tuberculosis administrators, advocates, and care providers have had to work hard to counter diminishing political commitment to local tuberculosis programming, ebbing public awareness, and ultimately unsatisfactory public health response to the needs of communities (Lönnroth et al., 2015).

In our discussions about the key challenges facing local public health departments, nearly all TCP employees were emphatic that local tuberculosis programs

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However, research suggests that VDOT may not be appropriate for all patients (Garfein et al., 2012), and my observations at the TCP suggest that in some cases, patients miss out on welcomed face-to-face interactions with care providers (see the discussion of the Cruz family in the previous chapter) or the informal opportunities for advocacy that can occur as a result of a home visit that allows for a richer relationship between home care providers and patients (see concluding remarks in this chapter).

need more money. Dr. Walter’s clear recognition of cyclic nature of the problem was reflected in her assessment that TCP’s programs are “falling apart again,” leaving the communities at risk for increased prevalence. Part of the problem, she explains, is that private doctors and community-based organizations have not been focusing enough attention on tuberculosis. Given current budget constraints, she does not have the resources for the relationship-building and sustained community education efforts necessary to make tuberculosis control, particularly preventative treatment, a top priority. Dr. Walter suggests that because tuberculosis prevention was not selected as one of the high-priority public health preventative services for the Patient Protection and Affordable Care Act (ACA), which expanded health insurance coverage when it was signed into law in March 2010 and mandated coverage by January 2014, the TCP is having trouble motivating community-based nonprofit and private health programming to focus on it. Without the financial incentive, she argues that such health organizations and care providers are necessarily focusing their primary efforts on other issues, in part for their own economic health.

While budgetary constraints impact treatment related services, they also influence a range of indirect services and programing related to community outreach, education, and collaboration. At the TCP, budget shortfalls have led to reductions in staffing. For example, the TCP has been without a Community Health Educator for several years. In the past, the person in this position developed and implemented strategies and programing to help promote tuberculosis awareness and acted as a liaison between individuals, communities, and institutions. At the TCP, community education and outreach is one of the most difficult components of tuberculosis care to fund. As budgets are cut, money must first be directed to essential elements of treatment.

Dr. Walter describes the TCP's current outreach tactics as "reactive", focusing primarily on basic outreach to the key community agencies that are engaged in disciplinary and regimenting practices (the sheriff's office, jails, or drug treatment centers) or responding to occasional invitations by groups for presentations (private care providers, for example). But there is a lot more they would like to be able to do. For example, Dr. Walter noted that it is vital for tuberculosis to be included in local high school health curriculums. The TCP was in the process of developing a tuberculosis unit and piloting it in a local high school until the CDC defunded the initiative. Other TCP employees described the importance of better integrating tuberculosis education into existing HIV education programs, building a more informative and interactive website for the TCP that could serve as a portal for information for the community, developing radio or television campaigns for more effective outreach, and helping community care providers incorporate tuberculosis awareness and screening into their regular practices.

Because the population that needs to be tested is very large and distributed across wide geographical distances, Dr. Walter argues that it is vital to help private care providers and community-based health organizations better understand the particularities of tuberculosis in the region, including helping them develop proactive preventative services for patents with latent tuberculosis infection, residents who are highly mobile, undocumented immigrants, and seasonal migrant workers and their families. While she and other key administrators at the TCP feel stymied amidst tightening budgets, they remain hopeful that more precise diagnostic tools and easier treatment regimes would provide the incentive for local health providers and organizations to keep tuberculosis in the forefront of their agendas before latent infection turns into active disease. In particular, Dr. Walter pinpoints a lack of funding support and awareness at the federal level as a hindrance to such goals, always cautious to explain that it will be impossible to fulfill her vision for the TCP in the context of a steady decline in funding across public health programming.

Moments of Formal and Informal Response to Local Context

Even considering the limitations of the current tuberculosis control system, my fieldwork allowed me to glimpse moments when TCP employees were able to intervene beyond the directives of treatment and surveillance alone. The formal and informal vehicles for intervention all emanated from a desire by the employees to address needs specific to the local community and patients they worked with. Notable among the formal interventions at the TCP is the CureTB Referral program, which was established in 1997 as a way to improve continuity of care by following up with patients who were moving between San Diego and Tijuana. In an interview, a CureTB worker explained to me that since its earliest days the grant and state funded program has expanded to include continuity of care referrals for people with active, latent, and suspected tuberculosis, contact investigation notifications, and clinical history information investigations for tuberculosis patients and contacts who travel between the United States, Mexico, and Central America. Certainly embodying a surveillance function, the program has been valuable to the TCP and broader community beyond surveillance alone by making it easier for patients to travel between or move across the border. This in turn has generated positive outcomes for the TCP because less people have stopped their treatment and more families are notified if they have potentially been exposed to active tuberculosis.

Informal interventions were various, most often taking the form of advocacy work that extended beyond the scope of tuberculosis-specific care. On several occasions I observed nurses and caseworkers performing this kind of informal advocacy work. On the way to a site visit one afternoon, the Public Health Nurse (PHN) I was accompanying explained her perspective to me. “I *have* to be involved in peoples’ lives. They don’t really have a choice, but usually people are really welcoming. So I try my best to be helpful to them.” Once at the site, I saw her philosophy in action. After reviewing her patient’s tuberculosis-related treatment, she followed up about some seemingly unrelated symptoms that he had been experiencing. Upon hearing that he had recently traveled nearly one and a half hours to see a specialist on the other side of the county who accepted his state-subsidized insurance, the PHN stopped her note taking to help him verify his level of coverage and find a provider closer to home who filled these requirements. Less than a day later, she was able to find a solution that helped the patient receive quality care closer to home, which was also a relief to his son who had previously been missing work to drive his father to his appointments.

On another occasion, a nurse counseled a patient about what he could expect procedurally before and after a non-tuberculosis-related surgery he had scheduled the following week. She also advised him on specific post-surgery questions to ask and warned him that if certain follow-up procedures were not performed that he was well within his rights to demand them from his doctors. Later on she shared her perspective with me that “Once you get your patients started on their treatment plan, tuberculosis is usually a really small part of what you’re doing with your patients”. From her perspective, advocacy was a “no brainer”.

Although they often existed beyond my ability to document because of their often unspoken or spontaneous character, informal interventions were important to the identity of TCP employees and to their sense that the work they did was meaningful or fulfilling. Informal interventions represent an important, though informal, way knowledge is transferred at the TCP in that learning more about the lives of patients also helped inform how doctors, nurses, and administrators approach coordination of their care. They also often indirectly improved the ability of TCP employees to do their formal job by helping patients create home and health environments that made their tuberculosis treatment more effective.

Budget shortfalls for local tuberculosis programs, decreasing research and development budgets, and the related dearth of new tuberculosis drugs and vaccines play an important and intersecting role in limiting the capacity of local departments to fulfill the mission of DOTS. These issues signal a disconnect between the stated goals for local health departments and the mechanisms that facilitate meeting such goals. A commitment by governments to adequately and consistently fund local public health programs is crucial to long-term success. In addition, it is also essential that resources for tuberculosis research and development be expanded and that system-level controls are established that help ensure a quality drug supply is consistently available. Even if existing pharmacological research and development agendas for tuberculosis control can be critiqued as overly circumscribed by biomedical agendas (eclipsing social, economic and cultural solutions/resources), current withdrawals from such research are significant because they undermine a system that is designed to support biomedical solutions. The problem of budget shortfalls for local tuberculosis programs and of large-scale divestment of research and development efforts each point to a lack of incentive in the profit-driven pharmaceutical industry and a lack of commitment by wealthy governments to continue investing in expensive research projects for diseases that principally affect the poor and to sustain strong public health systems even in low-endemic regions.

Race and Ethnicity in the Characterization of the Border as a Site of Contagion

Racialized ideology underwrites and converges with the effects of the system-level complications discussed in previous sections–drug shortages, research and development divestment, and budget decreases for tuberculosis programs. Tuberculosis is indicative of a broader and evolving relationship between anti-immigrant rhetoric and medical policy that has helped delineate a line between citizens and immigrants, while at the same time racializing illness and health (Reitmanova & Gustafson, 2012).[65] At the local level, the San Diego border region is steeped with layers of meaning, nuance, and contestation. Simultaneously as an international "conduit" and "barrier," the boundary between the United States and Mexico functions as a "way of seeing" as

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[65] It is important to note that the category of immigrant is a slippery term that has many meanings. On one hand, the term immigrant refers to the permanent or semi permanent movement of a body across a national border. But not all bodies that cross borders are immigrants, nor are they treated to the same, intensive screening process. In addition, though not always easily separable from the first. King (2003) explains, "in the social and political arenas, 'immigrant' is often used less as a description of the contingent movement of bodies through physical space, and more as a description…for essential racial or ethnic characteristics" (p. 47).

much as it does a material entity for control by helping to shape popular perceptions and metaphors about the region (Nevins, 2002, p. 5-8). Part of this optic is the long history of the association of disease and contagion with racially and ethnically delineated populations, which is intensified in discourses and practices of immigration, naturalization and public health.

At least since the turn of the 20th century, the characterization of tuberculosis in the Southern California/Mexico border region has exemplified the complex ways in which illness and sociopolitical identities are mutually constructed. Dualistic conceptions of the disease in relation to distinct demographics within the region emerged from Southern California's reputation at the turn of the 20th century as a destination for healing for wealthy tuberculosis patients who could afford expensive, resort-like accommodations (Abel, 2007; Miller, 1982) as well as from anxieties around immigration that are evident in health campaigns during the 1930s, for example, that began focusing on Mexicans in particular as more susceptible to tuberculosis. These campaigns ultimately established a targeted push to deport even authorized migrants and immigrants (Molina, 2006b; Nevins, 2010).

Not only unique to Southern California or to tuberculosis, the imaginary threat of outsiders against an idealized national body politic has been a familiar preoccupation across domains of literature, news, politics and medicine alike since the formation of the modern state.[66] Thinking through the forms that this preoccupation has taken can

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[66] For work on tuberculosis specifically, see Abel's (2007) account of the politics and social responses to tuberculosis in California. Other tuberculosis-related scholarship includes Reitmanova and Gustafson's (2012) analysis of racializing and medicalizing discourses of tuberculosis related to Canadian immigrants,

help clarify the nature and extent of the ways they are embedded into the Southern California landscape in unique ways. In particular, narratives of public health have tended to recapitulate explanations of disease transmission on a bodily level just as the ascendency of germ theory focused public health efforts on exterminating invaders of the body. At the end of the 19th century, nativist intellectuals warned of an 'invasion' of the nation-state by immigrant disease breeders, using this rhetoric to influence immigration reform (Ott, 1996, p. 67) even while immigrant bodies were often exploited in the labor market (Molina, 2006a).[67]

The United States Immigration Act of 1891 marked a clear political formalization of the reciprocal relationship between medicine and a xenophobic nativist ideology. Paralleling the ascendancy of bacteriology as the primary science structuring medical practice, the Immigration Act of 1891 established a legal difference between the able bodied and the 'other' with a striking racial component by outlining groups of people who were legally restricted from entering the United States, including immigrants who were poor, mentally ill, carriers of disease, or from particular countries

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and Ott's (1996) history of tuberculosis in American culture, including a detailed look at the racializing of the disease during the turn of the 20th century.

For research that extends beyond the frame of tuberculosis alone, see Kraut (1994), Markel (2004), Markel and Stern (2002), Nevins (2010), and the edited volume by Bashford (2007), among many examples.

[67] Groups in the United States who were targeted by authorities and public health entities during this time included former slaves, Jews, Italians, Chinese, and Mexicans (Rosenkrantz, 1972). Many of these groups were categorized as 'new' immigrants and distinguished from 'old' immigrants who predominantly came from Western Europe and were considered less worrisome by public opinion and policymakers because they were often more educated, less prone to disease (justified through racist scientific findings), and easier to assimilate than their 'new' counterparts (Markel and Stern, 2002). Also under scrutiny were the nation's poor, who were believed to be at higher risk for the disease not just because the lived and worked in crowded, poorly ventilated spaces, but because they were thought to have failed to comply with public health recommendations out of ignorance or maliciousness. Public health officials and politicians also worried about the economic burden that low-income patients posed to the state (Abel, 2007).

(Markel and Stern, 2002).[68] With the recognition of tuberculosis as a contagious disease, it was added to the list of conditions that could be used to prohibit entry into the United States in 1913 (Roberts & Scheper-Hughes, 2011).[69]

Tuberculosis research and practice at the turn of the 20th century exemplified the links between national isolationist policy and scientific research. In particular, there was a tension between the newly dominant scientific theory of infection, which gained prominence with the 1882 discovery that mycobacterium caused tuberculosis, and the

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[68] The turn to primarily microbiological explanations of disease and the broad scientific embrace of bacteriology in the late 19th and early 20th centuries meant that for the first time, authorities and public health entities presumed to be able to control disease through direct intervention thanks to newly visible germs (Markel & Stern, 2002). Classificatory efforts such as the collection and mapping of vital statistics became important political, legal, and social mechanisms that helped establish normed understandings of the body, the individual and the nation by helping to invent standards that marked the deviant and diseased as entities that were distinct from the normal and healthy. With the establishment of measurable criterion that marked abnormality was an embrace of the *norm*, which replaced its previous counterpart, the *ideal* (Davis, 1997, p. 13). While ideal implies a kind of unattainable exclusivity to which people can only aspire, the concept of a norm implies that the majority of the population is, or at least ought to be, included within its boundaries. In constructs of normalcy, however, the boundaries produce the center.

But the appearance of inclusivity is the very key to their disciplinary power (Davis, 1997). Garland-Thomson (2007) goes as far as to argue that the concept of normalcy is *the* defining principle that defines value and shapes human behavior and experience in late modernity (p. 114). Linked to notions of progress, the idea of the averaged or normal person is rooted in a drive towards efficiency on the part of modern institutions by means of statistical enumeration that renders populations generalizable. This allows institutions to make cost/benefit analyses such that they can manage large populations without having to micromanage deviations.

[69] As our understanding of microbiology expanded, so too did a preoccupation with how people and germs travel internationally. In their study of the emergence of modern classification systems, *Sorting Things Out*, Bowker and Star (2000) suggest that individuals began to associate relationally with the previously invisible microbes and bacteria that had not before been conceptually visible. They argue that new languages and practices of self emerged in relation to new health information, and with them, a series of classification systems that linked science and commerce took shape across the domains of business, science and medicine, education, and government.

The enduring power of such systems was the appearance of inevitability as standards of common sense or ‘natural’ ways of life. This information and classification upsurge also included the development of international information-sharing practices in relation to medical knowledge and public health practice. International information-sharing procedures were responding to the increasing mobility of people and things and to the developing scientific knowledge that helped humans better understand microbes and bacteria. Efforts to control international passengers by quarantining ships traveling thorough particular areas, for example, represent an early application of such medically oriented classification practices that is still a part of international bureaucracy today (Bowker & Star, 2000, p. 18).

physicians and researchers who remained skeptical of germ theory (Ott, 1996; Wilson, 2006). In a reactionary push against bacteriology, some researchers again took up the theory of heredity that was popular before the discovery of *m. tuberculosis*, embracing a eugenics framework that established classificatory systems that sorted types of people according to hierarchies of health, ability, or intellect. Following a revival of Gregor Mendel's mid-19th century work on genetic inheritance, eugenicists worked to shift the predominant understanding of tuberculosis away from contagion alone. They hoped to focus instead on heredity as the defining trait of tuberculosis (Wilson, 2006) to which they postulated that even if a mycobacterium caused tuberculosis, heredity played a larger role in the ease of transmission and the severity of the progression of the disease vis-à-vis inherited resistances or susceptibilities to tuberculosis (Pernick, 1997). The theory of indirect heredity was promoted through extensive eugenically framed research that culled statistical comparisons from pedigree and family history charts.

Central to the project of linking tuberculosis with biological inheritance was Albert Govaerts, whose work on the genetic factors related to tuberculosis susceptibility focused primarily on racial and ethnic differences. Govaerts argued that certain races more easily acquired tuberculosis of a more fatal type, while others were less susceptible to infection altogether, even when living in underprivileged circumstances. Alternately, he argued that this immunity disappeared when marrying a person of another racial or ethnic background (Wilson, 2006). Like other eugenics-based research, Govaerts' efforts yielded material realities in the form of political and social control over groups of people deemed inferior, unfit, or disabled. In the case of tuberculosis, questions regarding a person's suitability for marriage and procreation were at the forefront. Govaerts, for example, opposed the marriage of two people with tuberculosis, while others advocated measures as extreme as forced sterilization for tuberculosis carriers (Wilson, 2006, p. 30-31). Importantly, the prominence given to heredity by eugenicists helped fortify the category of race as an important medical distinction in tuberculosis control and treatment (Pernick, 1997).

The classificatory schemas that predominate in a given time or place are closely allied with the financial, institutional, and ethical orientations of their authors. Although the science supporting the eugenics movement has been discredited as speculative and unethical, the production of difference through essentialist racial classifications has outlasted the eugenic research of the early 20th century. As in the past, essentialist explanations of disease still pervade our national consciousness and are commonly expressed in the media, reflected in public health policy, and enacted in everyday clinic speech in relation to origin narratives where groups of people or geographic locations are identified as being the source of disease.[70]

Locally, San Diego County's geographic proximity to the United States/Mexico border and its status as the home of one of the largest refugee resettlement programs in

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[70] For example, in 2014 conservative news media, notably Fox News, latched onto reports that more children than ever were crossing into the United States to escape violence in Central America. Using fear as their central trope, conservative news outlets began referring to this immigration increase as a health crisis, claiming that Americans were at high risk of catching tuberculosis and other diseases that the young immigrants were importing.

Despite counter reports presenting clear evidence that the assertions by conservative news outlets were exaggerated (see Pearson, 2014 [July 10]), reports by conservative media disputed Department of Health and Human Services assessments that the children were by and large healthy and that appropriate measures were being taken for those who were not. Instead, they claimed that that the Department was willfully hiding the 'real' conditions that tuberculosis was spreading quickly and drug resistant cases may have been found. The common theme across such reports was the fear-based tone that reporters, radio hosts, and news announcers took in relation to these young people (for example, see Starnes, 2014 [July 7]).

the United States augment associations between foreigners and disease.[71] Fueling public health, media, and popular discourses of race, ethnicity or immigration status is that half of all tuberculosis instances in the United States occur in just four states where immigration is higher than the national average: California, Texas, New York and Florida (Scott, Kirking, Jeffries, Price & Pratt, 2015). Further, epidemiological research that pairs tuberculosis incidence with country of origin often cites immigration as a major cause in the presence of active tuberculosis disease in low-incidence countries like the United States, although this research can be misleading or incomplete.[72]

In the context of diagnosis and treatment at the TCP, a tension regularly appears between the task of addressing disparities related to national origin and racial or ethnic

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[71] Although public health researchers, policymakers, and epidemiologists often discuss San Diego in relation to its closest neighbor, Mexico, the immigrant and refugee population in San Diego is increasingly diverse. TCP staff explained that predominant new groups at the time of research included refugees from Iraq and Afghanistan. In addition, more Haitians had been arriving as asylum seekers, rather than traveling to Florida, which had historically been their principal port of entry.

