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# What is Health?

Exploring Conflicts in Perceptions of Health and Illness

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Margaret Ginoza

**READERS: JANET GRAY, MICHELE TUGADE**

Thesis submitted in partial fulfillment of the requirements for a major in the Program in Science, Technology, and Society (STS)

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## Introduction

Throughout the centuries, cultural explanations for illness and disease have covered a broad spectrum, ranging from imbalanced humors and miasmas to modern germ theories and genetic approaches. Humankind has always been invested in defining, identifying, and fixing illness. Overtime, these definitions and solutions have changed immensely. A key feature of most explanations of illness is the fact that it is an aberration from health – but what *is* health?

In 1861, American spiritualist Andrew Jackson Davis defined physical health as “symmetry of development, energy of Will, harmony of function, and bodily purity”. Though perhaps outdated and not scientifically based, this definition rings surprisingly true in another prominent, secular definition put forth almost a century later. The World Health Organization (WHO), in the preamble to the WHO constitution adopted in 1948, defines health as follows: “Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.” With this definition, the WHO takes a strong stance in placing the state of health as the pinnacle of human well being, any minor deviance from which labels and individual or circumstance as “unhealthy.” In this definition, health becomes an *asymptotic concept*, “an ideal on the horizon that can be approached but never reached” (Wylie 1970)

This definition is clearly suited for the WHO purpose and mission. In promoting global health, a narrow definition of health allows the organization wide leeway within which to pursue a variety of goals. The WHO facilitates hundreds of programs on topics ranging from communicable disease control to violence

prevention to trade initiatives. Under a different definition of health, something like violence could be considered outside of the WHO umbrella, as it results from conflict between individuals rather than “disease or infirmity”, while trade initiatives might seem an economic matter, but this strict definition allows the WHO to encompass both.

On a societal level, this may be a useful definition of health, but what of the individual? A number of individuals and organizations have challenged this idea of health as a state of all-around perfection, presenting their own ideas of what “health” is, noting changes in disease patterns and social understanding since the definition was codified in 1948. Many of these definitions make health out to be an *elastic concept*, “[relating] health to an ability to resist threats of disease” (Wylie 1970). In an essay entitled “Healthy in a Falling Apart Sort of Way,” Jane E. Brody notes that many people in today’s society live functional and fulfilling lives despite dealing with a number of chronic illnesses and disabilities, suggesting that instead “The ability to cope with life’s ailments might be more a more important and realistic measure of health than complete recovery.” The prominent medical journal *The Lancet* expressed a similar sentiment in a 2009 editorial, stating, “health is defined not by the doctor, but by the person, according to his or her functional needs.” *The Lancet’s* conclusion was reflected in the title of the editorial alone: “What is health? The ability to adapt.”

### Canguilhem’s norms of health

These alternative definitions presented both draw significantly from the thoughts of French physician Georges Canguilhem, who tackled this topic in *The*

*Normal and the Pathological.* Canguilhem recognized the importance of understanding the complexities of health in order to truly understand illness: “ To govern disease means to become acquainted with its relations with the normal state, which the living man – loving life – wants to regain” (41). In understanding this relationship, Canguilhem presents the idea that health and illness are not disparate concepts, but rather interrelated and specific to the individual.

Canguilhem views health as a spectrum of norms, rather than a set of distinct boundaries between the normal (“healthy”) and the pathological (“ill”). One norm may be superior to another, “ when it includes what the latter permits and what it forbids” (182) and thus, “disease is still a norm of life, but it is an inferior norm” (183). This normal state may be defined “in terms of a normal relationship of adjustment to environments” (148). Though a state of illness may be limiting to a patient, Canguilhem asserts that it is possible to reestablish a balance in that inferior norm, coping within a narrowed environment. To Canguilhem, being well means being “capable of ordered behavior”, something which may be impossible to the acutely ill individual, but that they may be able to accomplish once they have developed some semblance of control over their illness, or cooperation with its limitations. This framework is valuable in understanding how people may adapt to an illness, and why individuals may perceive their own state of health in a way that is contrary to their pathological diagnosis, as will be explored in further chapters.

### **Text-specific terminology**

In order to continue to explore our understanding of health, it is necessary to first identify and define several concepts that will be integral to the subsequent

sections. Specifically, I will lay out the concepts of *symptoms*, *symptom burden*, and *diagnosis*, each of which will be essential to constructing our understanding of health and illness.

