Fevered Lives

Tuberculosis in American Culture since 1870

Katherine Ott

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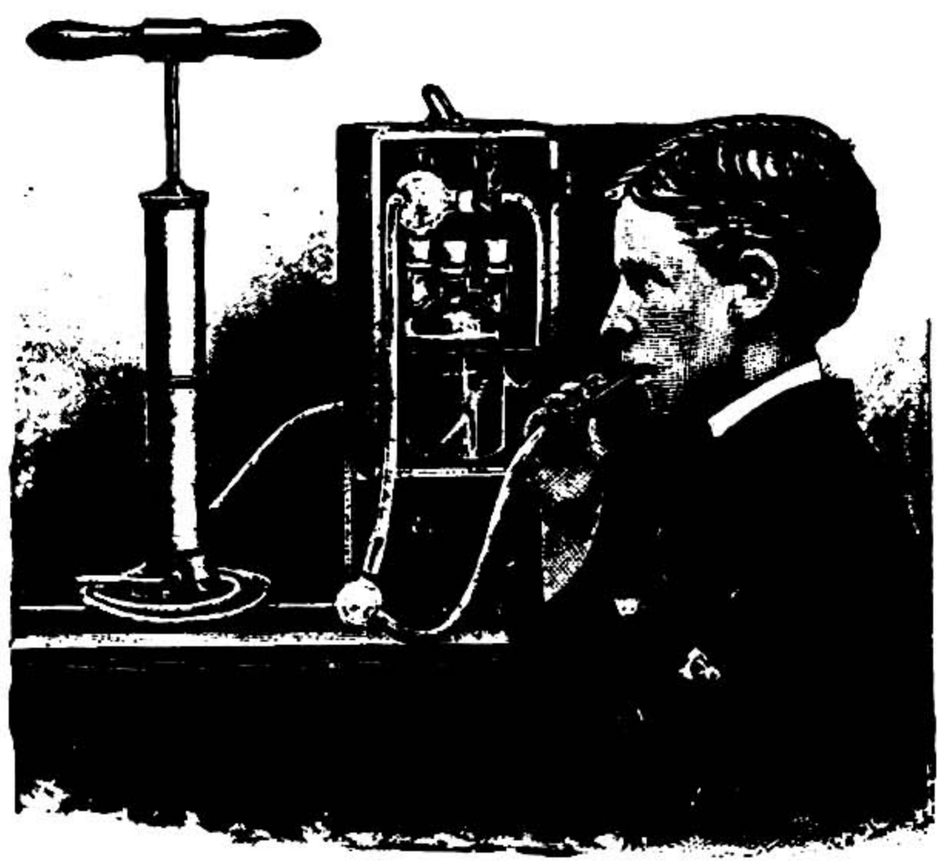

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As an interdisciplinary work, this book sometimes sacrifices subtlety in the generalizations necessary in boundary-crossing. The choices (and any errors) are of course my own, the risks gladly taken, the gains well worth it.

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Introduction: Thinking about Disease

One of the most commonplace sayings in the late nineteenth century was "Everyone is sometime or another a little bit consumptive." This is a curious and interesting expression for us, living one hundred years later, and in an era when we are appalled to find that tuberculosis even still exists. How is it possible that a person could be only "a little" bedeviled by a disease that was usually terminal? For people at the turn of the century, the term "consumptive" carried many meanings. Saying you were consumptive was sometimes an indirect way of saying you were tired and wished to be alone, or that you felt artistic, sensual, and vaguely dramatic. Or the speaker might have been conveying the philosophical reassurance that everyone is going to die someday, so the little cough or pain of the moment doesn't matter. Consumption was a disease not just of body, but also of mind and of spirit.[1]