[72] As the core discipline of public health, epidemiology is most concerned with the ways ‘agents’, ‘hosts’, and ‘environments’ interact (Hurtig, Porter, and Ogden, 1999, p. 554) in order to assess which population groups may be at risk for certain health issues and better inform health planning, programming and evaluation (Vaughan & Morrow, 1989). From the standpoint of epidemiology, then, categories weigh a patient’s risk of exposure against a projected susceptibility or resistance to disease thereby creating associations between specific categories and specific diseases. The classic examples are old age, which is associated with increased risk of heart disease, and cigarette use, which is associated with lung cancer (Reitmanova, 2009). Race and national origin are two often-cited epidemiological categories —along with other categories such as age, gender or socioeconomic status— that are used as indicators of risk or protective factors related to illness and health.

Although social scientists have argued that race and ethnicity are social rather than biological constructions and therefore inappropriate when employed as epidemiological variables, finding links between race, ethnicity or country of origin and specific health problems remains an enduring medical practice (Reitmanova, 2009). While this linkage can have positive outcomes by raising institutional awareness for issues that do not typically receive enough attention or funds for organizations and causes in need, this practice is also problematic because of the tendency to flatten or outright ignore factors other than a person’s race or ethnicity that might be more important to understanding their relationship to disease. Further, it cannot account for the range of intersecting social, economic, or political factors that help explain why there might be a higher prevalence associated with people of particular racial or ethnic backgrounds.

difference, while at the same time trying to employ practices that are just and unbiased. The TCP’s status as a government entity has particular implications for its mandated negotiation between these two agendas. As Dr. Walter explained in a formal interview, tuberculosis control is never separable from the framework of government and can never be framed in the same ways as traditional private or non-profit health work. As a result, tuberculosis control administrators have been nervous about what their message should be in regards to the relationship between disease and racial or national background, particularly from the standpoint of community and patient education and outreach. For example, Dr. Walter must regularly contend with queries from journalists who have internalized the focus on race and ethnicity as an explanatory discourse for the transmission of tuberculosis disease, and the first question they pose to her often centers on the nationality of a patient who has been reported as having active tuberculosis.

While immigrants and racial minorities may indeed constitute one of the largest demographics infected with tuberculosis, this does not necessarily mean that they transport active disease from their country of origin (King, 2003). When evoked in public health discussions about tuberculosis control, an emphasis on national borders and the people who traverse them often involves a subtle racializing of the disease itself by fortifying the association of the foreign “other” as contagious or as a likely carrier of disease. However, these discussions fail to interrogate the various forms of mobility or travel outside of immigration and inadequately accounts for social inequalities within its borders that have a significant impact on peoples’ relationships to illness and health.

Efforts at screening immigrants undoubtedly help safeguard against some disease transmission, but focus on immigration as a vector eclipses the equally significant role of localized social, political, and economic factors. Serious engagement with these dimensions of contagion require attention to the ways that difficult, intersections of race, poverty and immigration are inscribed in United States cultural discourse and public policy. A considerable part of problem is the lack of public heath resources and uneven socio-economic conditions within San Diego, which are centrally responsible for the local epidemic but difficult to reflect in traditional epidemiological research. For example, immigrant populations are often least likely to have insurance that might more effectively screen for symptoms of disease activation or access to regular health screens that might assist in passive case finding (Ku & Matani, 2001; Ziol-Guest & Kalil, 2012; Zuckerman, Waidmann & Lawton, 2011). Even with the promise of the ACA, which has increased health coverage for many people in the United States, experts warn that it fails to offer coverage for the people most in need of care, including those who are most likely to develop tuberculosis, such as new immigrants and undocumented residents (Morano, Zelenev, Walton, Bruce, & Altice, 2014).

The discourses that link foreigners to the cause of disease are powerful and can even appear within the training of medical professionals. For example, upon hearing about my project, a recently certified doctor informed me that during a practice test for a general knowledge medical exam in her last year of medical school, for every question that involved a person of Mexican descent, the answer was invariably tuberculosis. While it is important for doctors to be able to define patterns of disease, this practice exam offered a flimsy engagement with epidemiological data and risked labeling people through reductive stereotypes, while flattening the narrative of infection altogether. This raises two seemingly technical questions about tuberculosis infection that are loaded with political implications. If foreign born people living in the United States had latent tuberculosis in their home countries but do not “fall ill” until they come to the United States, (1) why is this the case and (2) how do we define sickness in relation to tuberculosis? That is, does sickness start at the moment of infection or at the moment latent disease becomes active?

In our discussions, Dr. Walter clearly demonstrated an awareness of and personal desire to mitigate the negative impact of the discourses of public health that engage in blanket statements of blame. Her sensitivity to this concern is perhaps representative of the tensions that emerge when local programs must respond to the epidemiological realities particular to their region without being able to do much to change the social and systemic issues to which the must respond. For San Diego, epidemiological reports reveal comparatively higher rates of tuberculosis and a foreign-born population that is disproportionately dealing with disease (Health and Human Services Agency, 2015 [March26]; Macchione, Wooten & Moser, 2014). However, despite Dr. Walter’s efforts to refocus the frames used by local constituents such as the press or private doctors, the TCP is also impacted by and recapitulates some of the dominant discourses that link disease to racial or national identity, often in subtle ways. At other times, foreignness explicitly begins to stand in for disease itself.

In case management meetings, for example, employees who presented the details of a patient’s situation often followed the convention of identifying a person by their name, age, and country of origin or heritage. This practice falls in line with the emphasis on the epidemiological findings for the region that are reproduced at multiple levels of daily practice at the TCP, including through official epidemiological reports for the government and information brochures for the community, clinic speak, and protocols for contact investigations. And yet, despite the hyper focus on race and nationality in the administrative and clinical contexts, the TCP lacks the financial resources necessary to better reach out to the county's diverse constituents in meaningful ways. For example, several years ago the TCP lost its Spanish-speaking Community Health Educator, vital for creating relationships with key community entities such as clinics, schools, religious organizations, or civic groups. The TCP still struggles with the void left with this loss but does not have the funding necessary to fill the position.

Reports and documents published by national and international organizations with branches that focus on tuberculosis such as the WHO or the CDC also perpetuate a less nuanced narrative of the etiology and prevalence of tuberculosis in low-endemic regions.[73] Quite often nationality or racial identity is simply paired with statistics about prevalence in a particular region without additional regional, cultural, political, or contextual information. Such a structure gestures towards a link between higher rates of tuberculosis disease and factors such as race, ethnicity or country of birth without offering a contextual look at why this might be so. The exceptions are occasional references to the need for an increased focus on outreach and education within

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[73] For examples of documents and reports with flattened discussions of nationality and racial identity in relation to tuberculosis prevalence see: *Reported Tuberculosis in the United States, 2013* (Centers for Disease Control and Prevention, 2014) or *Trends in tuberculosis–United States, 2014* (Scott, 2105). These represent a small selection of a long list of documents, indicating a strong institutional discourse.

particular communities. But this gesture, too, is flimsy because although lack of information about the biological aspects of transmission or appropriate courses of treatment is often cited as a major barrier to tuberculosis control, studies show that information alone does not change behavior because it cannot account for or mitigate the social and systemic constraints that also inform decisions related to healthcare (Farmer, 1996; Rubel & Garro, 1992).

Today as in the past, the relationships between nationality or racial/ethnic background and disease are often used to justify anti-immigrant agendas (Abel, 2007). The endurance of themes that link immigrants with disease raises many questions about the accessibility of the ‘American Dream’ to certain communities and helps cement the perspective that immigrants always bring disease with them. Characterizations of immigrant communities as health threats also contribute to the failure of public opinion and policymakers to recognize the diversity that exists within the experiences of immigrants as well as the similarities in experiences between some immigrant groups and other marginalized groups who were born in the United States but also experience high rates of tuberculosis burdened with high rates of tuberculosis (Reitmanova & Gustafson, 2012).

With regard to infectious disease, the social and economic borders that separate people within a country may be more substantial than the political borders distinguishing the boundaries between nation states (King, 2003, p. 49). Importantly, while nearly a third of the world’s population is infected with the tuberculosis bacillus, most people never progress from latent infection to active disease (Hartman-Adams, Clark & Juckett, 2014). A common talking point for tuberculosis awareness campaigns is the idea that anybody can become infected with tuberculosis. Tuberculosis is often framed in the media, public awareness campaigns, and patient education/outreach materials as an indifferent killer, capable of impacting the lives of anyone, anywhere.[74] This framing has often been employed as a strategy by tuberculosis advocates in an effort to compel attention and contributions from wealthy philanthropists, businesses, or governments that have dominant stakes in communities that are largely unaffected by tuberculosis. However, what is left unsaid in this perspective that attempts to equalize tuberculosis contagion is that certain groups are at far higher risk than others of developing and dying from active disease. The reality is that tuberculosis disproportionately impacts the world's poorest and most disenfranchised populations.

Chapter Conclusions

Working with Diverse and Vulnerable Populations

A significant portion of the work done at the TCP involves obtaining access to and treating vulnerable populations, not just for active disease but also for preventative latent tuberculosis treatment. This work is context and community specific, though situated within broader social and economic systems and responding to global tuberculosis control best practices. Vulnerability means many different things in this context, but often refers to people who are not yet patients and whose risk for tuberculosis is statistically higher because they work or live in crowded or unsafe

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[74] See, for example, the marketing surrounding the World TB Day, an annual event sponsored by the WHO's StopTB Partnership that is observed by all United Nations Member States. World TB Day marks the day in 1882 that Robert Koch announced his discovery of the tuberculosis bacillus in order to raise awareness about the scope of tuberculosis and global efforts to eliminate it. In 2007, the theme was "TB anywhere is TB everywhere," with press materials that emphasized the global connectedness of the bacillus itself as well as public health efforts to combat it.

facilities, abuse alcohol or drugs, or have limited or no access to healthcare services. In particular, the TCP often associates vulnerability with people in precarious financial situations. Because tuberculosis is a communicable disease, the state subsidizes the costs of its treatment so that a community's uninsured residents can access tuberculosis-related treatment at little or no cost, with additional help offered for transportation or housing for a limited number of patients with extreme circumstances.

While these important accommodations help ease some of the burdens associated with treatment, they often fall short of addressing the levels of need and scope of challenges impacting tuberculosis patients who are undergoing screening or treatment. I observed a great deal of distress among many TCP patients that impacted their experience of being diagnosed with and treated for tuberculosis. Discussions with administrative and clinical staff at TCP indicate that the stress results from patient needs and challenges that extend far beyond the scope supports the TCP was able to offer. For example, despite having access to free or highly reduced medications and tuberculosis-related medical services, missing work for appointments or because of treatment side effects or arriving late to work because of long wait times in the clinic was a significant concern raised by many patients because it posed a legitimate risk to their ability to keep their jobs or help support their families. This sort of vulnerability is significantly higher for people of lower socioeconomic status who do not have salaried employment or other forms of job security. The TCP is not able to compensate people for time missed at work due to long waits at the clinic or the expense of obtaining childcare, and these burdens often have a direct impact on the willingness of patients to seek care in the first place or whether they choose to pursue preventative treatment.

Vulnerability in the context of tuberculosis care also refers to patients who have other diseases and illnesses that interact or interfere with tuberculosis treatment. Questions of where tuberculosis begins and ends are blurred in the case of co-occurring illnesses. HIV/AIDS is one of the most significant co-occurring illnesses for tuberculosis management efforts because each disease often makes the other worse. Diabetes is also a growing problem in this respect because patients with both diabetes and tuberculosis experience poorer treatment outcomes and higher rates of relapse than people without diabetes, and tuberculosis can worsen glycemic control for people with diabetes (The Lancet Diabetes & Endocrinology, 2014). Many patients who received services at the TCP did not have the extra money to seek treatment for other co-occurring illnesses and diseases, which often interfered with the effectiveness of their treatment, not to mention their overall health. I often observed doctors and nurses negotiating the boundaries of the services they could provide as employees of the TCP. Occasionally, clinic staff members were able to stretch the definition of tuberculosis in order to offer screenings such as blood tests that would offer more information on a patient’s condition. However, because services rendered at the TCP must be related to treating the tuberculosis at hand, the doctors were often unable to order more tests and instead tried to convince patients to seek care at one of several local community clinics that offer low-cost alternatives for many basic services.

Finally, vulnerability in the context of tuberculosis control refers to patients who are reluctant to seek medical care at all. My interviews with clinical and administrative staff as well as patients suggest that many patients at the TCP lacked trust in the medical establishment as a whole. Patients often sought a screening or treatment because they were required by the state or their place of employment to undergo consultation. Outright avoidance of the TCP, even in the face of a formal request, was most common among undocumented populations, homeless populations, and people with substance abuse problems or serious mental health issues who lack social supports or a private support system. Undocumented residents or migrants are a population largely unseen at TCP, despite a formal policy of not asking questions about a person's immigration status. This comports with research that has shown that undocumented residents are significantly less likely to seek even basic medical care, much less specialized treatment for communicable diseases like tuberculosis (Asch, Leake, & Vargas, 1994; Bustamante, Hai, Garza, Carter-Pokras, Wallace, Rizzo, & Ortega, 2012). This marks a community that is vastly underserved across the United States.

Inverting Cure as Prevention

In addition to the economic, political, and structural barriers discussed in previous sections, San Diego County possesses unique considerations that impact the ability of the TCP to reach or adequately serve many of San Diego County's most vulnerable populations. These include the local public health system's tacit acceptances of and resistances to nationally and internationally established ways of conceiving or identifying risk groups, county-level management strategies responding to unreliable resource distribution, and a higher degree of mobility among the populations most effected by tuberculosis –the latter contributing to failure in follow up and tracking the long-term health of patients once their treatment concludes. Linking these factors is a hyper focus in public health policy and tuberculosis control programming on the complicity of individual patients who do not receive or complete treatment.

A focus on the individual as a vector for disease is not a new strategy in the history of communicable disease control, but the individual has been conceived of and approached in many different ways through time by the institutions of medicine and public health. In its current configuration, surveillance of the individual dominates the DOTS framework. However, despite the prevailing individual-centric focus, DOTS was designed as a tuberculosis management strategy that, at least in theory, requires attention to be placed on five core components that include attention broader social and structural factors that are key in the treatment and containment of tuberculosis.[75] In its foregrounding of directly observed therapy (aka DOT), the DOTS acronym, and indeed the longer name itself, is reflective of the ideological orientation toward the pharmacological and clinical role in public health and the hyper focus on individual action in tuberculosis control.

An overemphasis on individual responsibility and cost efficiency obscures many of the sociopolitical, structural, and environmental factors that contribute to tuberculosis prevalence and to the hardships people face while receiving treatment. It also obscures the ways that the priorities of the system itself insufficiently support its stated goals (e.g., drug shortages or inconsistent funding). Because the implementation of services

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[75] The five interrelated principles of DOTS are: (1) a political commitment by national governments to give the resources and support necessary to build strong tuberculosis control programs; (2) a strong network of laboratories; (3) standardized treatment, including directly observed therapy; (4) a consistent and effective drug supply; and (5) a system for monitoring and evaluation. In practice, however, direct observation often stands in as *the* representative for DOTS as a whole, often to the detriment of other aspects of the platform (Hurtig, Porter and Ogden, 1999). See the previous chapter for a more detailed discussion of the DOTS platform.

can only ever happen in the local context, there will likely always be some tension between the requirements of universal interventions and how local programs must try to adapt to what their local context requires of them. In order to strengthen existing local and international tuberculosis control efforts, future policy/plans need to deeply engage with the components of DOTS, beyond what has been done in the past. This kind of engagement should include, at minimum, a commitment by public and private entities to fund tuberculosis research and development initiatives, develop better systems for communicating about drug shortages, limit drug shortages by centralizing procurement and distribution, and a commitment at the federal and state level to consistent funding of public health budgets.

But medication, budgets, and research alone will not solve the tuberculosis burden. While drug shortages and funding shortfalls are intertwined system-level factors that impact local health departments, they leave underlying socio-political pressures that seem to run throughout tuberculosis treatment training and policy unaddressed. Policymakers need to give serious consideration to the cultural and political factors that influence shared experiences of illness and disease in order to build flexibility into local health systems and better respond to local contingencies, including better engaging underserved, vulnerable populations. An important factor to address when considering the kinds of changes that should be made to existing tuberculosis programing is connected to representation and policy related to social inequalities. Metaphors linking race or national origin to disease personify a fear of contamination. As illustrated in the example of the iconic figure of Typhoid Mary, such associations are durable because offer mythic embodiments of an otherwise nebulous threat. The focus on immigrants as an origin source for disease is a more pernicious instantiation of the hyper focus on individual complicity that is built into the logic of the current system of tuberculosis control in the United States and other wealthy, low-endemic nations. It produces difference vis-à-vis a framework that removes attention from the sociocultural landscapes that produce unequal disease burdens and places it instead on a compulsory if not zealous monitoring of the immigrant.

A Community-Centered Approach

This chapter has begun to tell a story about the intersection of global tuberculosis control initiatives and the ways people and local systems negotiate it. The dominant discourses reflected and reinforced within public health policy often sidestep critical engagement with the exploitative sociocultural forces and economic structures that disproportionately affect a community's poorest, undereducated and most underrepresented populations. Particularly for individuals and families who are impacted by structural disadvantages such as poverty, overcrowded living conditions, and unemployment, education about available services may not be the most important factor in deciding whether to seek or continue with medical treatment. Silvio Waisbord (2007) explains:

> This premise detaches TB-affected populations from the social context in which they experience and make healthcare decisions. It sidesteps social and power issues that shape health decisions and practices. It ignores how socio-cultural and health systems constrain healthcare choices, and that those choices are part of broader decisions about health, resource allocation, and gender roles in households and communities. (p. 2131)

From this perspective, addressing tuberculosis control through strategies of information distribution and treatment compliance alone is insufficient because, like the flattened discourses they mirror, this approach can obscure the particular sociocultural and discursive factors that act as barriers and facilitators in managing the disease.

Key to developing strong and adaptive local tuberculosis programs is finding ways to encourage and formalize the informal advocacy and outreach efforts by TCP staff that often go unrecognized because they are beyond the scope of official job descriptions. Such informal interventions represent engagements with the local community that are able to adapt and respond to the specific needs of their local context. Rather than beginning with an anonymous individual who comes to represent a universal whole, these informal interventions are valuable affordances that begin with the needs of specific communities. In an inversion of the universalized precept that cure functions as the best prevention, such moments provide clues to formulating action around the principle that better attending to and connecting with members of local communities helps create and sustain successful systems of public health care.

It is essential for policymakers in the United States to begin to prioritize the needs and strengths of local communities rather than continuing to operate from a largely uniform national template rooted in the global DOTS initiative. This change in the organizational logic and structure should include a commitment to prevention by developing adaptive programming that better offers traditionally disenfranchised and underserved community groups access to affordable, convenient, and safe treatment for latent tuberculosis infection.

Building tuberculosis control programs with enough flexibility to adjust programming based on the needs of local communities would invert the logic of cure as the best prevention and, by extension, the reigning logic that funnels money and attention into tuberculosis control only once a crisis has begun. Tuberculosis control programs that adequately reflect the specific needs and particularities of the local communities they serve would reinforce the importance of developing programing, partnerships, and clinical practices that are adaptable to the environments in which individuals live and interact. For policymakers, such an approach would demand that the diverse relationships, needs, and resources that exist within communities be treated as nonnegotiable factors in the establishment of effective systems of public health care and by extension become inseparable from how “tuberculosis control” itself is conceived, defined, and communicated.