In medical terminology, evidence of illness is distinguished between subjective *symptoms*, something the patient feels and can describe to others, and objective *signs*, which can be observed outwardly by the healthcare provider (Gulli, Ciatolla and Barnes 2011). For the purposes of my analysis, I will use the term symptom in a broader sense, referring to both signs and symptoms, or any change in body or mind directly attributable, as perceived by the patient, to a state of non-acute illness. By using this definition, I will maintain the subjective nature of symptoms, which is important to an understanding of disease as defined by the patient, while also recognizing the importance of a physical assessment in a physician's diagnosis of disease.

It is worth noting that in this definition, I specified non-acute illnesses. This is not to say that acute illnesses have no symptoms, but rather that in the interests of my analysis, I will look past such symptoms as a passing cough in order to more closely examine the symptoms that last long enough to accrue a label of serious illness. Thus, throughout my arguments I will focus primarily on non-acute states of illness, instead focusing primarily on longer term, chronic or recurring illness. A person experiencing an acute illness such as the common cold, provided there is no underlying disease state which would amplify the acute illness, can say with relative certainty that they will soon return to an illness free state – that “superior” norm of life to which Canguilhem refers (182). While this inferior “diseased” norm of life

may indeed impact an individual's ability to adapt to their environment over a period of hours or days, the superior norm reestablishes itself with such relative swiftness that the temporary illness can almost be considered a component of the normal state itself, rather than a truly inferior norm.

An amalgamation of symptoms and their compounded effects constitutes a *symptom burden*. Most commonly used definitions of symptom burden are clinician-derived, incorporating a spectrum of factors relating to a patient's experience of illness. Broadly, symptom burden has been defined as "a patient-reported outcome that encompasses both symptom severity and the patient's perception of the impact of the symptoms on daily living." The physician's interpretation of symptom burden often relies on numerical measures to quantify the burden, through symptom scorecards or mean numbers of symptoms. Given that symptom burden is a patient reported concept, however, means that it is important to consider what patients consider to be the definition to be, not simply how the physician assumes they will interpret it. A study of terminally ill cancer patients, asked open endedly to define *symptom burden*, returned a variety of answers, though several ideas were common (Gill, Chakraborty and Selby 2012). A prominent definition was the (in) ability to do usual activities, or as one patient explained, "Well, for me, symptom burden is how my symptoms affect me to do my normal routines everyday." Another provided an almost identical definition, stating, "symptom burden is how my symptoms negatively affect my day-to-day life. That's what symptom burden means to me, how it affects what I do on a daily basis." With the addition of a few other frequently mentioned factors, including "psychological suffering" and "specific severe



symptoms,” these definitions help develop our understanding of symptom burden from a lived perspective, beyond simply the definitions and tables used by physicians.

Symptom burden is a useful concept as it allows us to distinguish between the mere presence of symptoms and the actual impact they have on one’s ability to adapt to their changing environment. People who consider themselves “healthy” by the adaptive definition may still carry a low symptom burden, though this low burden may be enough to merit a clinical diagnosis of illness, and certainly enough to exclude a patient from the WHO definition of health. Meanwhile, a patient may carry a high symptom burden despite the lack of a clinical diagnosis, forcing us to confront the dilemma of physician authority vs. patient autonomy and self-determination.

*Diagnosis* is another term to which I will frequently refer. Diagnosis, by dictionary definition, is “the act of identifying a disease from its signs and symptoms” (Merriam-Webster.com n.d.). From a logistical standpoint, a diagnosis is “that condition established after study to be chiefly responsible for occasioning the admission of the patient to the hospital for care” (Moisio 2009, 46). As evidenced by these definitions, a diagnosis is an answer to the medical puzzle presented by a patient’s symptoms, one that opens the door to further treatment.

But a diagnosis has a profound impact on the individual in the social and metaphorical sphere as well. Indeed, “as a bodily inscription, the diagnosis etches onto a material body a representation of what it is to be ill, have an ill body, and be socially constructed as ill.” (Moss and Dyck 1999). A diagnosis is the ultimate label

of illness, one that allows (or forces) a patient to access spaces and resources reserved for those with a label of “ill.” The space occupied by “sick people” may provide tangible benefits to the ill person such as access to medical treatments, doctor’s prescriptions, insurance claims, and workplace accommodations. Placement in the realm of sickness can also act as a barrier to the world of the “healthy,” with the potential forced treatment, quarantine, difficulties obtaining insurance due to pre-existing conditions, and more.