The meaning of a disease evolves from the interrelationship of people, technology, medical doctrines, and state affairs. Illness is as dependent upon the palpable human experience of it as it is upon impersonal physiology and pathology. It is the material substance of a society that ultimately shapes, locates, and creates disease. Hence the cultural products accompanying consumptions, also called phthisis, the white plague, and wasting disease, differ from those of tuberculosis. There is neither a core "tuberculosis," constant over time, nor a smooth conceptual trajectory leading from the lungs of ancient Greeks to the AIDS ward of a modern hospital. What we call "tuberculosis" was not the same disease in 1850 that it was in 1900 or even 1950. The 1990s version of tuberculosis is quite unlike the disease people understood by

that name in earlier periods. Discussions about tuberculosis in the 1990s are actually addressing a third illness, one that is inchoate and as yet inadequately named. This "new" epidemic involves a different patient population and a post-AIDS, postindustrial, postmodern culture. At this writing, although molecular medicine has not yet reformed diagnosis and treatment, the next few years will bring yet another conceptualization of tuberculosis.

Illness is experienced by both sick and robust bodies, by doctors, laborers, husbands, daughters, priests, and scientists. Consequently, it is a jumble of ideas that shifts among groups and over time. It is a cultural artifact configured in people's bodies, in medical doctrines, and in the physical material of illness.[2] Today's medicine has carved out a scientific niche for itself within commerce and technology, and we in the late twentieth century speak knowingly about tuberculosis and Kaposi's sarcoma and cataracts. Our confidence in the authority of science and its definitions tends to crowd out the ambiguities and untidy questions that looking at history often introduces. The romantic stereotype in nineteenth-century literature of the gentle female invalid has only vague affinities with the immigrant sweatshop worker who also embodied the illness. Medical doctrine moves and bends around human experience.

To understand consumption and tuberculosis, it is necessary to look at them in their historical context. An example of how historical analysis can alter scientific understanding is found in a reading of nineteenth- and early twentieth-century morbidity and mortality figures. All authoritative numbers that we have come to assume as indications of the number of people who died of tuberculosis are clouded by numerous complicating factors.[3] Many of the ill never saw a doctor or a health official. Most poor people died without attendance by a physician, and their passing was reported by a midwife or undertaker. The assignment of only one cause of death excludes the cases in which people died of other causes before their tuberculosis was noted and ignores the existence of interrelated, multiple causes of death. It is difficult to decide exactly what has killed someone. A doctor's diagnosis could be subjective and eccentric because physicians were often poorly trained in the use of stethoscopes and microscopes. Attribution was further entangled by the fact that the clinical disease of tuberculosis resembled other ailments such as pleurisy, asthma, and bronchitis. A number of diseases,

such as silicosis, histoplasmosis, emphysema, and lung cancer, which are differentiated in biomedicine today were part of the constellation of tuberculosis in the nineteenth century.[4]

Reporting protocols at the turn of the century were either nonexistent or too ambiguous to be of much use. There was no standard nomenclature or systematic collection of vital statistics until well into the twentieth century.[5] Classifications in the annual reports of boards of health varied from region to region, since most towns and cities had no permanently functioning board of health or central collection bureau until after the turn of the century. Problems abounded with reporting and organizing. In 1908 only fifteen states were part of the federal registration area. Even after more uniform nomenclature and reporting of tuberculosis in the 1920s, the definition of the disease was subject to change every few years.[6] Complete national reporting of tuberculosis began in 1953.

The subjectivity that naturally follows from variations in physicians' judgments and interpretations of data has always been a problematic aspect of diagnosis.[7] In 1951, for example, a team of researchers studied physician and radiologist assessments of X-ray exams of 150 patients. The researchers found that evaluations among the readers differed one-third of the time, and within their *own* readings (being shown the same exam twice without being told so), one-fifth of the time.[8]

Subjectivity might also be called into play by the ethnicity, race, and gender of the patient and physician. Widespread stereotyping of individuals often led to misdiagnosis. Indeed, similar biases can be seen at work today: physicians tend not to find heart disease or AIDS in women, since they assume male carriers.[9] In the nineteenth century, white women with tuberculosis might be diagnosed as neurasthenic, and African-American men with the same ailment as demented. For all these reasons, disease and death rates tended to exclude African-American, Indian, Asian, and Latino people. In tabulations of morbidity and mortality rates, only white death and disease had significance.[10]