CHAPTER FIVE: TUBERCULOSIS AS A BOUNDARY OBJECT – NEGOTIATING AMONG SITUATED UNDERSTANDINGS OF DISEASE

As an object of knowledge as much as a biological fact, tuberculosis resists singularity, refusing to be defined in an absolute way. In her careful distinctions between shifting definitions of tuberculosis during the 20th century, Katherine Ott (1996) writes that the "meaning of a disease evolves from the interrelationship of people, technology, medical doctrines, and state affairs" (p. 1). From the consumptive romantic of the 19th century to more recent early 20th century depictions of the figure of overindulgence or moral weakness, the meaning and significance of tuberculosis continues to shift through time and place.[76] Teasing out the multiple experiences and impacts of tuberculosis demands that we pay attention to a complex web of diverse discourses, narratives, and practices.

In the 21st century, tuberculosis remains an entity with interpretive flexibility across diverse communities of practice. As such, tuberculosis functions as a boundary object that mediates across the work and experiences of multiple groups. In their seminal work, *Institutional Ecology, 'Translations' and Boundary Objects*, Star and Griesemer (1989) describe boundary objects as dynamic entities whose meanings change over time and according to perspective. They are flexible enough to adjust to a number of distinct outlooks, while sturdy enough to "maintain a common identity across sites" (p. 393). Objects become boundary when they are taken up across multiple

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[76] In addition to Ott (1996), see also Barnes (1995), Gandy & Zumla (2002), Héricourt (1920), Pôrto (2007), Snider and Roper (1992), and Sontag (1990), for just a few examples among many.

communities of practice, with each group employing the object in unique ways and with differing significations.[77] By addressing the problem of representation across intersecting social spheres, boundary objects perform the work of translation by allowing multiple and differing constituents to communicate or work together without demanding absolute consensus (Bowker & Star, 2000).

In this chapter I discuss how tuberculosis serves as a boundary object and pose questions about the many ways it is articulated across a range of constituents and contexts. When examined as a boundary object, tuberculosis offers an important starting point for interrogating the individual, community, and institutional practices and discourses that constitute the disease across multiple contexts in overlapping and discontinuous ways. By describing several of the ways tuberculosis inhabits a boundary position, my analysis aims to articulate some of the complex ways the disease functions as a mediator among communities of practice. I begin by defining the dominant construction of tuberculosis within the world of public health policy and practice, the biomedical framing of the disease, and I articulate how multiple communities of practice take up and modify this perspective in various ways. Woven into this discussion is an examination of cultural hegemony and institutional hierarchy as entry points for exploring how some meanings of tuberculosis becomes dominant, sanctioned in the policies or documents by influential public health agencies, while others are not heard at all or become subsumed by official discourses and practices. I also consider the

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[77] A term originally coined by Lave and Wenger (1991), Bowker and Star (2000) compare communities of practice to social worlds, defining them as “a set of relations among people doing things together” or “a unit of analysis that cuts across formal organizations, institutions like family and church, and other forms of association such as social movements” (p. 294).

many communities of practice and articulations of tuberculosis that I encountered during my research at the Tuberculosis Control and Refugee Health Program (TCP) of San Diego County, and I describe the material and ideological effects that dominant forms of articulating tuberculosis have on the ways the medical establishment and various publics view public health and infectious disease control. My effort here is to consider the potentialities for engaging with and theorizing tuberculosis as a boundary object, with an emphasis on articulating some of the varied communities of practice that engage with it as a concept, object, or consequence.

Conceiving Tuberculosis as a Boundary Object

My research suggests that tuberculosis functions as a boundary object that offers multiple lenses through which to view social, individual, and institutional power relations. As an entity that inhabits various contexts at once, tuberculosis occupies a kind of multiplicity that cannot be contained within a singular conceptual framework. Its many coexisting frames suggest that beyond its presence as a bacillus, tuberculosis travels through an array of hosts: bodies, communities, discourses, and practices.

Star and Griesemer (1989) identified four primary types of boundary objects: *repositories*, which index “piles” of objects in a standardized form (e.g., museums and libraries); *ideal types*, which are abstracted from all points of reference but easily able to be applied in local settings because of this abstraction (e.g., atlases and diagrams); *standardized forms*, which help regulate work methods across dispersed groups and by consequence delete local contingency; and *coincident boundaries*, which are objects with the same boundaries but different contents (e.g., the State of California and what it means to various communities) (p. 410-411). While each of these categories is worth considering in relation to tuberculosis, coincident boundaries carry a particular relevance for understanding the disease in the context of public health practice. As I discuss below, tuberculosis control is enacted through clinical and laboratory practice, health policy, public discourse, and individual experience. With the exception of clinical and laboratory practice, tuberculosis is often defined without explicit reference to the bacillus that causes the disease of the same name. Public health advocates often refer to the social genesis of the disease; epidemiologists discuss its geographic and cultural distribution; and policy makers configure it in relation to public safety measures or immigration reform, to name a few examples of many. Even when unspoken, however, the *M. tuberculosis* bacillus maintains its presence by forming a coincident boundary that provides a frame for many of the various conceptualizations of the disease that circulate within and near the world of public health.

In addition to the four boundary object types offered by Star and Griesemer (1989), Briers and Chua (2001) offer a fifth category, *visionary boundary objects*, which is also useful to consider in the context of tuberculosis control. As conceptual objects that are enacted as institutionalized best practices with "high levels of legitimacy within a particular community", visionary boundary objects possess a "sacred quality" that cannot easily be challenged (p. 242). Institutional best practices, for example, help define a boundary as visionary. Many aspects of the way tuberculosis is brought into being through the politics and policies of global public health possess a visionary quality that is difficult to challenge, in part due to the dependence by many nations and by the World Health Organization (WHO) itself on international financial institutions like the World Bank, whose power often translates to dominance of vision and priorities.

The broad conceptual flexibility afforded to tuberculosis by its various communities of practice is perhaps conditioned by the interdisciplinary nature of public health work itself. While public health may broadly comprise a community of practice, it interfaces with and is constituted by many diverse constituents, from doctors to community health educators, nurses, administrators, laboratory technicians, informatics specialists, and disease investigators (to name just a few). Nearly a century ago, not long after the dawn of bacteriology that was helped along by Robert Koch's 1882 discovery of the bacteria that causes tuberculosis and subsequent development of four postulates that established criteria for linking bacteria to diseases (Blevins & Bronze, 2010), public health expert Charles-Edward Amory Winslow offered what has remained a lasting definition of public health. Winslow's (1920) definition gestures to the broad scope of responsibility that public health undertakes:

> Public health is the science and art of preventing disease, prolonging life and promoting physical health and efficacy through organized community efforts for the sanitation of the environment, the control of communicable infections, the education of the individual in personal hygiene, the organization of medical and nursing services for the early diagnosis and preventive treatment of disease, and the development of social machinery which will ensure every individual in the community a standard of living adequate for the maintenance of health; so organizing these benefits in such a fashion as to enable every citizen to realize his birthright and longevity. (p. 30)

In addition to the wide-reaching goals of public health offered by Wilson, he also invoked the need for, at minimum, seven kinds of specialists, including doctors, nurses, bacteriologists, engineers, epidemiologists, statisticians and social workers in addition to other public health supports such as inspectors and administrators to monitor and organize the tasks at hand. Wilson's definition was, and continues to be, reflective of public health's intersecting interests across a number of domains of practice including medicine, education, and the role of social and environmental factors in maintaining health.[78] Because of the wide scope of public health, multiple communities of practice must coordinate services, policy, and infrastructure, despite their varying objectives and points of view.

The broad scope of public health also involves balancing and integrating interventions that operate at multiple levels/scales. For example, public health agencies draw from a range of health interventions that include procedures enacted at the level of individual patients (such as vaccinations or screenings) as well as population-level interventions (such as the regulation of smoking in public spaces or the treatment of water with fluoride). For tuberculosis control, local programs must negotiate community need while also fulfilling state and federal requirements. Federally, public health policy, regulations, and targets must comport with the standards outlined by supranational public health organizations such as the WHO that shape health policy, establish global standards, and influence funding flows through strategic partnerships with, for example, the World Bank in the case of the WHO. The resulting negotiation of shifts of focus within tuberculosis control efforts leads to differently inflected or

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[78] Starr (1982) observes that the expansiveness outlined by Wilson invites conflict: "Public health cannot make all these activities its own without, sooner or later, violating private beliefs or private property or the prerogatives of other institutions" (p. 180). This broad reach also raises questions related to the often imbalanced distribution of health, the justification public health practices, including a discussion of the limits and good of paternalistic interventions, and the responsibility of governments to care for the health of its population in relation to global flows of people ideas and diseases.

nuanced articulations of perspective in relation to global initiatives and local manifestations.

Defining Tuberculosis Across Multiple Communities of Practice

My research suggests some specific ways that tuberculosis is defined within public health tuberculosis control. Three primary definitions surfaced from the many descriptions that people utilized to talk about tuberculosis in the context of tuberculosis control: tuberculosis as a biomedical disease, a social disease, and a disease mediated by lived experience.[79] As I will discuss, there are communities of practice associated with each of these definitions, with overlap across membership. Many people tended to conceptualize the definition they employed to describe tuberculosis as somewhat bounded, but I suggest that there is movement across terms, emerging both as consensual negotiation and as struggles over power.

A Biomedical Disease

Currently the biomedical model plays a central role in defining the work of multiple communities of practice through the articulation of many dimensions of tuberculosis and the operationalization of its control. From global public health policymakers and the pharmaceuticals industry to local clinicians, laboratory

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[79] It is important to note that my research focused on activities emanating from the TCP. The three boundary positions of tuberculosis I explore here emerged as the most significant of all of the ways people talked about and defined tuberculosis within this context. Having said this, there were many communities of practice that I was not able to engage directly that would add depth to this analysis. I would like to connect with these groups in future iterations of my research. They include community faith leaders, urban planners, private doctors, local policy makers, law enforcement, educators, and community-based refugee assistance program employees, to name a few examples of many.

technicians, and administrators, the biomedical model shapes the agendas designed to respond to tuberculosis even as it has different valences for each and is reflected in distinct discourses, practices, and tools. The biomedical definition of tuberculosis in many ways comprises *the* dominant figuring of the disease, most notably because global tuberculosis control best practices have been developed from the biomedical model (Hurtig, Porter & Ogden, 1999).[80] Defined from a biomedical perspective, tuberculosis is both a category of bacillus and a category of disease, the former causing the latter. Notably, this particular bilateral framing of tuberculosis is historically linked to the formation of professional practice and institutions in relation to the consolidation of bounded forms of medical authority.

In *The Birth of the Clinic: An Archaeology of Medical Perception,* Foucault (1994 [1963]) charts the development of the medical profession and its institutions at the beginning of the 18th century. He links these developments to shifts in knowledge that changed the practice of medicine, employed an empirical framework to identify and catalog all of the body's various pathologies/deviances, and changed shared understandings of the human body. During this time, the discipline of medicine developed what Foucault termed the *medical gaze*. He writes, "The gaze is no longer reductive, it is, rather, that which establishes the individual in his irreducible quality. And thus it becomes possible to organize a rational language around it" (p. xv). Articulating its role in the historical consolidation of modern medical institutions,

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[80] Medical Anthropologist Erin Koch (2013) rightly notes that there is no singular manifestation of biomedicine, but instead varied biomedical technologies and interventions. She emphasizes the use of *biomedical* as an adjective (rather than *biomedicine* as a noun) to explain that such technologies and interventions share a "presumed hegemonic status" ordained by their orientations to scientific knowledge (p. 9) that draws upon "enlightenment-era notions about the natural world", particularly the separation of biological from social ways of knowing (p. 200).

Foucault contends that the medical gaze establishes the person as a patient, the doctor as an expert, and the body as internally surveillable and mappable. Medical discourse, by extension, organized itself in relation to other structures of power (e.g., social, economic) and positioned the material body as knowable and penetrable through observation. Conrad and Barker (2010) remark that Foucault's work demonstrated the ways that the discourses of medicine "can influence people's behaviors, impact their subjective experiences of embodiment, shape their identities, and legitimate medical interventions" (p. S69). This is certainly true of the biomedical approach to tuberculosis control today in which tuberculosis often functions as an entity separate from the person it inhabits, even while a person's experience of the disease and self is profoundly structured by social, economic, and regional characteristics as much as it is by the bacillus itself.

Biomedical histories of tuberculosis and strategies for its control since the birth of the modern clinic have tended to spotlight the technological interventions that have impacted how clinicians and policymakers approach treatment, notably Koch's discovery of the bacillus that causes tuberculosis at the end of the 19th century and the development of effective antibiotic treatments that went to market during the 1940s. These technological developments were important in establishing the authority of doctors and clinical institutions through the expansion of increasingly individualized treatments, which can be contrasted with previous techniques of control such as sanatoria or quarantine (Mason et al., 2015, p. 6). Further, the development of tuberculosis antibiotics commodified the treatment potentials of diseases like tuberculosis, helping to expand the pharmaceuticals industry during a time in which it was quickly growing and gaining power (p. 6). Mason et al. (2015) suggest that histories of tuberculosis demonstrate that many contemporary tuberculosis control measures are oriented towards the development of vaccines and drug treatments in their effort to contain the disease. While not all societies share this particular course of medicalization, the globalization of tuberculosis treatment strategies has meant that this particular biomedical ideology has been embedded into standards of classification and treatment and thereby globally disseminated.

Globally and regionally, the biomedical focus on antibiotic cure and patient compliance is wrapped up with longstanding relationships with the global and national pharmaceuticals industry. As discussed in Chapter Four, there is very little motivation on the part of pharmaceutical companies along with other private and public research organizations to invest in the development of new medications or vaccines for low-return conditions like tuberculosis. The pharmaceutical commodification of treatment that boosted the industry with the development of tuberculosis antibiotics is, perhaps ironically, the same viewpoint that has largely neglected tuberculosis in recent years. A largely unregulated pharmaceuticals market in the United States compounds this issue, particularly because prices for tuberculosis medications can increase dramatically with very little warning without built in controls that set an uppermost price (Médecins Sans Frontières & International Union Against Tuberculosis and Lung Disease, 2012). In addition, the United States Food and Drug Administration has very little authority to require that companies produce certain medications at a consistent level (Griffith et al., 2012). These points taken together suggest that the pharmaceuticals industry comprises a broad, though largely unified, community of practice informed by the biomedical model that defines tuberculosis not just as a biomedical disease but also as an unprofitable one.

The biomedical boundary configuration of tuberculosis also directs the actions and decisions of the doctors at the TCP, both directly through the diagnostic and treatment procedures they follow and indirectly through the national and global standards that have been designed to guide tuberculosis control practices across diverse regions. The current biomedical classification system for tuberculosis in the United States ranks the disease according to the American Thoracic Society's five-point scale based on its level of impact to people who have been exposed, ranging from people who are tuberculosis-free to those who have active disease and are need of immediate treatment.[81] Broadly mapping onto the framework outlined by the WHO's international classification of diseases,[82] this scale serves as a framework to guide diagnostic standards, treatment approaches, and reporting criteria for local public health personnel. While public health employees use American Thoracic Society's framework regularly at the local level as a way to standardize diagnosis and treatment, it is also rooted in the large-scale infrastructures used by national and international agencies to determine

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[81] *Class 0* means that there is no tuberculosis exposure, and the patient is not infected, as measured by the tuberculin skin test, while *Class 1* indicates that there has been a history of tuberculosis exposure, but that there is no evidence of infection as determined by a negative reaction to the skin test. *Class 2* suggests latent tuberculosis infection, while *Class 3* signals active tuberculosis disease that is verified by clinical, bacteriological, and/or radiographic evidence. *Class 4* means that there is tuberculosis infection, but it is not clinically active. This classification marked by a history of active tuberculosis infection or x-rays that are abnormal but stable with no clinical or radiographic evidence of current disease. Finally, *Class 5* defines a patient as a tuberculosis suspect. The most complex of categories, this category is used to indicate that a diagnosis is pending and that the person's status will be determined within 3 months and be placed in a new category depending on results. According to United States public health guidelines, people with Class 3 or Class 5 tuberculosis need to be reported to the local health department (American Thoracic Society, 2000).

[82] See the *International Statistical Classification of Disease and Related Health Problems* (World Health Organization, 1992).

policies and protocols for a myriad of concerns such as regulation of travel, the threshold guiding mandatory treatment, or permission to work in certain fields (education, healthcare, senior care, child care).

Other classification systems that shape tuberculosis as a biomedical boundary draw on the biomedical model and integrate it into extra-medical realms of authority with unique implications for the people they address. For example, the United States Citizenship and Immigration Services Agency uses its own classificatory schema to categorize tuberculosis among immigrants and refugees.[83] This schema was developed by the Centers for Disease Control and Prevention (CDC) as a way to identify "high-risk" individuals, and it carries consequences for entering the United States. This particular classification system implicates tuberculosis within the discursive and material construction of citizenship, ethnicity and race. Mandatory tuberculosis testing is enforced for the people classified as immigrants, refugees, and status adjusters, while those classified as non-immigrant or short-term transit visitors are not screened (Health and Human Services Agency, Centers for Disease Control and Prevention & National Center for Emerging and Zoonotic Infectious Diseases, 2009; Health and Human

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[83] *Class A* refers to people who have been diagnosed with tuberculosis disease and require treatment in their home country but have been granted a travel waiver before treatment is complete. *Class B1, Extrapulmonary* suggests that tuberculosis exists outside of the lungs, while *Class B1, Pulmonary* refers either to people who have been diagnosed with tuberculosis and successfully completed DOTS approved treatment before immigration or those with a medical history that suggests tuberculosis but whose lab results are negative. *Class B2* refers to people who have has a skin test that presents higher than normal but who otherwise do not appear to have tuberculosis. Finally, *Class B3* is used to indicate people who are contacts of someone known to have active tuberculosis (Health and Human Services Agency, Centers for Disease Control and Prevention & National Center for Emerging and Zoonotic Infectious Diseases, 2009; Health and Human Services Agency, Centers for Disease Control and Prevention & National Center for Emerging and Zoonotic Infectious Diseases, 2012).

Services Agency, Centers for Disease Control and Prevention & National Center for Emerging and Zoonotic Infectious Diseases, 2012).

While this system of classification has material consequences in the lives of immigrants and refuges in the United States, it also has unintended but direct impacts at the level of service delivery at the TCP. Importantly, these groups are not so easily bounded as distinct "communities," especially within the TCPs regional domain where temporary visitors, immigrants, refugees, and citizens share homes, relatives, places of worship, and employment. At the level of practice, doctors at the TCP indicate that immigrant and refugee patients are often reluctant to answer common diagnostic and treatment-related questions about the kinds of tuberculosis exposures they faced or treatments they completed in their home countries. Dr. Hall, one of the TCP's two part time physicians, theorizes that this happens when patients are worried that the doctors can influence the outcomes of their immigration or refugee status applications. As a result, Dr. Hall has modified her practice by offering an explanation to reluctant patients that tries to assure them that she is not responsible for immigration decisions and simply trying to better understand their history in order to design a treatment plan that is appropriate for them. She explains that her job at the TCP is only able to follow up on the screenings they completed before entering the United States or to offer preventative care or curative treatment when appropriate. Despite such assurances, she explains that patients are often reluctant to share information or, she suspects, answer the questions according to what they think the doctors want to hear.