Equally as challenging as the logistical barriers are the social barriers instilled by a diagnosis. Now labeled as ill, the patient can face stigmatization due to their diagnosis:

“Diagnosis does not function neutrally, to merely describe. It renders a moral judgment. It communicates a deficit in worth. “You are not active enough,” or “you are too active.” You are not sexual enough,” or “you are too sexual.” “You don’t eat enough,” or “you eat too much.” “You don’t make rational sense,” or “you are excessively rational.” In effect the diagnosis can function as a form of stigmatization, rendering one undesirably different” (Neimeyer 2000)

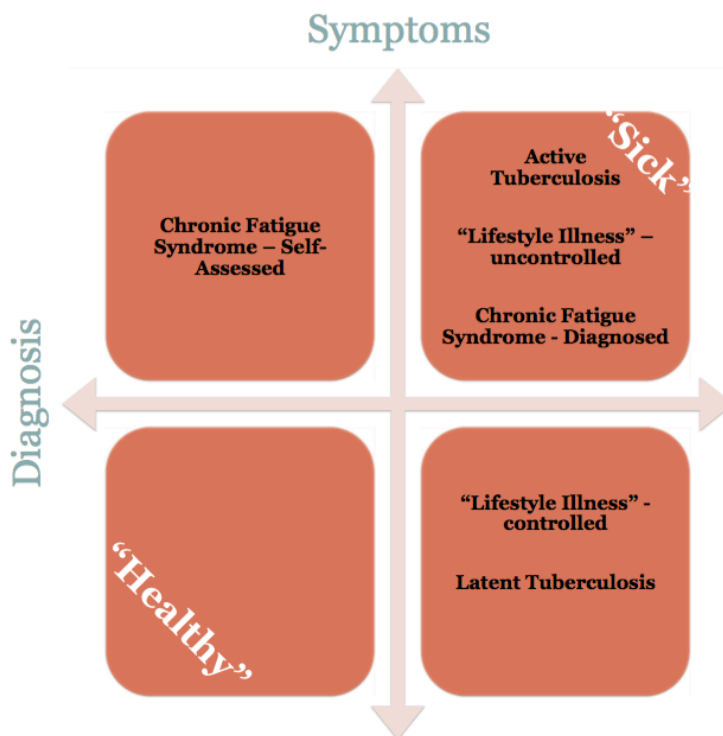
The application of a diagnosis may result in stigma for a number of reasons – fear of contagion, a sense of blame for the manner in which the disease was contracted, lack of understanding about the illness itself, and more. These stigmas will be explored in later chapters, particularly the latter.

### **Quadrants of health and illness**

So far, I have addressed two clear indicators of illness: symptoms and diagnosis. When an individual presents with both of these indicators, in a way that

disrupts their ability to adapt, it is easy to label this patient as ill. On the contrary, a patient with neither symptoms nor a diagnosis, who is happily adapting to their environment, can be thought of as healthy. However, we arrive at some difficulty when we consider the mismatch that lies in between: symptoms without diagnosis, or diagnosis without present symptoms.

In subsequent chapters, I will explore the issues presented by each of these four combinations of symptoms and diagnosis in the context of several forms of illness. Specifically, I will examine the cases of tuberculosis, hypertension, and Chronic Fatigue Syndrome. The following figure provides a simplified visual representation of the complexities I will be examining by way of these cases. Though the figure is presented as quadrants, it is important to recognize that each illness cannot be simply placed into a positive or negative box, but instead likely falls somewhere along a spectrum, with each individual case varying in its presentation.



While these examples are nowhere near comprehensive representations of all forms of illness, each case presents specific scenarios that complicate our idea of what it means to be healthy. In examining tuberculosis, I will look at the difference between latent and active infection, the possibility of forced quarantine, and the role of numeric thresholds in defining illness. Through Chronic Fatigue Syndrome, I will explore the barriers faced by patients experiencing symptoms and seeking diagnosis to validate their illness, the stigmatization of that ultimate diagnosis, as well as the financial difficulties faced by sufferers of “invisible” illnesses. Finally, through hypertension I will address the idea of “lifestyle” illness, heavily prevalent in an aging population with increased opportunity for medical management, allowing for “healthy” adaptation despite a label of chronic illness, or diagnosis without symptoms. I will also address the ideas of *preferential behavior* and *catastrophic reaction*, in terms of coping with a chronic illness. Throughout each section, I will develop an analysis of a number of concepts, including the importance of finding a balance between physician’s authority and patient autonomy, social constructions of illness, and ultimately what it means to be considered “healthy” or “sick”.