Another obstacle to the interpretation of statistics, diagnostic categories, and definitions is the fact that statistics and case reports do not always tabulate a verifiable end to the disease process but, rather, mark the point at which the patient, doctor, and society agree upon an interpretation of the medical circumstances.[11] An important factor in how a patient comes to accept a diagnosis is the way in which she or he

acquires information about symptoms and in turn gives significance to the symptoms experienced. Through talking with friends and health practitioners, watching television, and reading magazines and books, people are able to sort out their symptoms and malady from a variety of culturally available items. They link their experience to appropriate concepts and categories. For example, a person living in rural Idaho today is unlikely to attribute a headache and stinging eyes to smog, or to a common nineteenth-century problem such as arsenic poisoning; yet both would be a probable diagnosis in another time and place. The patient and physician eventually settle upon a mutually acceptable diagnosis. What we come to regard as illness is filtered through a mesh of cultural influences. At different moments, health practitioners and commentators located the origin of consumptions in excessive intellectual work, masturbation, germs, disturbed electrical energy, eating ethnic foods, and living on wet soil.

We usually think of illness as inherent within the body, that is, as existing solely within our physical selves as a virus in the blood or a congestive heart. But cultures give form and meaning to what happens within our bodies; social relations become material relations as they exist in time and space. In the case of consumption and tuberculosis, this phenomenon has resulted in the accretion of several layers of meaning. Medically, consumption is a wasting away of the flesh, and tuberculosis is a parasite that disrupts tissue systems and produces a host response with distinct pathological changes. Twentieth-century physicians and medical researchers deal directly with this level of meaning. Culturally, its meaning rests upon the social, political, and economic experiences of those dealing with the illness in their particular time and place. And finally, there is the meaning given to illness by later generations, by historians, or by those from other cultures, who try to interpret the nature of an illness in a context that has vanished. All these orientations come to form the public meaning and record of an illness.

External aspects of illness take shape in the material environment. The nineteenth century is full of significant sites of cultural meaning. Novelists, painters, playwrights, and ministers relied upon pivotal and evocative settings such as the orphanage, madhouse, poorhouse, inner sanctum, riverboat, and woodlot to engage their audiences.[12] In our own age, we immediately recognize such familiar and generic places as the

hurricane path, vacant lot, speed trap, no-smoking area, skyline, and wreck site.[13] These sites are both literal and symbolic of a host of cultural associations, concrete and metaphoric representations of cultural values and attitudes. The history of consumption and tuberculosis is filled with such sites. From the nineteenth-century sickbed to the late twentieth-century hospital room, such sites provide an innovative means for comprehending the substance of illness and medical practice. These nineteenth-century environments are lost to us today in their entirety—we can never visit them—but parts of them still exist in the hard surfaces of the objects that once filled them. Few, if any, of us have ever spent a fevered night in a sanitarium, but we are capable of imagining it when elements of that experience are recreated for us. These are figurative places, inhabited by the imagination.[14]

Being ill took place within a geographic space constituted by objects, tools, instruments, and people.[15] In the case of consumption and tuberculosis, we can grasp the context of illness through the figurative and literal locations significant in their history: the sickbed and sickroom, the healing wilderness into which invalids retreated and its attempted reconstruction within the walls of the chest, the microscopic world of the bacillus, the consumer marketplace of invalid goods, the stereotyped black body, the Lung Block, and the sanitarium. These are distinctive sites of tuberculosis—spaces inhabited by living beings and shaped by material objects.[16] Patients, practitioners, and the community came together to build the optimum environment for the illness and thus to define it and fix its identity within these spaces.