Dr. Hall's explanation signals how important it is for public health clinicians to understand that effectiveness of their work depends on their recognition of how they are implicated within discursive frames and institutional practices that regulate movement and belonging. It is often noted that infectious diseases like tuberculosis stubbornly transgress the borders of nation or class despite an array of institutions and protocols dedicated to containing it. A preoccupation with the fluidity of contagion, however, does not signal a breakdown of these boundaries as much as it does a continued policing of its transgressors along with the codification of a firmer set of guidelines demarking groups and nation states.[84]

A Social Disease

In addition to its biomedical definition, tuberculosis is also defined across a number of communities of practice in relation to its status as a social disease, with significant attention given to its links to poverty. The communities of practice that adopt a boundary framing of tuberculosis as a social disease primarily include social science researchers and public health advocates, although to a lesser extent it is also reflected in the language used by doctors and other care providers like those at the TCP. In the social framing of the disease, the bacterial etiology is backgrounded and tuberculosis is instead conceptualized as a disease profoundly shaped by inequalities of power, particularly in relation to individual and community socioeconomic status. Hurtig, Porter, and Ogden (1999) argue that tuberculosis control programming has largely been developed from the biomedical perspective, an effect of which has been a lack of qualitative research on the social and behavioral variables that impact tuberculosis and

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[84] For more on tuberculosis and the policing of national borders, see King's (2003) chapter, *Immigration, Race, and Geographies of Difference in the Tuberculosis Pandemic*.

other infections diseases. Most problematically to them, however, is that the information available suggests important “disjunctions between TB patients and providers and between the population and the policy makers” that stem from an undervaluing of the non-medical factors that help shape health (p. 558).[85]

Early on, Dubos and Dubos (1996 [1952]) framed tuberculosis as a social disease with unique characteristics that required interventions that extended beyond traditional biomedical approaches. They wrote that an understanding of tuberculosis “demands that the impact of social and economic factors on the individual be considered as much as the mechanisms by which tubercle bacilli cause damage to the human body” (p. xxxvii). Social science research has since reinforced the thesis offered by Dubos and Dubos, suggesting that tuberculosis represents a material manifestation of social inequalities as much as it does a biological reality (Farmer, 1999, p. 262). Eisenberg (1999), for example, suggests, “If poverty and war propagate disease, improved living conditions inhibit its growth” (p. 166). Similarly, Kim et al. (2005) argue, “Tuberculosis is, in every sense, both a cause and a result of poverty” (p. 848), while Benatar (2003), who also looks to income as a distinguishing variable, instead points to income disparity as an explanatory factor in general health inequities and tuberculosis prevalence. He cites the United States as an example of a country that exhibits worse health statistics than many other industrialized nations, despite accounting for far higher per capital healthcare expenditures than most. Meanwhile, he

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[85] Khan and Coker (2014) also point out that employing medico-technical answers to public health problems that require more comprehensive solutions is not only a problem in the world of tuberculosis control. The authors point to Sylvia Noble Tesh’s (1996 [1988]) work, *Hidden arguments: Political ideology and disease prevention policy*, which examines the relationships between politics and science in policy debates about disease control and prevention more broadly construed.

offers Cuba and Costa Rica as examples of poorer countries that have reached lower infant mortality rates and increased longevity compared with many wealthier nations. In this framing, tuberculosis becomes an entity that is dependent on lack of social and economic capital as much as it is a receptive lung.

The efforts by many social scientists and public health advocates to define tuberculosis as a social disease represent an attempt to shift what they see as a narrative of causality inherent in the biomedical model. In their attempt to reposition the *coincident boundary* (or frame) of tuberculosis, proponents of the social model of tuberculosis push back against the ways that a primarily biomedical articulation of the disease focuses almost exclusively on antibiotic interventions and the treatment outcomes of individual patients as primary strategies for a brand of tuberculosis control that implicates patients in what should be understood as a multilayered issue (Coker, 2000; Farmer, 1999). While the biomedical model often posits patient education (along with medication compliance, which is often presented as a matter of education) as a core component of effective treatment regimes, researchers and public health advocates who frame tuberculosis as a social disease argue that information alone cannot change behavior. More importantly, however, they are adamant that providing the patient with more information or education will never be able to account for or mitigate the social and systemic constraints that inform the healthcare decisions, needs, and experiences of individuals, families, and communities (Farmer, 1996; Ho, 2004; Rubel & Garro, 1992).

Mario Vega, for example, a tuberculosis and public health advocate based in San Diego County, is resolute in his assessment that global and national tuberculosis policy makers must carefully examine constraints within the existing system in order to better mitigate the broad range of social and economic factors that are unique to local communities and individuals. In particular, he argues that flaws in the system itself are essential to address in the fight to significantly reduce the tuberculosis burden. Such flaws exist beyond explanatory models that situate the individual as uneducated or uncooperative and are often a product of such a narrowly cast system of control. In our formal interview he explained:

> Around the world, nobody pays attention to changes that should be made in the environment or the system…Part of the problem is that all over the world people just see TB as a public health issue. There needs to be a change of paradigm…TB is a social problem with medical implications. Right now they just care about seeing the hole in someone's lung. They don't see your face, your family, your social or economic status, your community.

Vega's observations point to limitations embedded within the logic and design of the health system itself. Khan and Coker (2014) similarly explain that a hasty uptake of medico-technological solutions for tuberculosis control in lieu of working to strengthen the long-term viability of national health systems of countries is akin to "allowing a running tap to flood a room while you mop up the water rather than switching the tap off" (p. 647). Such approaches do a good job of treating tuberculosis based on immediate urgency but nothing to establish and work towards long-term goals.

A Disease Mediated by Individual Lived Experience

Bowker and Star (2000) explain that biomedical classification systems of disease tend to "exist in pure space" (p. 168), often excluding the spatial-temporal elements of disease that shape how people experience it. In the context of tuberculosis, the aim of biomedicine has classically been to answer the question of whether or not a person has tuberculosis (p. 173), which Bowker and Star frame as a spatial characterization of disease (i.e. the disease is localized within a particular portion of a particular body). Meanwhile, they argue that the patient's body and the self are woven together (though not fully bound) and are experiencing tuberculosis largely through the dimension of time. The incongruences of spatially-bound systems of diagnosis and cure produce "leakages" in the classification system (p. 168) in which spatial classifications distort a person's temporally driven lived experiences of the disease (p. 192). For the person with tuberculosis, spatially driven categorizations twist the subjective and experiential landscape of expectation in their inability to account for lived time (p. 184-192).

As Bowker and Star's example suggests, the self does not extend from only internal, emotional states but is also produced in conversation with external contexts such as historical contingencies, institutional processes, or cultural formations.[86] Judith Butler's (2005) reflection on the process of self-narration in her book *In Giving an Account of Oneself* articulates the self as something that is never fully knowable precisely because portions of experience are necessarily dependent on the intersubjective accounts of others. When we try to account for ourselves as an "I," our efforts are always already implicated in a set of relations and interactions with others that are beyond our individual ability for narration. Butler asserts that the limits of self-knowledge are as fundamental to narrating the self as the transparencies. This stands in stark contrast to theories that understand the person as a fully realized and complete entity. Her analysis suggests that selfhood is distributed, inseparable from the norms

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[86] See also Biehl, Good, and Kleinman (2007).

and frameworks from which it emerges. It also suggests that any accounting of one's self is always necessarily incomplete.

In this respect, it would follow that we cannot posit a singular or stable subjectivity of the tuberculosis patient. Likewise because of the uniqueness of spatio-temporal configurations, patients do not constitute a unified community of practice but rather combine to offer glimpses of tuberculosis as a disease mediated through lived experience that draws parallels across intersecting communities of practice and singular accounts of personal experience. With this said, there are particular groups/communities of patients whose unified experiences and discursive interactions can present qualities of a community of practice.

The experiences of Adrian Alarcon, for example, situate him as a person who was not fully interpellated as a patient by the structures of tuberculosis control. As I discussed in Chapter Three, his decision to attend church even while he was directed by the TCP to remain at home until his infectious phase concluded provides a compelling example of the ways the TCP's control measures intersect with the lives and needs of patients beyond their time interfacing with the public health system. His experiences align with other patients who also experienced incongruities with the public health system. As I discussed, Adrian represented a boundary patient in multiple ways, in part because his social connections (family, church, school) shaped his priorities and motivations and also because he straddled the working-class communities of his church and family while also inhabiting the largely privileged communities represented by his university and social circle there. For many tuberculosis patients, incongruities between their various subject positions and with the dictates of tuberculosis control can challenge aspects of their willingness to exist as a particular kind of subjects. In Adrian's case, this manifested in his resistance to receiving treatment according to the guidelines established by the TCP. While his extreme response may not be the case for all patients who struggle to reconcile their various subject positions, Adrian's story points to the ways particular groups of patients emerge with experiences that cohere them around qualities of a shared community of practice.

Another patient I met through my research at the TCP who struggled with making sense of her various, sometimes competing subject positions was Julia Wolf, who explained to me that she felt a constant tension between her identity as a tuberculosis patient and as a "normal" person with a life and desires beyond her diagnosis. Because her treatment for active tuberculosis disease lasted for such a long time and was both physically and mentally challenging, Julia indicated feeling conflicting pressures between her identities of patient and person (which she articulated to me as an identity outside of or separate from patienthood). Throughout our interview, she referred to the struggle she felt when trying to maintain her life as normally as possible, even with the pain associated with tuberculosis disease and the impact of her treatment as a constant presence. In particular, Julia worked hard to maintain her identity as a mother, partner, and "whole" human being during her treatment, despite extreme feelings of fear and isolation. Although Julia ultimately fulfilled the treatment plan given to her by her care providers, like Adrian, she felt incongruities between her various subject positions.

Julia described feeling surprised and embarrassed when she was required to wear a mask to clinic and hospital visits during her infectious period and then profoundly afraid that she had infected the people in her life, particularly those with whom she had frequent contact. But the point that she returned to most frequently during our interview was the deep feeling of distress she felt during the phase of isolation that was required as a part of her treatment plan, which was ultimately extended due to drug resistance. She spoke about intense changes to her relationships with family, friends, and self, even after her infectious period had come to an end:

> I felt like an outcast. It's like the 5th dimension. Its like traveling in another dimension, you know. Nobody comes. People back out on you. They don't hug you anymore. It's just weird…because all of a sudden you're just so isolated and you are almost like you are treated like a criminal. If you don't take your pill they can put you in jail. I mean all of a sudden it's just different. It really is…You know, you have cancer people come see you. You know, you have TB, nobody comes. It is psychologically very difficult…And people are not informed very well about it and they freak out, you know.

While Julia's experiences of being diagnosed with and treated for tuberculosis are unique to her own situation, they point to another theme that marks the experiences of many people with the disease, which is a sense of stigma and isolation. Across socioeconomic and cultural boundaries, patients who undergo treatment for tuberculosis report feelings of isolation, not just during the phases of physical isolation but throughout the entire course of treatment. This is due in part to the rigorous treatment plan required to treat tuberculosis and also the stigma still often associated with tuberculosis as a disease of poverty or one that is linked to HIV/AIDS (Courtwright & Turner, 2010; Kelly, 1999).

One solution for alleviating the stigma and isolation experienced by this community of practice/patients has been the use of patient support groups (Horter, Stringer, Venis & du Cros, 2014; Macq, Torfoss & Getahun, 2007). The idea of establishing a community of support for tuberculosis patients has a long history, albeit one with irregular implementation. Dr. Joseph Pratt built his career advocating for group therapy, beginning in 1905 with a small cohort of patients with pulmonary tuberculosis who could not find space at a sanatorium. An important component of the "class method" he originally developed for treating tuberculosis was that there was a sense of support and community created within the small groupings of tuberculosis patient cohorts who met together each week as a part of their treatment protocol ("Joseph H. Pratt,"1955; Sabin, 1990). This community of support existed in addition to the classical components of rest and open-air therapy being prescribed at the time. Pratt (1907) wrote that the weekly cohort meetings served as "a pleasant social hour for patients" who looked forward to them for the sense of camaraderie and friendly competition they inspired (gaining weight, for example) (p. 758). For the many critiques of tuberculosis sanatoria, as distorting both time and experience for patients (Bowker & Star, 2000),[87] one of the positive outcomes of the sanatoria movement was the sense of community it helped to foster for tuberculosis patients.[88]

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[87] See also *The Magic Mountain* (Mann, 1932) and *Timetables: Structuring the passage of time in hospital treatment and other careers* (Roth, 1963), who Bowker and Star (2000) discuss at length in their essay "Of Tuberculosis and Trajectories" in their book *Sorting Things Out: Classification and Its Consequences*.

[88] See Condrau (2001), Haugh (2009), and Reber (2006) for examples of a sense of community at sanatoria.

Today, many websites and patient support/advocacy groups have emerged with the aim of destigmatizing tuberculosis by sharing personal stories and by transforming the experience of treatment by connecting patients with one another, helping them to cohere as a community of practice. This has had the effect of engendering more interactions among patients who likely otherwise would not have communicated.[89] While there are clear reasons that support groups can help individuals facing stigma by connecting them with a broader community who can understand their experience to some degree, they also raise the important question of how they function across differences in patient communities. In particular, while patient support groups and online forums can contribute a great deal to helping people cope with loneliness or stigma, it is also important to consider how they function to de-racialize or remove class associations with the disease (or emphasize them). Another important consideration is the ways that support groups might recapitulate the reorganization of state powers in advanced liberal societies that Rose (2007) proposes has helped distribute the responsibility of maintaining health across a number of extra-governmental entities such as regulatory commissions, private businesses, and individuals. As discussed in Chapter Two, Clarke et al. (2010) extended this argument by pointing the ways that patient

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[89] Among the many patient support groups and online forums that exist today, the *TB Photovoice Project* is an international endeavor that was established in 2005 as public charity by Romel Lacson in honor of his wife and daughter who died of tuberculosis. The *TB Photovoice Project* works with people and communities all over the world who are impacted by tuberculosis, helping them share images and tell stories about tuberculosis in order to generate awareness, reduce stigma, and improve health for individuals and communities.

Another example is *TB & Me*, which is a shared blogging project for people being treated for multi and extensive drug resistant tuberculosis from all over the world that is facilitated by Médecins Sans Frontières, the well-known international medical and humanitarian organization. The blog functions, in part, as an outlet for advocacy with stories about tuberculosis as told by the patients themselves. It also offers a form of community and support where tuberculosis patients can connect.

groups today are often established as a part of existing regulatory agencies such as research activities rather than positioned as independent units working to improve political processes (p. 13). This, too, is worthy of future consideration in relation to the ways various communities of patients inform tuberculosis control measures, particularly in the context of the discussion below about hegemonic negotiations of power involved in articulating various boundary positions.

Experiences like Adrian's, of being unable or unwilling to follow the treatment guidelines established by the TCP, or of Julia's acquiescence with the rules outlined for her despite feeling isolated and emotionally challenged throughout treatment speak to certain kinds of congruities among patients that present qualities of shared communities of practice. Other examples of patent groups whose experiences unify them as a kind of community of practice include: patients who are faced with the loss of their livelihood or ability to contribute to the financial stability of their family during their isolation and treatment; patients who face co-existing medical conditions that make their experience of treatment additionally physically and mentally challenging; patients who are distrustful of the public system as a whole and therefore seek not to participate in it; patients whose lives or livelihoods exist in more than one jurisdiction; or patients who face complex familial or social responsibilities, such as the Cruzes whom I discuss in Chapter Three.

Cultural Hegemony and Negotiation Over Meaning

A significant critique of boundary object theory is that while it provides a framework for considering multiple actors and networks, it fails to address specific power relationships, particularly between the local (individuals and communities) and the universal (discourses and best practices) (Huvila, 2011). In the context of tuberculosis control, the difficulty in accounting for local/universal power relationships maps directly onto the disjunctures associated with the "cure as prevention" paradigm that currently frames global best practices (See Chapters Three and Four). While disease and cure are both local (Bowker & Star, 2000, p. 168), the protocols shaping tuberculosis control are most often formulated as national policy guidelines that are in direct response to global best practice recommendations. As discussed in previous chapters, the interventions mounted at the national and international levels are often largely divorced from the local settings in which treatment and control is enacted. This can result in failures to meaningfully account for local need, strength, or variation. One example of this is the insufficient funding dedicated to developing lasting strategies for prevention/latent tuberculosis treatment in San Diego County, a significant need in the region. The global protocols shaping tuberculosis control are also significant because their discourses filter the understandings and actions of local actors, and the policy abstractions of these protocols bear upon and inflect local articulations of practice.

Hegemonic Negotiation and Institutional Hierarchy

Huvila (2011) suggests that a purposive analysis of cultural hegemony by researchers working in boundary object theory can begin to bridge the universal/local gap by highlighting direct links between power as a generalized occurrence and the practices of individuals and communities (p. 2528). While Star and Griesemer (2001) have suggested that the formation and maintenance of boundary objects is important to developing coherence across diverse social worlds, Huvila (2011) argues that this process is also always implicated in hegemonic negotiation.[90] Never a neutral act, the creation and maintenance of boundary objects functions as an exercise of power, even if highly implicit, that moves towards interpretive authority (p. 2536-2537). With this in mind, articulating tuberculosis as a boundary object, while carefully considering the kinds of hegemonic negotiations and institutional hierarchies at work, can help clarify the conventions of practice, policy, or concepts that become formalized as parts of the discursive and material social worlds of tuberculosis control best practices.

The work of public health advocates and social scientists to define tuberculosis as a social disease offers an example of the kinds of hegemonic negotiations involved in articulating policy for tuberculosis control. Specifically, the effort by scholars and advocates to highlight social, economic, or systemic shortcomings that impact tuberculosis as much or more than specific individuals and the particularities of their treatment protocols has begun to permeate the discourses adopted in global public health organizations. For example, Mario Raviglione, Director of the Global Tuberculosis Program at the WHO, and Ruediger Krech, Director of the WHO's Department of Ethics and Social Determinants of Health, have argued (2011) that the future of global tuberculosis control is not just dependent on considerable medical breakthroughs but also on meaningful efforts to stem health disparities linked to the "social determinants of health" that help cause tuberculosis (p. S7). In their editorial,

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[90] See Gramsci's (1971 [1929-35]) work on the cultural hegemony in *Selections from The Prison Notebooks* that describe the process of domination by consent that occurs by steering the dominant cultural beliefs, norms, and expectations of a given time and place. Direct coercion or force become unnecessary because people come to internalize particular power relations and social expectations as normal or common sense.

Tuberculosis: Still a Social Disease, the authors acknowledge the long history of researchers, physicians, and public health experts who have linked tuberculosis to social and environmental bases, and they highlight the need to learn from the their lessons, offering:

> [B]eyond better diagnosis and treatment, TB control and elimination will depend much on broad public health actions on communicable and non-communicable diseases, as well as on interventions outside the health sector... A key element and common denominator is to tackle poverty as an underlying cause of TB. (p. S7)

There are numerous examples of this kind of language in global health reports and policy, each espousing the importance of social, political and economic factors that contribute to the presence of tuberculosis. This discursive frame is also adopted in the language of doctors and other TCP employees, who often reference the social and economic barriers that certain patients and patient communities face.