## Tuberculosis

Tuberculosis (TB) is a bacterial infection caused by *Mycobacterium tuberculosis* (CDC 2012). Though it can attack all parts of the body, it mainly infects the lungs, and spreads from person to person through the air. If a person's immune system cannot keep the bacteria at bay, that person will develop TB disease, with symptoms including fatigue, weight loss, chills, fever, and the recognizable bloody cough.

Tuberculosis was once thought to have been almost eradicated in the United States, with infection rates declining into the late 1980s (Renwick 1993). But TB returned with a vengeance in the early 1990s, particularly amongst poor, HIV+, and immigrant communities. Fighting this resurgence requires more than simply identifying cases. To fully cure someone of TB can require intensive regimens of pills and injections for months or years, resulting in high rates of noncompliance as patients begin to feel better and stop taking their medication. As such, drastic measures are sometimes required, from daily visits with healthcare personnel to isolation or quarantine of infected individuals until they can be successfully treated.

### Drug-resistance and forced quarantine

It is impossible to begin to address the issues surrounding infection and quarantine without reference to perhaps the most famous carrier of an infectious illness in the American conscience: Typhoid Mary. Though Mary Mallon asymptotically carried a different bacterium, her story and experience of forced quarantine and stigmatization is essential background to his experience. An Irish

immigrant working as a cook in New York City at the turn of the 20<sup>th</sup> century, she unknowingly carried typhoid fever, passing it on to others through her cooking. Despite the fact that, beyond harboring the bacteria, doctors “acknowledged that in every way she was the picture of perfect health” (Keane 2014), she was arrested without warrant and placed into forced quarantine. Her diagnosis alone, despite lack of any apparent symptoms and her own insistence on her health, was enough for public authorities to deem it necessary to force her into a space created for the sole purpose of containing illness, simultaneously using the moral judgment inherent in the diagnosis to label her as a criminal.

There is, of course, merit to argument for forced quarantine – the health and safety of the general public must be considered. Perhaps, rather than arguing the general merits of quarantine procedure, it is the *forced* aspect we must consider – Is the resistance by the patient merely due to a desire for freedom despite potential dangers or due to a misunderstanding between patient and physician in their definitions of health and illness, and thus misalignment in their understanding of the threat level?

Consider the case of Andrew Speaker, a US citizen who made headlines in 2007 after travelling abroad while carrying multidrug-resistant tuberculosis (MDR-TB) (Valentine 2007). Speaker’s initial diagnosis came about after an x-ray for a rib injury incidentally revealed “a mass, suggestive of TB”. An early test showed his sputum to be clear of bacteria, but a later test showed the presence of the bacterium. Analysis determined the infection to be multi-drug resistant tuberculosis (MDR-TB), a dangerous strain that is “resistant to the most powerful first-line drugs.” Speaker

flew from Atlanta to Paris for his honeymoon on May 12, 2007. During the 13-hour flight, he wore no protective mask nor notified anyone of his diagnosis. The CDC lab later upgraded his diagnosis to extensively drug resistant TB (XDR-TB), significantly limiting treatment options.

CDC officials located Speaker in Europe, asking him to report to a hospital in Rome as they evaluated the options. Speaker and the CDC debate the exact details of what was said. Instead, Speaker boarded a plane from Rome to Prague, followed by another transatlantic flight to Montreal, even as officials attempted to add him to the no-fly list. After checking into Bellevue Hospital in New York, the CDC transferred Speaker to Atlanta under a federal isolation order – the first since 1963, when a passenger on a flight arriving in the US was suspected of having smallpox (Henson and Geltman 2014). Speaker’s smear test results later proved negative, making him a low risk for infecting others (Valentine 2007). Speaker eventually began drug treatment, with monitoring by health officials.