Most of the history of tuberculosis takes place in a world before electronmicroscopes and particle physics, before AIDS, atom bombs, and even commercial aspirin were dreamed of.[17] The story begins in a time when a person always put on a hat before venturing into the street, when horses and feet were the main modes of transportation, and before there were any herky-jerky silent movies to heighten the intensity of young imaginations. It begins with the first generation of doctors who learned to use binaural stethoscopes and clinical thermometers to correlate fever with pathology. Their medical training often involved no more than a five-dollar matriculation fee and a couple of courses, and they all made house calls.

At the institutional level, tuberculosis was one of the first diseases to come under control and definition by professional manager-bureau-

crats. In the nineteenth century, physicians and public health officers tried various means to control and abate the many diseases affecting people. Their efforts were usually local and cyclic, matching the character of the outbreaks. Malaria, yellow fever, cholera, and smallpox were the dramatic epidemic and episodic diseases of the eighteenth and nineteenth centuries. Health practitioners' efforts with tuberculosis, on the other hand, a common and constant disease, eventually resulted in an organized and permanent bureaucracy designed to deal with it.

Consumptions and tuberculosis were different manners of disease. They were not characterized by large-scale epidemics or dramatic visitations. They were endemic, debilitating constitutional illnesses to which people succumbed slowly, over a period of years. Unlike most epidemic diseases, they did not sweep through a city or region and then disappear for several years. Consumptions were always present, affecting great numbers of people, in all urban areas, infecting, reinfecting, dormant or active, throughout their lives. Because they crippled, weakened, or killed everyone with an active case, their legacy was one of destitution, alienation, and chaos. The afflicted were compelled to stop work, enter hospitals or sanitariums, lie and dissemble for self-protection, travel to remote and unsettled areas, and seek public relief. William Robertson, a physician and educator at the medical school of the University of Iowa, summed up the prospects for a person diagnosed with a consumption when he said it produced a "general wreck of material existence."[18]

The average physician at work practiced a rich mixture of common sense, folklore, popular knowledge, and medical doctrine. Elites and common people shared insights as well as absurdities. Nearly any nineteenth-century practitioner could be shown to be a quack by modern biomedical standards: many used creosote treatments, and most tried a variety of serums and antitoxins made from turtles and horses. While some physicians believed that hemoptysis (spitting of blood) was a sign of consumptions, others viewed it as vicarious menstruation (if a woman did not menstruate, the blood was assumed to accumulate and to exit elsewhere).[19] There was a casual mingling of medical and lay products; the borders between the two were fluid and in many cases nonexistent. With little differentiation, technologies and products from electrical devices to whiskey were marketed to and consumed by all levels of users. The back-and-forth flow of materials

among groups, from families to patients to doctors to nurses, reflected the preprofessionalized characteristics of consumptions in the nineteenth century, in contrast to the more rigidly stratified tuberculosis of the twentieth.

The history of tuberculosis chronicles how a romantic, ambiguous affliction became first a dreaded and mighty social truncheon, and finally an entity bound up in the public health and civic order. The transformation of one disease into another, of phthisis into consumption and of consumption into tuberculosis, took place during the great reshaping of social and professional relations after the Civil War. The period from the Civil War through the 1920s marked the emergence of a corporate capitalist vision for American society and high hopes for industrial progress. As one way of life broke apart, another one formed, and tuberculosis overlaid these changes.

Consumptions and tuberculosis were, in a real sense, different and separate diseases. Medical thinking on consumptions never reached consensus; indeed, vagueness was essential to diagnosis, whereas current biomedical thinking on tuberculosis is clear and emphatic. Doctors agree that it is an infectious disease (that is, it is spread from person to person by germs) caused by a mycobacterium.[20] Tuberculosis is not contagious, in that mere contact is not sufficient to spread it. It is usually airborne and can affect many parts of the body. All forms are associated with a rod-shaped (or tubercle) bacillus. When the tubercle bacillus infects a part of the body, it produces a characteristic lesion, called a tubercle, which is a mass of caseated material (a dry, amorphous mass of tissue). In pulmonary tuberculosis, the bacillus usually enters the lungs via droplets sprayed by a tuberculous cough or sneeze. Upon entering a healthy person, the bacillus may become encapsulated; it may then either break out during a period of stress or ill health or remain dormant indefinitely. In others, the bacilli immediately initiate a slow progress toward debilitation, usually running its course in two and a half to five years. In most cases, the tubercular person recovers without treatment and before the disease progresses.