While these examples indicate that some important gains have been made by health advocates and researchers to bring the social issues related to tuberculosis control into the lexicon of global public health organizations like the WHO, the incorporation of such language also raises questions related to the conceptual and semantic negotiations of meaning imbedded in such exchanges. Star and Griesemer (1989) suggest that the coherence of boundary objects is dependent on the extent to which various social worlds can coexist, offering the construction of boundary objects as a way to fulfill multiple and potentially conflicting goals (p. 413). Although they do not explicitly address cultural hegemony or institutional hierarchy, their assessment points to the ways that the establishment of boundary objects always functions as a negotiation. Particularly because consensus is not a requirement, as Bowker and Star

(2000) point out, certain interests can have more or less dominant stakes in the production of meaning. I suggest that this is certainly the case with globally articulated systems for tuberculosis control.

Despite the inclusion of language that frames tuberculosis as a social disease in global health discourse, very little has been done to address social and institutional reform. In 2006, the WHO launched the Global Plan to Stop Tuberculosis (Stop TB) to increase Directly Observed Therapy, Short-course (DOTS) coverage with outcome goals to be met by 2015. Part of this plan focused on the empowerment of people and communities with tuberculosis through a focus on advocacy and social mobilization, community participation in tuberculosis care, and the development of an international patient charter that outlined the rights and responsibilities of people with tuberculosis (Stop TB Partnership, 2006; Stop TB Partnership, 2007). In 2014, the WHO acknowledged that many of their 2015 targets would not be met and updated their strategy. Branding its newest iteration as the *End TB Strategy*, DOTS still remains a central feature to the global control platform. The first pillar of this new strategy is for national tuberculosis systems to emphasize integrated and patient centered care by focusing on early detection and access to affordable services (World Health Organization Executive Board, 2013; World Health Organization, 2015). The WHO also developed an accompanying resolution that calls on governments across the world to implement the strategy with high-level political commitment and financial backing.

While policy statements by the WHO acknowledge the importance of strong public health systems and the value of patient-centered care, they reflect limited social or system-level reform. There are several multi-layered reasons for this. Shrinking public health and tuberculosis control budgets as well as continued reliance on global financial institutions like the World Bank make it difficult to address context-specific problems. This is exacerbated by a public health system that connects funding and jobs to grant monies that incentivize standardized goals and programmatic efficiency over context-based problem solving (See the discussion of Khan & Coker, 2014 in Chapter Four). Furthermore, the current global protocols for tuberculosis control are implemented through universalized practice and minimize the role and experience of doctors while simultaneously limiting their capacity to individualize care (Khan, 2013).

For global tuberculosis policy, the definition that figures tuberculosis as primarily a biomedical disease functions as a *visionary boundary* with a kind of authority that is difficult to challenge because of its omnipresence within and beyond the domains of medicine and public health. Bowker and Star (2000) offer, “When formal characteristics are built into wide-scale bureaucracies such as the WHO, or inscribed in hospital software standards, then the compelling power of those beliefs is strengthened considerably” (p. 53). The dissemination described by Bowker and Star illustrates how visionary boundary objects, which are institutionalized as best practices with high levels of legitimacy, become difficult to challenge.[91] Beyond their formal status as authorized within official discourses or policy, visionary boundary objects are also dispersed across the technologies, belief systems, and practices of a particular domain.

In the world of global tuberculosis control, as with other domains of public health practice, struggles over meaning produce cascading implications for actors in

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[91] See the discussion of Briers & Chua (2001) above.

various capacities and help the entities that influence dominant discourses and practices maintain positions of power. That the rhetoric of tuberculosis as a social disease is often employed in global health policy without concrete action indicates an attempted cooption of resistive discourses by the hegemonic norm. However, despite the position of power associated with visionary boundary objects, hegemonic domination is a process, a constant endeavor that must be continually won and re-won (Williams, 1977). If orienting tuberculosis as a social disease critiques global control protocols as they exist, then its subsumption into formal institutional/power structures functions as an attempt to reconfigure boundaries according to the dominant logics and solidify the visionary nature of official accounts of tuberculosis.

Other Modes of Negotiating Meaning

Interactions between multiple boundary interpretations of tuberculosis also represent hegemonic negotiations. The process of diagnosis offers an example of this kind of interaction. Tuberculosis is complicated to diagnose and treat even under the most straightforward circumstances, in part because there is no single cause or localization in the body (Bowker & Star, 2000, p. 171) and also because the bacillus is frequently difficult discern due to its thick cell wall and talent to survive in relatively remote body cavities (American Thoracic Society, 2000). Adding to this, the active and latent phases that mark tuberculosis exist along a continuum of severity rather than as absolute categories (Schaaf & Zumla, 2009). Despite these variables, diagnosis at the TCP tends to happen more seamlessly than in many private clinical encounters, perhaps because the entire staff and the patient is oriented towards the question of whether a person does or does not have tuberculosis.

Like Adrian, Julia's diagnosis for active tuberculosis began in the private system. Also similar to Adrian's experience, Julia's diagnosis was nearly an act of chance (See Chapter Three for a discussion of Adrian's diagnosis). Although her experience of the disease and her life circumstances differed dramatically from Adrian's, the private doctors of each person missed the signals of active tuberculosis disease for an extended period of time in part because of the complexities involved in diagnosing tuberculosis but also because of the ways that multiple boundary definitions of tuberculosis inform the process of diagnosis itself.

Julia was visiting her private primary care doctor for a non-related health issue that involved having an x-ray, which revealed distressing lesions on her lungs. Despite this physical marker, diagnosing her condition as tuberculosis took weeks, in part because of her status as an upper-middle class naturalized citizen originally from Western Europe. "Nobody thinks that you have TB," she explained to me. She continued:

> They never think about TB. They always rule it out because, you know, I mean I don't come from a poor country. I really haven't been traveling in a poor country. And as you know TB is rare in rich countries…Everybody was telling me that is was very bad but they had no clue what I had. So it took a long, long time to be diagnosed.

After several weeks and many expert opinions, Julia's doctors concluded that she had active, multidrug-resistant tuberculosis.

Julia's circuitous path to diagnosis offers an example of the ways that multiple boundary positions of tuberculosis interact, often invisibly. In this case, her doctors were using epidemiological accounts of disease distribution and cultural perception that each suggested that tuberculosis was uncommon among upper-middle class immigrants from Western Europe. These explanations supplemented the biomedically-guided diagnostic techniques. That it took her care providers considerable time to formulate a diagnosis helps illustrate how different ways of knowing tuberculosis (in this case epidemiological, cultural, and biomedical) inform each other, even when they appear to form discrete ways of knowing. Even as Julia's experience challenges the idea that the disease can be articulated to clearly bounded social groupings, it also demonstrates the often unseen negotiation over meaning that occurs at all levels of practice.

Another example of negotiation over meaning relates to the terminologies used in tuberculosis treatment, which can help to evangelize certain kinds of subject positions. The word *compliant*, for instance, is clinic and policy shorthand for patients who take their medications as prescribed by their treating physicians. As a term, *compliant* effectively erases independent action or self-management on the part of the patient and implies a kind of docility or obedience to care providers. Similarly, *nonadherent* or *noncompliant* places treatment failures as a responsibility of the patient rather than of the complex dynamics between patient, practitioner, geopolitical location, system structure, or socioeconomic conditions.[92]

Reproduced across the discourses and practices of public health in local and global contexts, these terms point to the idealized patient of tuberculosis control, an imagined category of patient with no social or medical limitations who has readily agreed to and complied with a strict treatment regime. I argue that the ideal tuberculosis patient is one whose contradictions have been smoothed over in a negotiation over

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[92] See Trostle (1988) and Lerner (1997) for a historicization of the term 'noncompliant'.

meaning and power. The ideal patient is a figure who is conjured within global policy as a boundary response to discourses and communities of practice who challenge the status quo and in response to the incongruities felt by people like Adrian or Julia who have difficulty managing individual need against the requirements of a standardized system. The ideal patient also stands in opposition to the inadequate resources many local systems have when handling the specific needs of their communities. In this sense, the ideal patient is invoked to mitigate a system that cannot account for contingencies in its standardized policy.

Global tuberculosis platforms and local diagnostic and treatment-related activities are also formative of a seemingly different kind of subjectivity, this time figured as the antithesis of the ideal patient. This oppositional figure is equally imagined, existing as a flattened representation of the recalcitrant tuberculosis patient as a singular identity. This is the patient as noncompliant, as drug user, as immigrant, or as immunocompromised (to name a few examples among many). In this case, rather than emerging as a member of a shared community of patient experience, oppositional patients as singular identity materialize through epidemiological data, clinical discourse, media tropes, and public perception. They, like ideal patients, help smooth out contradictions in the standardized, global system of tuberculosis control by explaining systemic flaws in relation to deficiencies of the patients themselves.

Chapter Conclusions

The various classifications ascribed to tuberculosis carry with them profound implications for the daily lives of the people they address by generating material and ideological effects that impact social, medical, and political contexts. Boundary object theory is important for the work it can do to depict nuance across domains of scope and scale and demonstrate how the biomedical model and its global and national articulations as health policy do not simply dictate local practice but are also taken up and shaped by other frameworks within the context of the TCP's work.

Boundary object theory also expresses some of the ways that defining tuberculosis involves competing stakes. In particular, demarcating the broad boundary components of tuberculosis helps demonstrate that the perspectives and priorities of some communities of practice have a harder time existing within the dominant world of global tuberculosis control than others. This happens for many different reasons. Some local communities of practice, like the TCP, face greater obstacles and receive fewer resources because they have a higher-than-average case burden but are located within lower-endemic nations like the United States. As discussed in Chapter Four, tuberculosis funding tends to wax and wane in relation to the perceived threat tuberculosis and in times of economic downturn, regardless of the specific needs of communities or programs. The needs and perspectives of other communities of practice have a harder time (co)existing within the global structures of tuberculosis control because they are under-recognized within or isolated from dominant systems. For example, the experiences of disenfranchised or economically disadvantaged populations in specific local settings are often glossed over in policy discussions about tuberculosis control and represented instead as generalized publics.

Considering tuberculosis as a boundary object therefore enables us to tease out which perspectives are foregrounded in public health policy decision-making and clinical protocol and which are excluded from dominant tuberculosis control frameworks. Such an analysis can bring to light the often invisible shared spaces and incongruities between various communities of practice, including whose voice is not accounted for across the expansive stretches of scope and scale that comprise public health tuberculosis control.

DISSERTATION CONCLUSIONS

There are many stories of tuberculosis: of its causes and consequences, of social injustices, of public health reform, of biomedical developments, and of the communities, individuals and families impacted by the disease. By considering these multifaceted narratives of tuberculosis as means of understanding the activities of a local public health agency, this research aimed to develop a better understanding of how representations of the disease are connected with their materializations across global and local contexts. My examination of the ways that centrally defined protocols for control and cure create institutional and systemic constraints has been guided by the aim of fostering conversations that might shed light approaches or resources for preventing and treating tuberculosis that are not adequately pursued. These include alternative practices that are already being taken up in informal ways in community contexts like the Tuberculosis Control and Refugee Health Program (TCP) of San Diego County.

Informed to a large degree by a biomedical model that focuses on techno-medical oriented solutions, current globally-defined best practices figure tuberculosis control as a problem located largely within the body of individuals with active disease. By in large, the figuration of tuberculosis as a condition of germs inside of individual bodies has guided understandings and policies of public health management. As such, global tuberculosis control reveals a great deal about the kinds of selves that are imagined by current logics and best practices. The focus on the individual as a vector for disease deemphasizes important social, political, and economic factors that have a bearing on the unfolding of the disease, including important regionally based variations that change across time and place. In San Diego County as with many other parts of the world, medication shortages and sweeping divestments in tuberculosis research have served as indicators of limitations in global health infrastructures. Linked to drug shortages and research divestments, local tuberculosis control programs in the United States continue to face broad pullbacks in funding. Budget cuts have placed greater pressure on the ability of local health departments to fulfill even their basic duties, while further entrenching the individual-as-cure rhetoric embedded in the design of the current system.

Just as an ideology of individual responsibility underwrites many of the infrastructural shortcomings that impact local tuberculosis control efforts, a racialized ideology also impacts how we understand and treat the disease by flattening accounts of its etiology. The discourses and practices that link race or national origin to disease embody a particular “way of seeing” that associates disease and contagion with racially and ethnically delineated populations (Nevins, 2002). Such discourses personify a fear of contamination and emphasize the rhetoric of individual responsibility while downplaying important systemic and institutional shortcoming like drug shortages, pullbacks in funding for research and development, and public health budget cuts for local programming.

Because the delivery of public health services is complex, even within the structuring frameworks of standardized policy, it requires a high level of interface among a diverse set of actors across domains of scope and scale. Even at the local level, the diagnosis and treatment of tuberculosis includes a diverse array of actors: public administrators, policy makers, public and private doctors and nurses, laboratory technicians, disease investigators, patients, families, community organizations, law enforcement, social workers, case managers, educators, data management software developers, epidemiologists, pharmacists, and more. This work is highly interdisciplinary and collaborative, and it is also decidedly hierarchical. Investigating the various boundary positions of tuberculosis helps to articulate the kinds of negotiations involved in enacting control programs across the wide scope and scales involved in public health management.

Revisiting the Cure as Prevention Framework

Positioning tuberculosis as a boundary object has helped bring to life the ways that struggles over meaning reflect struggles over the maintenance of power. By extension, this orientation has allowed me to reexamine the "cure as prevention" framework that currently guides global tuberculosis control policy in ways that help explain the affordances and restrictions experienced by actors whose lives and/or labors are variously positioned in relation to the disease. As a concept, cure as prevention is rooted in the biomedical model and exemplified by the Directly Observed Therapy, Short-course (DOTS) protocol. It is characterized by a belief in the power of technology and medical advancement to repair illness and disease, and it is often dependent on the compliance of the patient to carry out its vision. Like the biomedical model that informs it, the cure as prevention paradigm equates the body to an instrument or machine in need of fine-tuning, promising to repair disease or to prevent it altogether.[93] It extends also beyond the domains of the clinic, laboratory, or hospital by informing expectations for recovery and the social status of healthy people and bodies.[94]

There are many advantages to this way of approaching illness and disease. The biomedical model has helped usher in significant medical advancements and interventions that have, without question, improved the quality and viability of human lives. But the biomedical model also carries with it some important implications for how we understand and manage illness, disease, and disability. At the level of policy and practice, the cure as prevention approach has had difficulty addressing the aspects of tuberculosis and attempts at its containment that are socially produced or that vary across culture and place. In addition, the cure as prevention model inverts the popular health adage that suggests prevention works as the best form cure, a transposition that

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[93] See the introduction to the dissertation for a discussion of the biomedical model's links to a machine-like rationality, including commentary informed by Komesaroff (1995), Leder (1998), Lupton (1995), Segal (1997) and others.

[94] Many authors have taken up the concept of cure in relation to the individual and social body. For example, Morris (1998) writes that our "anxieties about death have shifted from the fact of dying to the methods that medicine will use to keep us alive" (p. 16). From this perspective, a drive towards cure obliges continued treatment, even in the face of death. In this sense, death or dying is inscribed as a failure to heal and helps define the limits of cure itself.

In another example, Gray (2009) figures the promise of cure to fix or prevent illness and disability as an attempt to normalize disabled bodies. She writes, "The grand narrative of assimilation always rests on this desire to find 'the cure', as it appears to offer the only suitable societal response to supposedly deficient disabled bodies" (p. 323-324). In this instance, certain bodies and people are rendered manageable only with the assimilating authority of the model of cure.

The regulatory work of this perspective, as manifested in the form of the hope for extended life and the push towards assimilation, however, offer a glimpse into the ways that a mandate for cure extends beyond biomedical domains alone to inform social ways of knowing and acting. Not only confined to people at the end of life, experiencing chronic illness or labeled as disabled, this regulatory logic also works on people for whom cure is presumed to function. Such is the case of tuberculosis.

has diverted important attention and resources away from finding and treating patients with latent tuberculosis.

The label of “cured” is not a clearly bounded health status in the context of tuberculosis control. In a strictly biomedical sense, cure most often refers to the moment when active disease is eliminated. However, disease elimination as a marker of cure is not so straightforward for tuberculosis. The first layer of complexity is that not everyone infected with tuberculosis becomes sick. As a result two tuberculosis conditions exist: active disease and latent infection. Medicines are said to cure tuberculosis, although treatment cannot fully eliminate all bacteria from the body, nor can it provide a guarantee that the remaining tuberculosis will not become active in the future. Likewise, treatment for latent tuberculosis infection can only help prevent future activation. Meanwhile, tuberculosis patients with active disease are frequently categorized as cured at the six-month treatment marker, although antibiotic courses often last 9 months or longer, and once a person completes their course treatment they are still at risk for reactivation. This means that the label of “cured” is applied even while the patient is still taking medicine, with the remaining treatment acting as a form of insurance against any outlying persistent infection.

Given the amorphous meaning of cure in the context of tuberculosis treatment, it is ironic that the prevention framework operationalizes cure in a way that assumes complete recovery. Ultimately, with the treatment technologies at our disposal today, the bacteria that cause tuberculosis can never be fully eradicated from the body.[95] Furthermore, in its privileging of a definition of cure that necessitates the presence of active/communicable disease, the cure as prevention model undervalues important efforts to help stem the tuberculosis crisis worldwide through preventative tuberculosis treatment as a means of reducing transmission. Such preventative efforts read as less important because they are not dealing directly with active disease, although the case could be made that they are dealing with the active disease of tomorrow.

In addition, the biomedical model's expectation of cure does not adequately account for the medical subject's experiences of tuberculosis that continue after the time an illness has run its course. When tuberculosis ceases to be communicable, the process of diagnosis and treatment constitutes a fuzzy space in which people are often suspended between distinctions of well and ill. The patient is neither wholly well nor easily identified as ill. The implications of this kind of liminality manifest in critical life domains. For example, tuberculosis medications can make patients feel weak and/or nauseous, often impeding how they are able to function. However, because they are no longer infectious, they are marked as cured and often must return to work or life as usual even while continuing to take medications that make them feel sicker than they would if they stopped taking them altogether.

When public health orientations serve to frame tuberculosis in relation to discrete moments of physical crisis for which solutions are presumed to inhabit the biological domain (remedied through antibiotic treatment), the burden of cure is placed

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[95] It is worth noting that this is true of a number of important contagious diseases including Hepatitis C or HIV and raises important questions about the broad implications of this for considerations of cure in relation to the individual and social body.

on the individual or, worse, his or her body parts. The resonances of such burdens are powerful. In the case of tuberculosis, cure operates as a manufactured state of bodily exception in which persisting remnants of the illness experience, including the bacteria itself, are incommensurate with the concept of the “cured” subject.

Reimagining Tuberculosis Control as a Communicative Space

My research indicates that many of the burdens and barriers of tuberculosis extend well beyond the willingness and ability of patients, compliant or not, to adhere to standardized diagnosis and treatment protocols. These impediments and encumbrances are also linked to unjust sociopolitical structures, unmet community need, and system-level constraints that predispose local and national decision makers to value programmatic decisions that focus on solving short-term problems rather than developing long-term goals. This is perhaps most obvious in the focus of current tuberculosis control efforts to treat active tuberculosis cases, while detection and treatment programs for latent tuberculosis infection remain woefully underfunded and underdeveloped. It is also apparent that in the wax and wane of tuberculosis control funding, local programs are left struggling to carryout baseline services. My research also indicates a strong need for flexibility in treatment protocol and fluidity across the various definitions of tuberculosis and the communities of practice that employ them.