Physicians insist that Speaker was made aware that he should not travel, and that his illness was potentially contagious to others. Speaker, meanwhile, maintained that he was told he was not contagious, and did not consider himself to be seriously ill. According to news sources, he “never thought he was sick enough to infect others. He felt fine two weeks ago, walking around, jogging and trying cases as usual” (ABC News 2007). This puts him in a similar situation to Mary Mallon: No (or minimal) symptoms, but a diagnosis that labels him sick and dangerous, in need of quarantine. In each case, public interest, patient autonomy, and physician’s authority find themselves in conflict.

As demonstrated by these cases, conflict between a patient's experience of their own health and a physician's official diagnosis, if not addressed, can lead to complex and potentially dangerous situations. From Speaker's point of view, his infection resulted in no symptom burden or major impact on his self-perceived health. He may have felt that any restriction on travel placed by the CDC as asking him to subject himself to an inferior norm, a norm of illness that prevented him from fully enjoying his honeymoon as a healthy person could. Meanwhile, from the perspective of the CDC, the infection itself had already lowered Speaker's health status to an inferior norm, which could only be returned to a healthy norm through treatment. The CDC also would have considered the health of the general population, and not of the singular individual, as the presence of untreated TB in the population would put others at risk. Populations and communities can therefore be viewed as entities possessing a singular state of health, based on the individuals that comprise them. Andrew Speaker threatened the states of health for the spaces in which he traveled, and therefore was labeled as "sick" despite his lack of individual symptoms.

### Testing and numeric thresholds for illness

Not all cases of infection result in forced quarantine, yet the same disconnect between patient and doctor still plays an important role in less newsworthy cases. Nearly one-third of the world's population is estimated to have Latent Tuberculosis Infection (LTBI), "a state of persistent immune response to stimulation by *Mycobacterium tuberculosis* antigens without evidence of clinically manifested active TB" (CDC 2012). These patients carry the TB bacterium, but it is kept in



control by their immune systems, preventing the infection from developing into full-blown, symptomatic tuberculosis.

Latent TB is most commonly discovered by a tuberculin skin test, in which a small amount of purified protein derivative is injected into the skin, usually on the forearm (Jasmer, Hopewell and Nahid 2002). After 48-72 hours, the site of the injection is examined, and any induration is measured. An infected individual will develop a cutaneous reaction to the tuberculin, and as such any induration larger than a threshold measurement is considered a positive result. However, this threshold measurement varies certain patient characteristics, with smaller measurements for higher risk groups being labeled as positive, whereas the same measurement on a lower risk patient would be considered a negative or inconclusive result. For example, a high-risk patient would receive a positive result with an induration of 5mm or more, while a low-risk patient would need an induration of 15mm or more to receive a diagnosis of LTBI.

It is recommended that asymptomatic individuals should not be tested for latent tuberculosis unless they have epidemiological risk factors for active tuberculosis. These factors fall generally into three categories: increased risk of exposure to infectious cases, increased risk of tuberculosis infection, and increased risk of active tuberculosis once infection has occurred. As mentioned previously, within these risk factors, there is a difference in positive threshold based on severity of risk (and thus likelihood of contracting active infection). This usage of risk factors to determine the need for testing and subsequent treatment makes sense as a medical strategy for targeting those most likely to be ill, but raises an interesting

question: Is an individual with no risk factors, who may indeed have latent tuberculosis but goes untested, any more or less sick than the healthcare worker whose latent TB is discovered during a yearly health screening?

It may be said that because many of the risk factors for latent tuberculosis are such that the individual already has an existing diagnosis and is already likely to be in poor health – HIV infection, diabetes, certain cancers and drug treatments, among others – the diagnosis of latent TB for these patients merely adds to their previous state of illness. These patients are already labeled as ill, and the diagnosis and treatment of TB will only prevent increased illness, but not return the patient to a healthy state. However, a number of the risk factors carry no assumption of current illness, only a likelihood of exposure to other ill persons. Individuals with these risk factors include healthcare workers, foreign-born persons, and others with potential exposure to active tuberculosis cases. When considering and comparing these persons, how do we label some as healthy, and others as sick, despite the same apparent symptoms (or lack thereof)?

One review of Latent Tuberculosis Infection presents the following scenarios, as part of an exercise in TB identification and treatment:

“Patient 1, a 44-year-old man who recently immigrated from Peru, is found to have induration of 16 mm in diameter on a tuberculin skin test. He received bacille Calmette–Guérin (BCG) vaccine as an infant and is asymptomatic.