The scientific cause of tuberculosis was unsubstantiated until 1882, when Robert Koch in Germany isolated the tubercle bacillus. The first effective biomedical treatment for it was found in 1944, when Albert Schatz, working under Selman Waksman, discovered the antibiotic streptomycin through his work with soil samples. Today tuberculosis

is treated with chemotherapy for about a year. After the first couple of weeks the patient is not infectious. Until the use of streptomycin, tuberculosis therapies might ease symptoms, but there was no lasting treatment.

Pulmonary tuberculosis peaked in the United States in the middle of the nineteenth century. Although it continues at epidemic levels in certain urban and impoverished areas where preventive health care is negligible, such as on Indian reservations, in prisons, and among the homeless, the disease is no longer of popular interest. Since those most at risk today are also elderly, poor, or non-English-speaking, they are largely powerless, silent, and invisible. The most recent risk group, and one with complex cultural associations, consists of AIDS patients. In contrast to the tuberculosis of fifty or one hundred years ago, the "new" tuberculosis exists in a society increasingly skeptical of the promise of biotechnical medicine and freighted with thousands of people struggling with the reality of AIDS. Medical technology has also changed vastly. Tuberculosis today is a high-tech disease, with DNA fingerprinting and fluorescence microscopy for the physician and ultraviolet light and negative pressure hospital rooms for the patient. Computer imaging and molecular medicine will undoubtedly redefine tuberculosis yet again in the years ahead. It is a world apart from the illness experienced and treated in the second half of the nineteenth century and commonly called consumption.

The history of consumption and tuberculosis is a chronicle without closure. It is filled with phantoms and puzzles, with long-since-disappeared inhabitants and their faded thoughts, people who once looked outside themselves and ventured to record what they found. Our bond with this past is the timeless experience of getting sick. The history of illness is about how we as a culture, varied and complex, cope with our mortality, difference, and debility and how we place ourselves within and make sense of the communities around us. It is clear that people did sicken and die, but it is far less clear what debilitated them and why. As a twentieth-century Hippocrates might say, healing is often a matter of time, sometimes of opportunity, and always of explanation.

1

Sickbed and Symptoms in the 1870s and 1880s

Medical practice in the 1870s and 1880s was virtually a free-for-all. No one approach predominated: a consumptive might consult a homeopath, allopath, hydropath, osteopath, or a practitioner of any of dozens of other more obscure medical theories, including an aging but impenitent phrenologist.[1] The anarchy in medicine allowed for all manner of theory and practice, and experts on consumption were drawn from the ranks of ministers, moralists, physicians, and astute neighbors.[2] The illness itself was characterized by a fluid group of behaviors, signs, and symptoms, with shifting connotations.[3] Diagnosis depended largely upon a patient's temperament, which could be sanguinous, lymphatic, bilious, or nervous.[4] However, as in other areas of medicine, there was no consensus upon what each signified. Physicians used the term "consumption" to identify several varieties of wasting disease that involved weight loss, fever, and lung lesions, indicated by coughing and expectoration. The relational pattern defined as a consumption could be further broken down into catarrh, empyema, phthisis, tubercle, and so on, depending upon the exact symptoms and signs. In a sense, there were nearly as many consumptions as there were patients. Practitioners used the term "tuberculosis" to refer to a condition in which elastic lung fibers, called tubercles, were coughed up. What people called tuberculosis throughout most of the nineteenth century was not the bacterial condition that came to be called by that name later. As one physician explained, pulmonary tuberculosis was "a great constitutional malady, which plays its most prominent part in the lungs."[5] In the years after

the bacillus was identified (1882), only patients who produced the germ along with their expectoration were said to have tuberculosis.