Elaborating the global/local relationships that are central in current tuberculosis control best practices has helped highlight the potentially productive role of reimagining tuberculosis control as a *communicative space*. Action researchers who are interested developing a theory of practice that better guides participatory research have taken up communicative spaces as a point of study.[96] Following Habermas' (1974, 1984) engagement with what he saw as an erosion of communicative opportunities in the public sphere brought on by mass culture and a culture of consumption, action researchers have defined communicative spaces as a principle mode for engendering critical discourse among members of a community. Communicative spaces in the context of action research are important for their focus on a "critical awareness of and attention to the obstacles that get in the way of dialogue" (Wicks & Rearson, 2009).

The burdens and barriers of tuberculosis cannot likely be fully eliminated without large-scale systemic change. However, highlighting current potentials and creating openness to unforeseen possibilities within existing tuberculosis control infrastructures can help develop solutions that better balance the requirements of the overarching system with the needs of its local manifestations. Reframing tuberculosis control as a communicative space does not devalue the contribution of biotechnical solutions in addressing the number of active tuberculosis cases worldwide. It does, however, offer a conceptual framework for better understanding the constraints and opportunities for negotiating the powerful forces that control policy and resources for public health, including recognizing the agency of a variety of communities of practice for whom tuberculosis exists as multiple rather than singular.

In this sense, tuberculosis control reimagined as a communicative space lassos community-specific strengths and takes seriously the informal acts of outreach and advocacy that are already being carried out in local contexts. It allows us to consider the moments in which people have agency or the system offers affordances. For example,

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[96] See Beaven (2013), Godin et al. (2007), and Wicks and Reason (2009).

in Chapter Three my research identified a number of positive contributions to tuberculosis control at the local level, such as companionship and advocacy, that were carried out by TCP staff members but that remain largely unrecognized as valuable by the formal system. The example of the Cruzes illustrates how patients who feel isolated and often look forward to daily visits from their DOTS delivery worker or assigned public health nurse for the sense of companionship and reassurance they felt. I also noted how nurses sometimes acted as informal advocates for patients, helping them secure appropriate care outside of the domain of tuberculosis.

My fieldwork made me privy to many additional examples of this kind of informal advocacy and care work; for example, doctors who helped patients locate low-cost community clinics or communicable disease investigators and case managers who helped patients enroll in public assistance programs that did not relate directly to their tuberculosis treatment (but did help improve their overall health). In addition to informal actions such as companionship and advocacy, the TCP also interfaces with a number of community-centered coalitions and organizations that, although undervalued by the formal system, act as powerful agents of change. But this begs the question: What would tuberculosis control look like if we could better incorporate community resources such as Adrian's church and pastor into tuberculosis management systems?

Most often occurring as informal byproducts of the behaviors of individual actors, moments of companionship, outreach, or advocacy by TCP staff members existed largely external to the current system. I attribute this to the fact that they do not directly fulfill the instrumental expectations of DOTS protocols and are not included in internal or external assessments of how well the local system is functioning. Having said this, such informal actions support the functioning of the system at the local level and overall, even if they are not evaluated as such.

The cure as prevention framework reinforces a relationship to care and cure that minimizes the moments of agency and action beyond those that are part of the formal system's managerial and regulatory functions. The instrumentality of the cure as prevention framework points to a dominant narrative in global tuberculosis control that privileges biomedical interpretations of health and illness and, in turn, informs the social processes in which disease without cure is marginalized as a failure on the part of individual patients. It is in these moments that bounded distinctions between complete health or complete illness begin to break down and proves such clear-cut differentiations to be more illusory than substantive. It is also in these moments that defining the communicative potentials of tuberculosis control becomes fruitful. If dominant discourses of health and cure reinforce the bounds of the abject by positioning the disease as a conundrum of the problem body and as a mode of alterity, reimagining tuberculosis control as a communicative space pushes at the rough edges of normative representation.

REFERENCES

Abel, Emily K. (2007). *Tuberculosis and the politics of exclusion: A history of public health and migration to Los Angeles*. New Brunswick, NJ: Rutgers University Press.

Airhihenbuwa, C. O., & Obregon, R. (2000). A critical assessment of theories/models used in health communication for HIV/AIDS. *Journal of Health Communication, 5*(sup1), 5-15.

American Thoracic Society. (2000). Diagnostic standards and classification of tuberculosis in adults and children. *American Journal of Respiratory and Critical Care Medicine, 161*(4), 1376-1395.

Armstrong, D. (1993). Public health spaces and the fabrication of identity. *Sociology, 27*(3), 393-410.

Asch, S., Leake, B., & Gelberg, L. (1994). Does fear of immigration authorities deter tuberculosis patients from seeking care? *Western Journal of Medicine, 161*(4), 373-376.

Barnes, D. S. (1995). *The making of a social disease: Tuberculosis in nineteenth-century France*. Berkeley: University of California Press.

Barton, A. (2013). CDC report on U.S. TB drug shortage reflects local and global challenges. *Science Speaks: HIV & TB News*. http://sciencespeaksblog.org/2013/01/17/cdc-report-on-u-s-tb-drug-shortage-reflects-local-and-global-challenges/#axzz2IJJASilP

Bashford, A. (Ed.) (2007). *Medicine at the border: Disease, globalization and security, 1850 to the present*. Houndmills, Basingstoke, Hampshire: Palgrave Macmillan.

Bayer, R., & Wilkinson, D. (1995). Directly observed therapy for tuberculosis: History of an idea. *The Lancet, 345*(8964), 1545-1548.

Benatar, S. R. (2003). Global poverty and tuberculosis: Implications for Ethics and Human Rights. In M. Gandy & A. Zumla (Eds.), *The return of the white plague: Global poverty and the "new" tuberculosis* (pp. 222-236). London: Verso.

Biehl, J. G. (2005). *Vita: Life in a zone of social abandonment*. Berkeley: University of California Press.

Biehl, J. G., Good, B., & Kleinman, A. (2007). *Subjectivity: Ethnographic investigations*. Berkeley: University of California Press.

Bishop, J. P. (2008). Rejecting medical humanism: Medical Humanities and the metaphysics of medicine. *Journal of Medical Humanities, 29*(1), 15-25.

Blanc, D. C., & Nunn, P. (2000). Incentives and disincentives for new anti-tuberculosis drug development: A situation analysis. Geneva: World Health Organization.

Blevins, S. M., & Bronze, M. S. (2010). Robert Koch and the 'golden age' of bacteriology. *International Journal of Infectious Diseases, 14*(9), e744-e751.

Booker, M. J. (1996). Compliance, coercion, and compassion: Moral dimensions of the return of tuberculosis. *Journal of Medical Humanities, 17*(2), 91-102.

Bourgois, P. I., & Schonberg, J. (2009). *Righteous dopefiend*. Berkeley: University of California Press.

Bowker, G. C., & Star, S. L. (2000). *Sorting things out: Classification and its consequences*. Cambridge: MIT Press.

Briers, M., & Chua, W. F. (2001). The role of actor-networks and boundary objects in management accounting change: A field study of an implementation of activity-based costing. *Accounting, Organizations and Society, 26*(3), 237-269.

Brodine, S., Cunningham, L., Fraga, M. A., Garfein, R., Kiy, R., Méndez, J., …Smith, J. (2010). Tuberculosis in the San Diego-Tijuana border region: Time for bi-national community-based solutions. San Diego: International Community Foundation.

Brown, W. (2005). Neoliberalism and the end of liberal democracy *Edgework: Critical essays on knowledge and politics* (pp. 37-59). Princeton: Princeton University Press.

Bruner, J. (1990). *Acts of meaning*. Cambridge: Harvard University Press.

Bruner, J. (2004). Life as narrative. *Social Research: An International Quarterly, 71*(3), 691-710.

Burch, S., & Sutherland, I. (2006). Who's not yet here? American disability history. *Radical History Review*(94), 127-147.

Butler, J. (2005). *Giving an account of oneself* (1st ed.). New York: Fordham University Press.

Byrne, K. (2011). *Tuberculosis and the Victorian literary imagination*. Cambridge: Cambridge University Press.

Cabrera, O. A., Hodge, J. G., & Gostin, L. O. (2009). Express tuberculosis control laws in selected US jurisdictions: A report to the Centers for Disease Control and Prevention. Centers for Law and the Public's Health: A Collaborative at Johns Hopkins and Georgetown Universities.

California Department of Public Health. (2014). Tuberculosis program assessment tool. https://www.cdph.ca.gov/programs/tb/Documents/TBCB-TPAT-FINAL.pdf

Cantwell, M. F., Snider, D. E., Cauthen, G. M., & Onorato, I. M. (1994). Epidemiology of tuberculosis in the United States, 1985 through 1992. *Journal of the American Medical Association, 272*(7), 535-539.

Centers for Disease Control and Prevention. (1993). Initial therapy for tuberculosis in the era of multidrug resistance: Recommendations of the advisory council for the elimination of tuberculosis. *Morbidity and Mortality Weekly Report, 42*(No. RR-7), 1-8.

Centers for Disease Control and Prevention. (1995). Recommendations and reports: Essential components of a tuberculosis prevention and control program. *Morbidity and Mortality Weekly Report, 44*(RR-11), 1029-1029.

Centers for Disease Control and Prevention. (2010). Establishing a holistic framework to reduce inequities in HIV, viral hepatitis, STDS, and tuberculosis in the United States. Atlanta, GA: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention.

Centers for Disease Control and Prevention. (2011). Strategic planning for tuberculosis (TB) elimination in the United States and prevention and control of TB globally. Atlanta: Centers for Disease Control and Prevention, Division of Tuberculosis Elimination.

Centers for Disease Control and Prevention. (2012). Notes from the field: National shortage of Isoniazid 300 mg tablets. *Morbidity and Mortality Weekly Report, 61*(50), 1029-1029.

Centers for Disease Control and Prevention. (2013a). Impact of a shortage of first-line antituberculosis medication on tuberculosis control — United States, 2012–2013. *Morbidity and Mortality Weekly Report, 62*(20), 398-400.

Centers for Disease Control and Prevention. (2013b). Interruptions in supplies of second-line antituberculosis drugs — United States, 2005–2012. *Morbidity and Mortality Weekly Report, 62*(2), 23-26.

Centers for Disease Control and Prevention. (2014). Reported tuberculosis in the United States, 2013. Atlanta, GA: Department of Health and Human Services, Centers for Disease Control and Prevention.

Centers for Disease Control and Prevention Health Alert Network. (2013). Recommendations for drug allocation, tuberculosis prevention, and patient care during Isoniazid shortages. Centers for Disease Control and Prevention Emergency Risk Communication Branch; Division of Emergency Operations; Office of Public Health Preparedness and Response.

Centers for Law and the Public's Health. (2009). Tuberculosis control laws and policies: A handbook for public health and legal practitioners. Baltimore, MD: Centers for Disease Control and Prevention.

Cerwonka, A. (2007). Nervous conditions: The stakes of interdisciplinary research. In A. Cerwonka & L. H. Malkki (Eds.), *Improvising theory: Process and temporality in ethnographic fieldwork* (pp. 1-40). Chicago: The University of Chicago Press.

Chalke, H. D. (1962). The impact of tuberculosis on history, literature and art. *Medical History, 6*(4), 301-318.

Chambers, R. (2015). In conversation: Ambassador Eric Goosby readies for the fight to defeat tuberculosis. http://www.huffingtonpost.com/ray-chambers/in-conversation-uns-newly_b_6913322.html

Charmaz, K. (1991). *Good days, bad days: The self in chronic illness and time*. New Brunswick, N.J.: Rutgers University Press.

Charon, R. (2001a). Narrative medicine: A model for empathy, reflection, profession, and trust. *Journal of the American Medical Association, 286*(15), 1897-1902.

Charon, R. (2001b). Narrative medicine: Form, function, and ethics. *Annals of Internal Medicine, 134*(1), 83-87.

China Tuberculosis Control Collaboration. (1996). Results of directly observed short-course chemotherapy in 112, 842 Chinese patients with smear-positive tuberculosis. *The Lancet, 347*(8998), 358-362.

Clarke, A. (2005). *Situational analysis: Grounded theory after the postmodern turn*. Thousand Oaks, CA: Sage Publications.

Clarke, A., Mamo, L., Fosket, J. R., Fishman, J. R., & Shim, J. K. (2010). *Biomedicalization: Technoscience, health, and illness in the US*. Durham, NC: Duke University Press.

Clift, C. (2013). The Role of the World Health Organization in the international system. London: Chatham House.

Coker, R. J. (2000). *From chaos to coercion: Detention and the control of tuberculosis*. New York: St. Martin's Press.

Coker, R. J. (2003). Public health impact of detention of individuals with tuberculosis: Systematic literature review. *Public Health, 117*(4), 281-287.

Collins, K., Munoz, F., Moser, K., Cerecer-Callu, P., Raab, F., Flick, A., . . . Garfein, R. (2013). Experience with mobile technology among patients with tuberculosis in San Diego, California and Tijuana, Mexico. *Journal of Mobile Technology in Medicine, 2*(4s), 13-13.

Condrau, F. (2001). "Who is the captain of all these men of death": The social structure of a tuberculosis sanatorium in postwar Germany. *Journal of Interdisciplinary History, 32*(2), 243-262.

Conquergood, D. (1991). Rethinking ethnography: Towards a critical cultural politics. *Communications monographs, 58*(2), 179-194.

Conquergood, D. (2002). Performance studies: Interventions and radical research. *The Drama Review, 46*(2), 145-156.

Conrad, P., & Barker, K. K. (2010). The social construction of illness: Key insights and policy implications. *Journal of Health and Social Behavior, 51*(1 suppl), S67-S79.

Corker, M., & Shakespeare, T. (2002). *Disability/postmodernity: Embodying disability theory*. London: Continuum.

County of San Diego Health and Human Services Agency (n.d.). Adopted operational plan fiscal years 2013-2014 and 2014-2015. http://www.sdcounty.ca.gov/auditor/pdf/adoptedplan_13-15_hhsa.pdf

Courtwright, A., & Turner, A. N. (2010). Tuberculosis and stigmatization: Pathways and interventions. *Public Health Reports, 125*, 34-42.

Cox, H. S., Morrow, M., & Deutschmann, P. W. (2008). Long term efficacy of DOTS regimens for tuberculosis: Systematic review. *British Medical Journal, 336*(7642), 484-487.

Daniel, T. M. (2006). The history of tuberculosis. *Respiratory Medicine, 100*(11), 1862-1870.

Daniels, C. (2014). Epidemic: Killer TB spreads as research plummets *Expert Voices: Live Science Op-Ed*. http://www.livescience.com/48342-tb-cases-grow-as-disease-research-fades-away.html

Davis, L. J. (1997). *The disability studies reader*. New York: Routledge.

Davis, L. J. (1997). Constructing normalcy: The bell curve, the novel, and the invention of the disabled body in the nineteenth century. In L. J. Davis (Ed.), *The disability studies reader* (pp. 9-28). New York: Routledge.

Davis, L. J., & Morris, D. B. (2007). Biocultures manifesto. *New Literary History, 38*(3), 411-418.

Descartes, R. (1972 [1664]). *Treatise of man* (T. S. Hall, Trans.). Cambridge: Harvard University Press.

Descartes, R. (1989 [1649]). *The passions of the soul* (S. Voss, Trans.). Indianapolis: Hackett Pub. Co.

Dormandy, T. (2000). *The white death: A history of tuberculosis*. New York: New York University Press.

Dowdle, W. R., & Centers for Disease Control and Prevention. (1989). A strategic plan for the elimination of tuberculosis in the United States. *Morbidity and Mortality Weekly Report, 38*(S-3), 1-25.

Dubos, R. J., & Dubos, J. (1996 [1952]). *The white plague: Tuberculosis, man, and society*. New Brunswick: Rutgers University Press.

Dutta, M. J. (2007). Communicating about culture and health: Theorizing culture-centered and cultural sensitivity approaches. *Communication Theory, 17*(3), 304-328.

Dutta, M. J. (2010). The critical cultural turn in health communication: Reflexivity, solidarity, and praxis. *Health Communication, 25*(6-7), 534-539.

Eisenberg, L. (1999). Does social medicine still matter in an era of molecular medicine? *Journal of Urban Health, 76*(2), 164-175.

Enarson, D. A. (1991). Principles of [International Union Against Tuberculosis and Lung Disease] IUATLD collaborative tuberculosis progammes. *Bulletin of the International Journal of Tuberculosis and Lung Disease, 66*, 195-200.

The Lancet Diabetes & Endocrinology. (2014). Diabetes and tuberculosis—A wake-up call. *The Lancet Diabetes & Endocrinology, 2*(9), 677.

European Medicines Agency. (2013). Press release: European medicines agency recommends two new treatment options for tuberculosis. London: European Union.

Fadiman, A. (1997). *The spirit catches you and you fall down: A Hmong child, her American doctors, and the collision of two cultures* (1st ed.). New York: Farrar, Straus, and Giroux.

Farmer, P. (1992). *AIDS and accusation: Haiti and the geography of blame*. Berkeley: University of California Press.

Farmer, P. (1996). Social inequalities and emerging infectious diseases. *Emerging infectious diseases, 2*(4), 259–269.

Farmer, P. (1997). Social scientists and the new tuberculosis. *Social Science & Medicine, 44*(3), 347-358.

Farmer, P. (1999). *Infections and inequalities: The modern plagues*. Berkeley: University of California Press.

Farmer, P. (2000). The Consumption of the Poor: Tuberculosis in the 21st century. *Ethnography, 1*(2), 183-216.

Fätkenheuer, G., Taelman, H., Lepage, P., Schwenk, A., & Wenzel, R. (1999). The return of tuberculosis. *Diagnostic Microbiology and Infectious Disease, 34*(2), 139-146.

Fokazi, S. (2014). Breakthrough against drug-resistant TB. *Independent Online, 2014*(March 4). http://www.tbonline.info/posts/2014/3/5/breakthrough-against-drug-resistant-tb/

Ford, L. A., Crabtree, R. D., & Hubbell, A. (2009). Crossing borders in health communication research: Toward an ecological understanding of context, complexity, and consequences in community-based health education in the US–Mexico borderlands. *Health Communication, 24*(7), 608-618.

Fortun, K. (2012). Ethnography in late industrialism. *Cultural Anthropology, 27*(3), 446-464.

Foucault, M. (1977). *Discipline and punish: The birth of the prison* (1st American ed.). New York: Pantheon Books.

Foucault, M. (1980). *Power/knowledge: Selected interviews and other writings, 1972-1977* (C. Gordon Ed. 1st American ed.). New York: Pantheon Books.

Foucault, M. (1994 [1963]). *The birth of the clinic: An archaeology of medical perception*. New York: Vintage Books.

Foucault, M. (2000 [1974]). *The birth of social medicine* (Vol. 3). New York: New Press.

Foucault, M. (2003 [1963]). *The birth of the clinic* (3rd ed.). London: Routledge.

Foucault, M. (2008). *The birth of biopolitics: Lectures at the Collège de France, 1978-79* (M. Senellart Ed.). New York: Palgrave Macmillan.

Fox, W. (1958). The problem of self-administration of drugs; With particular reference to pulmonary tuberculosis. *Tubercle, 39*(5), 269-274.