Chest radiography shows fibronodular opacities in the upper lobe. Patient 2, a 27-year-old schoolteacher who was born in the United States, has induration of 17 mm on a tuberculin skin test, no symptoms, and a normal

chest radiograph. Should these patients receive treatment for latent tuberculosis infection?" (Jasmer, Hopewell and Nahid 2002).

The authors, at the end of their review of testing and treatment procedures, present the following treatment plans for the two patients:

"Patient 1 described in the vignette should be presumed to have tuberculosis infection; his history of BCG should be ignored. However, because of the abnormality on his chest radiograph, treatment for latent tuberculosis infection should not be started until sputum cultures are negative for *M. tuberculosis*. After cultures are negative, the preferred regimen would be isoniazid given for nine months. Patient 2 is at low risk for the development of tuberculosis and should not have been tested. Nonetheless, she has latent tuberculosis infection, as evidenced by her tuberculin reaction of more than 15 mm. However, she should not be treated, because she has no conditions that increase her risk of progression to tuberculosis and it is unknown when she became infected. One cannot conclude that she has had recent tuberculin conversion, because she has not had a negative tuberculin test within the past two years."

The authors do not go so far as to label either patient as "ill" or "healthy", simply providing a diagnosis and treatment. However, as we have begun to establish, diagnosis is only one aspect of defining health.

Patient 1, in this case, has received a diagnostic label that seems to place him towards the "ill" end of the health spectrum. His lack of symptoms, however, seems to imply that he may consider himself healthy otherwise (the article does not

provide a patient perspective, so this is speculative). If the sputum cultures return positive, indicating active infection, this would place him more firmly towards the “ill” category.

One additional factor would provide a significant push towards a label of sickness over health: the patient’s willingness to accept the treatment suggested. Though the patient may have a minimal symptom burden, the treatment can bring with it a burden of its own. The patient may be asked to accept treatment under direct monitoring to ensure compliance, which in this case may last up to nine months, causing a significant disruption in personal routine. The isoniazid recommended can also have toxic effects, including hepatitis, rash, and peripheral neuropathy. Patients receiving such treatment are advised to avoid alcohol consumption, as it may increase the risk of hepatitis. For the nine months that the patient receives treatment, he has assumed an inferior norm, one that prohibits alcohol consumption and restricts daily activity in order to ensure compliant treatment. Once he has been cured, he may regain that superior norm, provided the treatment has not resulted in lasting toxic effects. As such, it is possible that patients undergoing such treatment may come to see themselves as ill, despite the fact that the symptom burden is attributable to the treatment and not the disease process itself.

Patient 2, on the other hand, is more difficult to label definitively as “ill”. While she has been diagnosed with LTBI, the authors do not recommend treatment, and would not have recommended testing in the first place. If she had never been tested, and otherwise experienced no issues with her health, both doctors and

patient would likely have chosen a “healthy” label. Her diagnosis, however, calls the label into question, and forces us to once again consider how large of a role a diagnosis plays in determining an individual’s state of health. In this case, the decision to forgo treatment seems to give the diagnosis lesser weight, so long as it is kept between patient and doctor. Unlike the case of Andrew Speaker, where his illness was viewed as dangerous to those around him (particularly because of the infection’s drug resistant nature), this patient is not seen as a threat to the general population’s state of health.

An important distinction between the three cases of illness so far presented may be the level of threat implied by the infection, to the patient or to others. Andrew Speaker’s tuberculosis was considered a threat both to himself and the community, resulting in a publicly applied label of illness, isolation, and drug treatment. This is very reminiscent of Mary Mallon, who “was not sick herself, but the presence of pathogenic bacilli in her body defined her as hazardous to others” (Leavitt 1996). Patient 1’s infection, meanwhile, is simply a threat to himself. Thus, the patient’s perception of his own health is not necessarily trumped by medical authority the same way Speaker’s was. And in the case of Patient 2, neither she nor the community is at risk, meaning that despite the technical diagnosis, she can be viewed as generally healthy.

We have examined several examples of tuberculosis infection, particularly latent infections, each presenting their own complications to the question of defining health. But with all of these complications, there is one important factor to remember: TB can be cured. The treatment may be long and strenuous, especially in

the case of drug resistance, but there is still the hope of a cure in most cases. While TB cannot be dismissed in the same way as the common cold, an entirely new set of complications arise when addressing chronic, lifelong conditions. These conditions, once diagnosed, are expected to stick with the patient through much of the rest of their life. In the following section I will examine one such condition, Chronic Fatigue Syndrome.