The presence of a consumptive "look," constitution, or diathesis was essential for diagnosis.[6] "Consumption is the most flattering of all diseases, as well as the most insidious and fatal," Elizabeth Bigelow wrote in her 1876 senior thesis at the Women's Medical College of Pennsylvania. Young Dr. Bigelow, like thousands of others of her generation, had observed the wreckage of tuberculosis in her own family. She described the victim's "extreme emaciation, stooping form, feeble step . . . panting breath after the slightest exertion . . . bright eyes of pearly whiteness, transparent skin . . . hectic flush [which] give an unnatural beauty to the countenance . . . At this stage, the only help is death and it soon comes."[7] Another student, in the same graduating class, wrote of the illness, "We see it in the puny, swarthy, ghostlike child. The sickly offspring of the infected parent, and also in the haggard and cavernous appearance of a once strong and muscular man who has been caught in the death-gripe [*sic*] of the fatal destroyer by imprudent excess and exposure."[8] These poignant descriptions, a mixture of personal experience, contemporary medical thought, and popular understanding, would have been readily affirmed by most middle-class people in the 1870s and 1880s.

A widely used medical textbook of the period described the diathesis or look of the consumptive as follows:

> Tall, slim, erect, delicate looking, having scarcely any fat. While they present usually a pretty oval face, a clear complexion, bright eyes and large pupils, the skin is very thin, soft and delicate, and through it bluish veins are visible. The hair is fine and silky, often light, the eyelashes being long. Tubercular subjects cut their teeth early, and are generally precocious and clever, walking and talking soon. They are excitable and active in body and mind.[9]

This description differed among medical experts only in the particulars writers found especially telling, such as freckles, curved fingernails, or bulbous fingertips.[10] An experienced physician recognized at first glance a patient who presented a diathesis of wasted frame, flushed cheek, bright eyes, and lank hair.[11] Writers in lay journals offered nearly identical descriptions. One observer, for example, explained that the thin, ovoid, softened face associated with a consumptive habitus "com-

pared with horses and cattle who have been what is called 'over-bred'; such animals are described as having too much nerve and too little bone and muscle; they have no 'staying power.' "[12] A person of the opposite form, that is, "with large breast, and its accompanying small lungs, an enlarged and powerful heart, well-developed abdominal viscera, and a hearty appetite, rarely, if ever, becomes consumptive."[13]

In popular fiction of the era, readers recognized the signs of a consumption immediately: in Constance Fenimore Woolson's *East Angels*, Mrs. Thorne grows weak and dies after lingering for fifteen pages. Then another character, pale, delicate Margaret, collapses with fever. As she reaches out with thin, transparent hands, loved ones gasp at the sight of her large, bright eyes and the blue veins protruding at her temples, the physical prolegomena to death.[14]

This idea of a "tubercular diathesis" had an antique lineage. Observers as far back as Hippocrates believed they could identify a consumptive person by certain distinct external signs. Hippocrates attributed a smooth white body and winglike shoulder blades to a *habitus phthisicus.*

Over the centuries, people have expressed this psychological and social need to associate outer, visible signs with inner turmoil and decay in myriad ways. Medieval lepers carried bells on sticks; twentieth-century children with whooping cough wore white armbands. There is a long folk tradition of parental warnings about masturbation's producing warts and hairy palms. The indicators for disease, artificially created to aid the unafflicted in identifying the afflicted, changed form over the centuries, from the ominous red *X* on a door to a complex and abstract but equally fabricated physiognomy of illness. The commonly accepted physiognomic indicators of consumptions were crucial to recognizing the illness and lost persuasiveness only with the dominance of biotechnical medicine. Closely related to this aspect of the psychosocial origins of the physical diathesis was the general construct of physical types, which had undergone a popular revival earlier in the century. As an offshoot of the Enlightenment, the growth of systems to classify all things in the natural world led observers to develop a science that differentiated among plants, races, individuals, animals, and so on. Such Enlightenment thinkers as Buffon and Condorcet introduced the possibility of ideal human types and provided those so inclined with a rationale for classification of people. The search for the underlying