Frank, A. W. (1990). Bringing bodies back in: A decade review. *Theory, Culture & Society, 7*(1), 131-162.

Frank, A. W. (1995). *The wounded storyteller: Body, illness, and ethics*. Chicago: University of Chicago Press.

Frick, M. (2014). Flatlined: US government investments in tuberculosis research and development, 2009–2012. New York: Treatment Action Group.

Frick, M, & Jimenez-Levi, E. (2013). 2013 report on tuberculosis research funding trends, 2005–2012 *Tuberculosis Research and Development*. New York: Treatment Action Group.

Frieden, T. R. (1999). Directly observed treatment for tuberculosis. *The Lancet, 353*(9147), 146.

Frieden, T. R., & Driver, C. R. (2003). Tuberculosis control: Past 10 years and future progress. *Tuberculosis, 83*(1–3), 82-85.

Frieden, T. R., Lerner, Barron H., & Rutherford, B. R. (2000). Lessons from the 1800s: Tuberculosis control in the new millennium. *The Lancet, 355*(9209), 1088-1092.

Gandy, M., & Zumla, A. (2002). The resurgence of disease: Social and historical perspectives on the ‘new’ tuberculosis. *Social Science & Medicine, 55*(3), 385-396.

Gandy, M., & Zumla, A. (2003). *The return of the white plague: Global poverty and the "new" tuberculosis*. London: Verso.

Garfein, R., Collins, K., Munoz, F., Moser, K., Cerecer-Callu, P., Sullivan, M.,…Patrick, K. (2012). High Tuberculosis treatment adherence obtained using mobile phones for video directly observed therapy: Results of a binational pilot study. *Journal of Mobile Technology in Medicine, 1*(4S), 30-30.

Garland-Thomson, R. (2007). Shape structures story: Fresh and feisty stories about disability. *Narrative, 15*(1), 113-123.

Garner, P. (1998). What makes DOT work? *The Lancet, 352*(9137), 1326-1327.

Geertz, C. (1973). *The interpretation of cultures: Selected essays*. New York: Basic Books.

Geffen, N. (2011, 1 July). Battling the white plague: A brief history of Tuberculosis. http://www.tbonline.info/posts/2011/6/29/battling-white-plague/#id7

Gler, M. T., Skripconoka, V., Sanchez-Garavito, E., Xiao, H., Cabrera-Rivero, J. L., Vargas-Vasquez, D. E.,…Wells, C. D. (2012). Delamanid for multidrug-resistant pulmonary tuberculosis. *New England Journal of Medicine, 366*(23), 2151-2160.

Godin, P., Davies, J., Heyman, B., Reynolds, L., Simpson, A., & Floyd, M.. (2007). Opening communicative space: A Habermasian understanding of a user-led participatory research project. *The Journal of Forensic Psychiatry & Psychology, 18*(4), 452-469.

Gostin, L. O. (1995). Tuberculosis and the power of the state: Toward the development of rational standards for the review of compulsory public health powers. *University of Chicago Law School Roundtable, 2*, 219-277.

Gramsci, A. (1971 [1929-35]). *Selections from the prison notebooks of Antonio Gramsci* (Q. H. a. G. N. Smith, Trans.). London: Lawrence and Wishart.

Grange, J. M. (1999). The global burden of tuberculosis. In J. D. H. Porter & J. M. Grange (Eds.), *Tuberculosis: An interdisciplinary perspective* (pp. 3-32). London: Imperial College Press.

Gray, A., & Manasse, H. R. Jr. (2012). Shortages of medicines: A complex global challenge. *Bulletin of the World Health Organization, 90*(3), 158.

Gray, C. (2009). Narratives of disability and the movement from deficiency to difference. *Cultural Sociology, 3*(2), 317-332.

Griffith, M. M., Gross, A. E., Sutton, S. H., Bolon, M. K., Esterly, J. S., Patel, J. A.,…Scheetz, M. H. (2012). The impact of anti-infective drug shortages on hospitals in the United States: Trends and causes. *Clinical Infectious Diseases*.

Guttman, N., & Ressler, W. H. (2001). On being responsible: Ethical issues in appeals to personal responsibility in health campaigns. *Journal of Health Communication: International Perspectives, 6*(2), 117-136.

Habermas, J. (1975). *Legitimation crisis*. Boston: Beacon Press.

Habermas, J. (1984). *The theory of communicative action*. Boston: Beacon Press.

Hall, H. Irene, C., Adolfo, Y., Paula W., & Braden, C. R. (2012). Lexicon, definitions, and conceptual framework for public health surveillance. *Morbidity and Mortality Weekly Report, 61*(3), 10-14.

Harries, A. D., Salaniponi, F. M., & Kwanjana, J. H. (1999). Directly observed treatment for tuberculosis. *The Lancet, 353*(9147), 146-147.

Hartman-Adams, H., Clark, K., & Juckett, G. (2014). Update on latent tuberculosis infection. *American Family Physician, 89*(11), 889-896.

Haugh, S. (2009). The hill of health: Aspects of community at the Waipiata Tuberculosis Sanatorium, 1923-1961. *Health and History, 11*(2), 1-20.

Health and Human Services Agency. (2015 [March 26]). Comparison of national, state and county data for tuberculosis, 2007-2014. San Diego, CA: County of San Diego Tuberculosis and Refugee Health Branch.

Health and Human Services Agency, Centers for Disease Control and Prevention, & National Center for Emerging and Zoonotic Infectious Diseases. (2009). CDC immigration requirements: Technical instructions for tuberculosis screening and treatment, using cultures and directly observed therapy.

Health and Human Services Agency, Centers for Disease Control and Prevention, & National Center for Emerging and Zoonotic Infectious Diseases. (2012). Guidelines for screening for tuberculosis infection and disease during the domestic medical examination for newly arrived refugees.

Héricourt, J. (1920). *The social diseases: Tuberculosis, syphilis, alcoholism, sterility*. London: George Routledge & Sons, LTD.

Hewlett, B. S., & Hewlett, B. L. (2008). *Ebola, culture, and politics: The anthropology of an emerging disease*. Belmont, CA: Thomson.

Ho, M.-J. (2004). Sociocultural aspects of tuberculosis: A literature review and a case study of immigrant tuberculosis. *Social Science & Medicine, 59*(4), 753-762.

Holman, C. D. J. (1992). Something old, something new: Perspectives on five 'new'public health movements. *Health Promotion Journal of Australia, 2*(3), 4-11.

Horter, S., Stringer, B., Venis, S., & du Cros, P. (2014). "I can also serve as an inspiration": A qualitative study of the TB&ME blogging experience and its role in MDR-TB treatment. *PLOS One, 9*(9).

Hughes, B., & Paterson, K. (1997). The social model of disability and the disappearing body: Towards a sociology of impairment. *Disability & Society, 12*(3), 325 - 340.

Hurtig, A.-K., Porter, J. D. H., & Ogden, J. A. (1999). Tuberculosis control and directly observed therapy from the public health/human rights perspective. *The International Journal of Tuberculosis and Lung Disease, 3*(7), 553-560.

Huvila, I. (2011). The politics of boundary objects: Hegemonic interventions and the making of a document. *Journal of the American Society for Information Science and Technology, 62*(12), 2528-2539.

Jacobson v. Massachusetts, 197 US 11 (1905).

Jacquet, V., Morose, W., Schwartzman, K., Oxlade, O., Barr, G, .Grimard, F., & Menzies, D. (2006). Impact of DOTS expansion on tuberculosis related outcomes and costs in Haiti. *BMC Public Health, 6*(1), 209.

Joseph H. Pratt, Pioneer. (1955). *New England Journal of Medicine, 253*(5), 203-204.

Kelly, M. P., & Field, D. (1996). Medical sociology, chronic illness and the body. *Sociology of Health & Illness, 18*(2), 241-257.

Kelly, P. (1999). Isolation and stigma: The experience of patients with active tuberculosis. *Journal of Community Health Nursing, 16*(4), 233-241.

Keshavjee, S., & Farmer, P. (2012). Tuberculosis, drug resistance, and the history of modern medicine. *New England Journal of Medicine, 367*(10), 931-936.

Khan, M. S., & Coker, R. J. (2014). How to hinder tuberculosis control: Five easy steps. *The Lancet, 384*(9944), 646-648.

Kim, J. Y., Shakow, A., Mate, K., Vanderwarker, C., Gupta, R., & Farmer, P. (2005). Limited good and limited vision: Multidrug-resistant tuberculosis and global health policy. *Social Science & Medicine, 61*(4), 847-859.

Kimerling, M. E., Kluge, H., Vezhnina, N., Lacovazzi, T., Demeulenaere, T., Portaels, F., & Matthys, F. (1999). Inadequacy of the current WHO re-treatment regimen in a central Siberian prison: Treatment failure and MDR-TB. *The International Journal of Tuberculosis and Lung Disease, 3*(5), 451-453.

King, N. B. (2003). Immigration, race and geographies of difference in the tuberculosis pandemic. In M. Gandy & A. Zumla (Eds.), *The return of the white plague: Global poverty and the "new" tuberculosis* (pp. 39-54). London: Verso.

Koch, E. (2011). Local microbiologies of tuberculosis: Insights from the Republic of Georgia. *Medical Anthropology, 30*(1), 81-101.

Koch, E. (2013). *Free market tuberculosis: Managing epidemics in post-Soviet Georgia*. Nashville, TN.: Vanderbilt University Press.

Kochi, A. (1997). Tuberculosis control--Is DOTS the health breakthrough of the 1990s? *World health forum, 18*(3-4), 225-247.

Kochi, A. (1999). Directly observed treatment for tuberculosis. *The Lancet, 353*(9147), 147.

Komesaroff, P. A. (1995). *Troubled bodies: Critical perspectives on postmodernism, medical ethics, and the body*. Durham: Duke University Press.

Kraut, A. M. (1994). *Silent travelers: Germs, genes, and the "immigrant menace"*. New York, NY: Basic Books.

Krueger, K., Ruby, D., Cooley, P., Montoya, B., Exarchos, A., Djojonegoro, B. M., & Field, K. (2010). Videophone utilization as an alternative to directly observed therapy for tuberculosis. *The International Journal of Tuberculosis and Lung Disease, 14*(6), 779-781.

Ku, L., & Matani, S. (2001). Left out: Immigrants' access to health care and insurance. *Health Affairs, 20*(1), 247-256.

Lave, J., & Wenger, E. (1991). *Situated learning: Legitimate peripheral participation*. Cambridge: Cambridge University Press.

Lawlor, C. (2006). *Consumption and literature: The making of the romantic disease*. Basingstoke, England: Palgrave Macmillan.

Lawlor, C., & Suzuki, A. (2000). The disease of the self: Representing consumption, 1700-1830. *Bulletin of the History of Medicine, 74*(3), 458-494.

Bevan, A. L. (2013). Creating communicative spaces in an action research study. *Nurse Researcher, 21*(2), 14-17.

Leder, D. (1998). A tale of two bodies: The Cartesian corpse and the lived body. In D. Welton (Ed.), *Body and flesh: A philosophical reader* (pp. 117-129). Malden, MA: Blackwell Publishers.

Lee, N. S. (2007). *Curing consumers: How the patient became a consumer in modern American medicine* (Dissertation, 3258828). San Diego: University of California, San Diego.

Lerner, B. H. (1997). From careless consumptives to recalcitrant patients: The historical construction of noncompliance. *Social Science & Medicine, 45*(9), 1423-1431.

Lessem, E. (2014). Drug shortages threaten US anti-TB efforts. *Treatment Action Group*. http://www.livescience.com/44770-tuberculosis-drug-shortages.html

Lessem, E., Wegener, D. H., & Farrow, K. (2014 [Nov.1]). Solving the silent crisis: High-level working meeting to resolve and prevent domestic TB drug shortages *TB Notes Newsletter*. Atlanta, GA: Centers for Disease Control and Prevention and Treatment Action Group.

Levi, J., Segal, L. M. , St. Laurent, R., & Lang, A. (2013). Investing in America's health: A state-by-state look at public health funding and key health facts: Trust for America's Health; Robert Wood Johnson Foundation.

Levy, J. M. (2005). Narrative and experience: Telling stories of illness. *NEXUS, 18*(1), 8-33.

Lieblich, A., Tuval-Mashiach, R., & Zilber, T. (Ed.). (1998). *Narrative research: Reading, analysis and interpretation*. London: Sage.

Lienhardt, C., & Ogden, J. (2004). Tuberculosis control in resource-poor countries: Have we reached the limits of the universal paradigm? *Tropical Medicine & International Health, 9*(7), 833-841.

Lienhardt, C., Ogden, J., & Sow, O. (2003). Rethinking the social context of illness: Interdisciplinary approaches to tuberculosis control. In M. Gandy & A. Zumla (Eds.), *The return of the white plague: Global poverty and the "new" tuberculosis* (pp. 195-206). London: Verso.

Lienhardt, C., Rowley, J., & Manneh, K. (1999). Directly observed treatment for tuberculosis. *The Lancet, 353*(9147), 145-146.

Lin, P. L., & Flynn, J. L. (2010). Understanding latent tuberculosis: A moving target. *The Journal of Immunology, 185*(1), 15-22.

Lincoln, Y. S., & Denzin, N. K. (2003). *Turning points in qualitative research: Tying knots in a handkerchief*. Walnut Creek, CA: AltaMira Press.

Linton, S. (1998). *Claiming disability: Knowledge and identity*. New York: New York University Press.

Lönnroth, K., Migliori, G. B., Abubakar, I., D'Ambrosio, L., de Vries, G., Diel, R.,… Raviglione, M. C. (2015). Towards tuberculosis elimination: An action framework for low-incidence countries. *European Respiratory Journal, 45*(4), 928-952.

Lowes, R. (2013). EU regulators okay 2 drugs for drug-resistant TB. *Medscape Medical News*. http://www.medscape.com/viewarticle/814884

Lupton, D. (1994). Toward the development of critical health communication praxis. *Health Communication, 6*(1), 55-67.

Lupton, D. (1995). *The imperative of health: Public health and the regulated body*. London: Sage Publications.

Macchione, N., Wooten, W. J., & Moser, K. S. (2014). Tuberculosis Control Program 2013 annual report. San Diego, CA: County of San Diego Health and Human Services Agency, Tuberculosis and Refugee Health Branch.

MacGregor, R. R. (1993). Tuberculosis: From history to current management. *Seminars in Roentgenology, 28*(2), 101-108.

Macq, J., Torfoss, T., & Getahun, H. (2007). Patient empowerment in tuberculosis control: Reflecting on past documented experiences. *Tropical Medicine & International Health, 12*(7), 873-885.

Mann, Thomas. (1932). *The magic mountain* (H. T. Lowe-Porter, Trans.). New York: The Modern library.

Marcus, G. E., & Fischer, M. (1986). *Anthropology as cultural critique: An experimental moment in the human sciences*. Chicago: University of Chicago Press.

Markel, H. (2004). *When germs travel: Six major epidemics that have invaded America since 1900 and the fears they have unleashed* (1st ed.). New York: Pantheon Books.

Markel, H., & Stern, A. M. (2002). The foreignness of germs: The persistent association of immigrants and disease in American society. *Milbank Quarterly, 80*(4), 757-788.

Mason, P. H., Roy, A., Spillane, J., & Singh, P. (2015). Social, historical and cultural dimensions of tuberculosis. *Journal of Biosocial Science, FirstView*, 1-27.

Mattingly, C., & Garro, L. C. (2000). *Narrative and the cultural construction of illness and healing*. Berkeley: University of California Press.

McConnell, J. (1999). The real millennium bug. *The Lancet, 353*(9157), 946.

McKenna, L. (2013). An obligatory overhaul to address domestic TB drug shortages: Bold strategies are required to remedy frequent stock-outs and supply interruptions. *TAGline*. http://www.treatmentactiongroup.org/tagline/2013/fall/obligatory-overhaul-address-domestic-tb-drug-shortages

Médecins Sans Frontières, & International Union Against Tuberculosis and Lung Disease. (2012). DR-TB drugs under the microscope: Sources and prices for drug-resistant tuberculosis medicines, 2nd ed. http://www.msfaccess.org/sites/default/files/MSF_assets/TB/Docs/TB_report_UTM_2012_ENG_DecFinal.pdf

Médecins Sans Frontières, & International Union Against Tuberculosis and Lung Disease. (2012). DR-TB drugs under the microscope: Sources and prices for drug-resistant tuberculosis medicines (2nd ed.).

Médecins Sans Frontières, & International Union Against Tuberculosis and Lung Disease. (2013). DR-TB drugs under the microscope: Sources and prices for drug-resistant tuberculosis medicines, 3rd ed. http://www.msfaccess.org/sites/default/files/MSF_TB_Report_UTM3rdEdition-2013.pdf

Mera, F. E. (1935). History of the sanatorium movement in America. *Chest Journal, 1*(1), 8-9.

Migliori G, B., Espinal, M., Danilova I, D., Punga V, V., Grzemska, M., & Raviglione M, C. (2002). Frequency of recurrence among MDR-TB cases "successfully" treated with standardised short-course chemotherapy. *The International Journal of Tuberculosis and Lung Disease, 6*(10), 858-864.

Mill, J. S. (2004 [1859]). *On liberty*. New York: Barnes & Noble.

Miller, L. E. (1982). San Diego's early years as a health resort. *The Journal of San Diego History, 28*(4).

Miramontes, R., Pratt, R., Price, S. F., & Navin, T. R. (2013). Trends in tuberculosis — United States, 2012. *Morbidity and Mortality Weekly Report, 62*(11), 201-205.

Mirsaeidi, M., Farshidpour, M., Banks-Tripp, D., Hashmi, S., Kujoth, C., & Schraufnagel, D. (2015). Video directly observed therapy for treatment of tuberculosis is patient-oriented and cost-effective. *European Respiratory Journal*.

Mirsaeidi, M., Hashmi, S., & Schraufnagel, D. E. (2014). Patient-centered tuberculosis treatment with using video-direct observed therapy. *American Journal of Respiratory and Critical Care Medicine, 189*, A2563.

Mol, A. (2002). *The body multiple: Ontology in medical practice*. Durham: Duke University Press.

Molina, N. (2006a). Medicalizing the Mexican: Immigration, race, and disability in the early-twentieth-century United States. *Radical History Review*(94), 22-37.

Molina, N. (2006b). *Fit to be citizens? Public health and race in Los Angeles, 1879-1939*. Berkeley: University of California Press.

Moodie, A. S. (1967). Mass ambulatory chemotherapy in the treatment of tuberculosis in a predominantly urban community. *The American review of respiratory disease, 95*(3), 384-397.

Morano, J. P., Zelenev, A., Walton, M. R., Bruce, R. D., & Altice, F. L. (2014). Latent tuberculosis infection screening in foreign-born populations: A successful mobile clinic outreach model. *American Journal of Public Health, 104*(8), 1508-1515.

Morens, D. M. (2002). At the deathbed of consumptive art. *Emerging infectious diseases, 8*(11), 1353-1358.

Morris, D. B. (1998). *Illness and culture in the postmodern age*. Berkeley: University of California Press.

Murray, J. F. (2004). A century of tuberculosis. *American Journal of Respiratory and Critical Care Medicine, 169*(11), 1181-1186.