## Chronic Fatigue Syndrome

In discussing Tuberculosis, I examined the way that a disconnect between a doctor and patient can result in conflict if a patient feels themselves to be healthier than their diagnosis would imply. But what if it is the other way around?

Chronic Fatigue Syndrome (CFS) is a complex, controversial, and debilitating illness that goes by many names, including Myalgic Encephalomyelitis (ME), chronic fatigue immune dysfunction syndrome (CFIDS), and others.<sup>1</sup> It is characterized by the titular symptom of profound fatigue, which disrupts daily life, as well as a myriad of other potential symptoms involving numerous body systems. No specific cause is known for CFS, though it is believed that there may be one or more causes or triggers including “infections, immune disorders, stress, trauma, and toxins” (CDC 2015). The CDC uses the following case definition in identifying cases:

1. The individual has had severe chronic fatigue for 6 or more consecutive months and the fatigue is not due to ongoing exertion or other medical conditions associated with fatigue (these other conditions need to be ruled out by a doctor after diagnostic tests have been conducted)
2. The fatigue significantly interferes with daily activities and work
3. The individual concurrently has 4 or more of the following 8 symptoms:
  - Post-exertion malaise lasting more than 24 hours

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<sup>1</sup> There is some controversy over whether CFS and ME are in fact the same illness, as well as whether the name “chronic fatigue syndrome” does a disservice to diagnosed patients by simplifying the complex illness to simple fatigue. I will primarily use the term CFS, however I acknowledge this debate, which can be further explored in the report *Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness*.

- Unrefreshing sleep
- Significant impairment of short-term memory or concentration
- Muscle pain
- Pain in the joints without swelling or redness
- Headaches of a new type, pattern, or severity
- Tender lymph nodes in the neck or armpit
- A sore throat that is frequent or recurring

These symptoms should have persisted or recurred during 6 or more consecutive months of illness, and they cannot have first appeared before the fatigue. (CDC 2015)

A criteria recently developed by a committee for Institute of Medicine, though not as of yet adopted by the CDC, proposed another criteria that, while maintaining the major fatigue component, would replace the list of possible symptoms with other more definitive diagnostic requirements: Post-exertional malaise, unrefreshing sleep, as well as one or both of cognitive impairment and orthostatic intolerance (Beyond ME/CFS 2015).

Evidenced by both of these criteria however, is the fact that there is no such thing as a definitive diagnosis for CFS. There is no blood test, skin prick, or lab result that will allow a doctor to definitively tell a patient that they have CFS. The CDC acknowledges that the complexity and remitting patterns of the illness can present diagnostic challenges. Perhaps most the most difficult challenge to diagnosis is the fact that, though often profoundly disabled, many CFS patients do not appear ill at all. And yet, a diagnosis can be profoundly important to a patient with CFS, for



whom a definitive label of illness can provide validation to their own experiences of illness and disability.

I have previously spent an entire chapter challenging the role of a diagnosis as the defining feature of illness, but the case of CFS flips that on its head, as we move to new quadrants of the health spectrum. Contrary to latent tuberculosis, CFS patients carry a symptom burden – often a massive one. The exact symptoms may come and go, and the severity may fluctuate, but in all cases daily life is significantly impacted. As Peggy Munson, a CFS patient and writer gathering stories of other sufferers, explained, “most of us lose our jobs, some of our friends, the capacity to enjoy simple activities, and a great deal of our freedom to act spontaneously” (P. Munson, *On Life* 2000, 156). This loss of freedom comes with the assumption of a new norm, one that may limit the sufferer to their bed for weeks on end, to their home for months or years. Without a diagnosis, CFS patients fall into that gray space between health and illness, knowing from their own experience that something is wrong, but lacking the official validation to prove it. Though the patient can define their own personal experience of illness, they need the validation of a doctor’s diagnosis to access the resources they need to persevere through the illness. As Munson noted, “Illness can exist without understanding or definition, but without these two things, it will rarely be helped” (P. Munson, *Introduction* 2000, 10).