National Association of County and City Health Officials. (2014). 2013 national profile of local health departments. http://nacchoprofilestudy.org/wp-content/uploads/2014/02/2013_National_Profile021014.pdf

National Tuberculosis Controllers Association, & Centers for Disease Control and Prevention Advisory Group on Tuberculosis Genotyping. (2004). Guide to the application of genotyping to tuberculosis prevention and control: Handbook for TB controllers, epidemiologists, laboratorians, and other program staff Atlanta, GA: US Department of Health and Human Services & the Centers for Disease Control and Prevention.

Navin, T., McNabb, S., & Crawford, J. T. (2002). Tuberculosis genotyping network, United States: The continued threat of tuberculosis. *Emerging infectious diseases, 11*(8), 1187.

Nevins, J. (2002). *Operation Gatekeeper: The rise of the "illegal alien" and the making of the US-Mexico boundary*. New York: Routledge.

Nevins, J. (2010). *Operation gatekeeper and beyond: The war on "illegals" and the remaking of the US–Mexico boundary*. New York: Routledge.

Obregon, R., & Waisbord, S. R. (2012). *The handbook of global health communication*. Chichester, West Sussex: Wiley-Blackwell.

Ochs, E., & Capps, L. (1996). Narrating the self. *Annual Review of Anthropology, 25*, 19-43.

Ogden, J., Walt, G., & Lush, L. (2003). The politics of 'branding' in policy transfer: The case of DOTS for tuberculosis control. *Social Science & Medicine, 57*(1), 179-188.

Ong, A. (2006). *Neoliberalism as exception: Mutations in citizenship and sovereignty*. Durham, NC: Duke University Press.

Ott, K. (1996). *Fevered lives: Tuberculosis in American culture since 1870*. Cambridge, MA: Harvard University Press.

Oxlade, O., Vaca, J., Romero, E., Schwartzman, K., Graham, B., Hernandez, L.,… Menzies, D. (2006). The long-term health and economic benefits of DOTS implementation in Ecuador. *Canadian Journal of Public Health, 97*(1), 14-19.

Pasipanodya, J. G., & Gumbo, T. (2013). A meta-analysis of self-administered vs. directly observed therapy effect on microbiologic failure, relapse, and acquired drug resistance in tuberculosis patients. *Clinical Infectious Diseases, 57*(1), 21-31.

Paterson, K., & Hughes, B. (1999). Disability studies and phenomenology: The carnal politics of everyday life. *Disability & Society, 14*(5), 597-610.

Pauwels, K., Huys, I., Casteels, M., & Simoens, S. (2014). Drug shortages in European countries: A trade-off between market attractiveness and cost containment? *BMC Health Services Research, 14*(1), 438.

Pearson, R. (2014 [July 10]). Disease threat from immigrant children wildly overstated. *Texas Observer*. http://www.texasobserver.org/disease-threat-immigrant-children-wildly-overstated/

Pernick, M. S. (1997). Eugenics and public health in American history. *American Journal of Public Health, 87*(11), 1767-1772.

Petersen, A. R. (1996). Risk and the regulated self: The discourse of health promotion as politics of uncertainty. *Journal of Sociology, 32*(1), 44-57.

Petersen, A. R., & Lupton, Deborah. (1996). *The new public health: Health and self in the age of risk*. St. Leonards, Australia: Allen & Unwin.

Pollack, A. (2015, September 20). Drug goes from $13.50 a tablet to $750, overnight. *New York Times*. http://www.nytimes.com/2015/09/21/business/a-huge-overnight-increase-in-a-drugs-price-raises-protests.html?hp&action=click&pgtype=Homepage&module=second-column-region&region=top-news&WT.nav=top-news&_r=0

Pollack, A. (2015, September 21). Big price increase for tuberculosis drug is rescinded. *New York Times*. http://www.nytimes.com/2015/09/22/business/big-price-increase-for-tb-drug-is-rescinded.html

Pôrto, Â. (2007). Social representations of tuberculosis: Stigma and prejudice. *Revista de Saúde Pública, 41*, 43-49.

Pratt, J. H. (1907). The class method of treating consumption in the homes of the poor. *Journal of the American Medical Association, XLIX*(9), 755-759.

Pronyk, P., & Porter, J. (1999). Public health and human rights: The ethics of international public health interventions for tuberculosis. In J. D. Porter & J. M. Grange (Eds.), *Tuberculosis: An interdisciplinary perspective* (pp. 99-120). London: Imperial College Press.

Public Health Services, Community Health Statistics Unit. (2014). San Diego County demographics profile: Central region 2012 population estimates *County of San Diego Community Profiles by Region and Subregional Area*. San Diego: County of San Diego, Health & Human Services Agency.

Pym, A. S., & Cole, S. T. (1999). Post DOTS, post genomics: The next century of tuberculosis control. *The Lancet, 353*(9157), 1004-1005.

Raviglione, M., & Krech, R. (2011). Tuberculosis: Still a social disease. *The International Journal of Tuberculosis and Lung Disease, 15*(6), S6-S8.

Raviglione, M. C. (2003). The TB epidemic from 1992 to 2002. *Tuberculosis, 83*(1), 4-14.

Raviglione, M. C., & Pio, A. (2002). Evolution of WHO policies for tuberculosis control, 1948–2001. *The Lancet, 359*(9308), 775-780.

Reber, V. B. (2006). The sanatorium age: Pennsylvania and Argentina, 1900-1945. *Pennsylvania History: A Journal of Mid-Atlantic Studies, 73*(4), 412-445.

Reeder, L. G. (1972). The patient-client as a consumer: Some observations on the changing professional-client relationship. *Journal of Health and Social Behavior, 13*(4), 406-412.

Rees, G. (2010). The ethical imperative of medical humanities. *Journal of Medical Humanities, 31*(4), 267-277.

Reichman, L. B., & Hershfield, E. S. (2000). *Tuberculosis: A comprehensive international approach* (2nd ed.). New York: Dekker.

Reitmanova, S. (2009). "Disease-breeders" among us: Deconstructing race and ethnicity as risk factors of immigrant ill health. *Journal of Medical Humanities, 30*(3), 183-190.

Reitmanova, S., & G., Diana L. (2012). Exploring the mutual constitution of racializing and medicalizing discourses of immigrant tuberculosis in the Canadian press. *Qualitative Health Research, 22*(7), 911-920.

Resnik, D. B. (2004). The distribution of biomedical research resources and international justice. *Developing World Bioethics, 4*(1), 42-57.

Ricœur, P. (1984). *Time and narrative*. Chicago: University of Chicago Press.

Roberts, E. F. S., & Scheper-Hughes, N. (2011). Introduction: Medical migrations. *Body & Society, 17*(2-3), 1-30.

Rose, N S. (2007). *Politics of life itself: Biomedicine, power, and subjectivity in the twenty-first century*. Princeton: Princeton University Press.

Rosen, g. (1993 [1958]). *A history of public health* (Expanded ed.). Baltimore: Johns Hopkins University Press.

Rosenkrantz, B. G. (1972). *Public health and the State: Changing views in Massachusetts, 1842-1936*. Cambridge: Harvard University Press.

Roth, J. A. (1963). *Timetables: Structuring the passage of time in hospital treatment and other careers*. Indianapolis: Bobbs-Merrill.

Rouillon, A. (1991). The mutual assistance programme of the IUATLD. Development, contribution and significance. *Bulletin of the International Union Against Tuberculosis and Lung Disease, 66*(4), 159-172.

Rubel, A. J., & Garro, L. C. (1992). Social and cultural factors in the successful control of tuberculosis. *Public Health Reports, 107*(6), 626-636.

Ryan, F. (1993). *The forgotten plague: How the battle against tuberculosis was won--and lost* (1st American ed.). Boston: Little, Brown.

Sabin, J. E. (1990). Joseph Hersey Pratt's cost-effective class method and its contemporary application: Some problems in biopsychosocial innovation. *Psychiatry, 53*(2), 169-184.

Sandahl, C. (2002). Considering disability: Disability phenomenology's role in revolutionizing theatrical space. *Journal of Dramatic Theory and Criticism, 16*(2), 17-32.

Sandahl, C., & Auslander, P. (2005). *Bodies in commotion: Disability and performance*. Ann Arbor: University of Michigan Press.

Schaaf, H. S., & Zumla, A. (Eds.). (2009). *Tuberculosis: A comprehensive clinical reference*: Elsevier Health Sciences.

Scott, C., Kirking, H. L., Jeffries, C., Price, S. F., & Pratt, R. (2015). Tuberculosis trends — United States, 2014. *Morbidity and Mortality Weekly Report, 64*(10), 265-269.

Scott, C., Kirking, H. L., Jeffries, C., Price, S. F., & Pratt, R. (2015, March 20). Trends in tuberculosis — United States, 2014. *Morbidity and Mortality Weekly Report, 64*(10), 265-269.

Segal, J. (2005). *Health and the rhetoric of medicine*. Carbondale: Southern Illinois University Press.

Selgelid, M J. (2008). Ethics, tuberculosis and globalization. *Public Health Ethics, 1*(1), 10-20.

Selgelid, M. J., Kelly, P. M., & Sleigh, A. (2008). TB matters more. In M. Boylan (Ed.), *International Public Health Policy and Ethics* (Vol. 42, pp. 233-247): Springer Netherlands.

Shakespeare, T. (2006). *Disability rights and wrongs*. New York: Routledge.

Shapiro, J. P. (1984). *No pity: People with disabilities forging a new civil rights movement*. New York: Times Books.

Sharf, B. F., & Street, R. L. Jr.(1997). The patient as a central construct: Shifting the emphasis. *Health Communication, 9*(1), 1-11.

Shrestha-Kuwahara, R., Wilce, M., Joseph, H.A., Carey, J.W., Plank, R., & Sumartojo, E. (2004). Tuberculosis research and control. In C. R. Ember & M. Ember (Eds.), *Encyclopedia of medical anthropology: Health and illness in the world's cultures*. New York: Kluwer Academic/Plenum Publishers.

Siebers, T. (2008). *Disability theory*. Ann Arbor: University of Michigan Press.

Smith, I. (1999). Stop TB: Is DOTS the answer? *Indian Journal of Tuberculosis, 46*, 81-90.

Snider, D. E., & Roper, W. L. (1992). The new tuberculosis. *The New England journal of medicine, 326*(10), 703-705.

Snider, G. L. (1997). Tuberculosis then and now: A personal perspective on the last 50 years. *Annals of Internal Medicine, 126*(3), 237-243.

Snyder, S. L., & Mitchell, D. T. (2001). Re-engaging the body: Disability studies and the resistance to embodiment. *Public Culture, 13*(3), 367-389.

Sontag, S. (1990). *Illness as metaphor and, AIDS and its metaphors* (1st Anchor Books ed.). New York: Doubleday.

Stanford, L. (1970). San Diego's medico-legal history: 1850-1900. *The Journal of San Diego History, 16*(2).

Star, S. L., & Griesemer, J. R. (1989). Institutional ecology, 'translations' and boundary objects: Amateurs and professionals in Berkeley's museum of vertebrate zoology, 1907-39. *Social Studies of Science, 19*(3), 387-420.

Starnes, T. (2014 [July 7]). Immigration crisis: Tuberculosis spreading at camps. *Foxnews.com*. http://www.foxnews.com/opinion/2014/07/07/immigration-crisis-tuberculosis-spreading-at-camps.html

Starr, P. (1982). *The social transformation of American medicine*: Basic Books.

Stop TB Partnership. (2006). The Stop TB Strategy: Building on and enhancing DOTS to meet the TB-related Millennium Development Goals. Geneva: World Health Organization.

Stop TB Partnership. (2007). From DOTS to the Stop Tb Strategy: Meeting of 22 high burden countries and core groups of the Stop TB Partnership: World Health Organization.

Strauss, A. (1978). A social world perspective. *Studies in Symbolic Interaction, 1*, 119–128.

Suárez, P. G., Watt, Catherine J., Alarcón, E., Portocarrero, J., Zavala, D., Canales, R…Dye, C. (2001). The dynamics of tuberculosis in response to 10 years of intensive control effort in Peru. *Journal of Infectious Diseases, 184*(4), 473-478.

TBOnline. (2014, 21 March). Otsuka: Response to TB CAB, CRAG, TAG open letter. 12 March. http://www.tbonline.info/media/uploads/documents/otsuka_tag_letter_mar_2014-2.pdf

Tesh, S. N. (1996 [1988]). *Hidden arguments: Political ideology and disease prevention policy*. New Brunswick, NJ: Rutgers University Press.

Tomes, N. (2000). The making of a germ panic, then and now. *American Journal of Public Health, 90*(2), 191-198.

Tones, B. K. (1986). Health education and the ideology of health promotion: A review of alternative approaches. *Health Education Research, 1*(1), 3-12.

Treatment Action Group. (2014). Hello Generics: News on the fight to end HIV/AIDS, viral hepatitis, and tuberculosis. *TAGline, 21*(2), 1-2.

Trostle, James A. (1988). Medical compliance as an ideology. *Social Science & Medicine, 27*(12), 1299-1308.

Trust for America's Health. (2014). Key health data about California. http://www.healthyamericans.org/states/?stateid=CA#section=3,year=2014,code=undefined

Turner, B. (2001). Disability and the sociology of the body. In G. L. Albrecht, K. D. Seelman & M. Bury (Eds.), *Handbook of disability studies* (pp. 252-264). Thousand Oaks, CA: Sage Publications.

Union of the Physically Impaired Against Segregation. (1976). Fundamental principles of disability. London.

Uplekar, M., Walley, J., & Newell, J. (1999). Directly observed treatment for tuberculosis. *The Lancet, 353*(9147), 145.

US Department of Justice, Civil Rights Division. (2005). A guide to disability right laws. http://www.ada.gov/cguide.pdf

Vargas B., Arturo, F., Hai, G., Jeremiah, C.-P., Olivia, W., Steven, P., Rizzo, J. A., & Ortega, A. N. (2012). Variations in healthcare access and utilization among Mexican immigrants: The role of documentation status. *Journal of Immigrant and Minority Health, 14*(1), 146-155.

Vaughan, J. P., & Morrow, R. H. (1989). *Manual of epidemiology for district health management*. Geneva: World Health Organization.

Ventola, C. L. (2011). The drug shortage crisis in the united states: Causes, impact, and management strategies. *Pharmacy and Therapeutics, 36*(11), 740–757.

Visweswaran, K. (1994). *Fictions of feminist ethnography*. Minneapolis: University of Minnesota Press.

Volmink, J, & Garner, P. (2007). Directly observed therapy for treating tuberculosis. *Cochrane Database of Systematic Reviews*(4).

Waisbord, S. (2007). Beyond the medical-informational model: Recasting the role of communication in tuberculosis control. *Social Science and Medicine, 65*(10), 2130-2134.

Wallis, R. S., Pai, M., Menzies, D., Doherty, T. M., Walzl, G., Perkins, M. D., & Zumla, A.. (2010). Biomarkers and diagnostics for tuberculosis: Progress, needs, and translation into practice. *The Lancet, 375*(9729), 1920-1937.

Ward, J. W., & Warren, C. (2007). *Silent victories: The history and practice of public health in twentieth-century America*. Oxford: Oxford University Press.

Wicks, P. G., & Reason, P. (2009). Initiating action research: Challenges and paradoxes of opening communicative space. *Action Research, 7*(3), 243-262.

Williams, R. (1977). *Marxism and literature*. Oxford: Oxford University Press.

Williams, S. (2000). Chronic illness as biographical disruption or biographical disruption as chronic illness? Reflections on a core concept. *Sociology of Health & Illness, 22*(1), 40-67.

Wilson, P. K. (2006). Confronting "hereditary" disease: Eugenic attempts to eliminate tuberculosis in progressive era America. *Journal of Medical Humanities, 27*(19-37).

Winslow, C. E. (1920). The untilled fields of public health. *Science, 51*(1306), 23-33.

World Bank. (1993). World development report 1993, Investing in health. Oxford: Oxford University Press.

World Health Organization. (1974). WHO expert committee on tuberculosis, ninth report *Technical Reports Series, Number 552*. Geneva: WHO.

World Health Organization. (1992). International statistical classification of disease and related health problems (10th ed.). Geneva: World Health Organization.

World Health Organization. (1993). WHO declares tuberculosis a global emergency *Press release*. Geneva: WHO.

World Health Organization. (1994a). TB: A global emergency, WHO report on the TB epidemic. In K. Klaudt (Ed.), *Who report on the TB epidemic* Geneva: WHO.

World Health Organization. (1994b). WHO tuberculosis programme: Framework for effective tuberculosis control. In K. Klaudt (Ed.). Geneva: WHO.

World Health Organization. (2001). Global DOTS expansion plan: Progress in TB control in high-burden countries, 2001 one year after the Amsterdam Ministerial Conference. Geneva: WHO.

World Health Organization. (2006). *Constitution of the World Health Organization, Forty-fifth edition*. http://www.who.int/governance/eb/who_constitution_en.pdf

World Health Organization. (2007). Implementing the WHO Stop TB Strategy: A handbook for national tuberculosis control programs. Geneva: WHO.

World Health Organization. (2010). Treatment of tuberculosis guidelines (Fourth ed.). Geneva: WHO.

World Health Organization. (2013). Global tuberculosis report 2013. Geneva: WHO.

World Health Organization. (2014b). Global tuberculosis report 2014. Geneva: WHO.

World Health Organization. (2015). Gear up to end TB: Introducing the End TB strategy. Geneva: World Health Organization.

World Health Organization Executive Board. (2013). Global strategy and targets for tuberculosis prevention, care and control after 2015. Geneva: World Health Organization.

Xianyi, C., Fengzeng, Z., Hongjin, D., Liya, W., Lixia, W., Xin, D., & Chin, D. P. (2002). The DOTS strategy in China: Results and lessons after 10 years. *Bulletin of the World Health Organization, 80*, 430-436.

Yew, W. W. (1999). Directly Observed Therapy, Short-course: The best way to prevent multidrug-resistant tuberculosis. *Chemotherapy, 45, Supplement 2*, 26-33.

Zhenkun, M., Lienhardt, C., McIlleron, H., Nunn, A. J., & Wang, X. Global tuberculosis drug development pipeline: The need and the reality. *The Lancet, 375*(9731), 2100-2109.

Ziol-Guest, K. M., & Kalil, A. (2012). Health and medical care among the children of immigrants. *Child Development, 83*(5), 1494-1500.

Zola, I. K. (1991). Bringing our bodies and ourselves back in: Reflections on a past, present, and future "medical sociology". *Journal of Health and Social Behavior, 32*(1), 1-16.

Zuckerman, S., Waidmann, T. A., & Lawton, E. (2011). Undocumented immigrants, left out of health reform, likely to continue to grow as share of the uninsured. *Health Affairs, 30*(10), 1997-2004.

Zumla, A., Mwaba, P., Squire, S. B., & Grange, J. M. (1999). The tuberculosis pandemic—Which way now? *Journal of Infection, 38*(2), 74-79.

Zumla, A., Nahid, P., & Cole, S. T. (2013). Advances in the development of new tuberculosis drugs and treatment regimens. *Nature Reviews Drug Discovery, 12*(5), 388-404.

Zwarenstein, M. (1999). Directly observed treatment for tuberculosis. *The Lancet, 353*(9147), 147-148.

Zwarenstein, M, Schoeman, J. H., Vundule, C., Lombard, C. J., & Tatley, M. (1998). Randomised controlled trial of self-supervised and directly observed treatment of tuberculosis. *The Lancet, 352*(9137), 1340-1343.