### **Disbelief and failure to diagnose**

A common feature of CFS narratives is encountering profound disbelief, from the medical community or general public. As one parent of a CSF patient explained, “Rather than admit, ‘We have no cause, we have no cure, we have no clue (and maybe

even we don't really care),' the medicine men more often lift a collective skeptical eyebrow and state: nothing is really sick here" (M. Munson 2000, 191). CFS symptoms are often glossed over, or attributed to some other "non-medical" cause, such as depression. Because of the invisibility of the illness, both in knowledge and in the patient's appearance, doctors may brush off a patient's complaints as trivial. Munson collected such stories, one woman reporting that "her doctor said she was too 'blond and beautiful' to be so 'exhausted'; another responded that her doctor said she was too much of a 'beautiful young redhead' to be so ill" (P. Munson, Introduction 2000, 8).

Many patients experience this disbelief on a personal scale, from friends, family, and coworkers. For those without a diagnosis, it can be hard to explain their illness to friends. As one patient put it, "we're still a decidedly practical people and if someone is ill we want proof. A test, a diagnosis. Evidence" (Wall 2000, 23). CFS patients often have nothing to offer, nothing to explain their inability to go about their previous healthy lives. A simple explanation of "illness" doesn't cut it – "because so many people with CFIDS simply disappear from the social fabric, deprived of an accurate language for their condition, they are often shunned by the people around them" (P. Munson, Paradox 2000, 122). Even for those who have been supported by their physician and given a diagnosis of CFS, the name itself is not always a satisfactory answer for those seeking an explanation of illness. After all, we all experience fatigue at some point, and chronic fatigue syndrome simply does not sound "medical" enough for many people to accept.

The diagnosis of CFS has also been extensively challenged in the public sphere. A book by literary critic Elaine Showalter, *Hystories*, played a major role in this challenge, playing into public opinion against CFS sufferers when it was published in 1997. Showalter, neither a physician nor a psychiatrist, asserted that CFS, among other maladies, is merely a form of “contemporary hysteria,” comparing it to the likes of satanic ritual abuse and UFO abductions. Showalter used her feminist interpretation of hysteria, as “a product of women's social circumstances” to discount the experiences of CFS patients. While there are significant gendered implications to be considered when studying certain illnesses, including CFIDS and many autoimmune diseases such as lupus that seem to disproportionately affect women, to pass off all unexplained female illness as hysteria can be dangerous. As one critic noted, “she overlooks an equally common diagnostic error: the psychologizing of problems with organic causes” and that “in the absence of medical certainty, the belief that all such symptoms are psychological in origin is no improvement over the belief that none of them are” (Tavris 1997).

### **Financial impacts of diagnosis**

Because many CFS sufferers are no longer able to leave the house for long periods of time, let alone work, it often becomes extremely important to secure insurance and disability benefits to make up for lost income and support the sufferers and their families. In these situations, an official diagnosis of CFS can be both a blessing and a curse.

The US Social Security Administration considers CFS to be a “medically determinable impairment,” which a patient can prove by “providing appropriate evidence from an acceptable medical source,” specifically a licensed physician (Social Security Administration 2014). This means that, provided a patient can secure an official diagnosis and empirical documentation of their disability, they may be eligible to receive disability benefits through Social Security. However, the documentation required includes objective medical signs, such as lab tests or physical manifestations of symptoms. This can make it difficult for patients to document major symptoms that show no outward evidence, and self-reported symptoms alone are often denied (Hotfelder n.d.). Thus, it is clear that for the Social Security Administration, health and illness are defined almost exclusively by physicians and scientific results, without regard for patient experience. While denial of a claim does not imply that a patient is “healthy”, it makes it clear that the denied patient is not sick enough to receive the resources reserved for the “ill”.

Patients seeking insurance benefits, meanwhile, may encounter the opposite problem. Many patients may be uninsured or, because many patients lose the ability to work before they are diagnosed, lose the insurance benefits provided by their employer. When these patients are most in need of healthcare coverage, they may find difficulty securing this resource supposedly intended to support the ill. Prior to recent legislation that prevented such occurrences, many patients found themselves unable to purchase an insurance policy due to their “preexisting condition” – the irony of finally receiving an official diagnosis. Some states have programs for uninsurable people, such as the Colorado Uninsurable Health Insurance Plan

(CUHIP) but they may require costly payments and high levels of out of pocket expenses, making them inaccessible. Nadine Goranson, a CFS patient who lost her insurance from her employer due to inability to work, was denied by other insurance companies and could not afford the cost of CUHIP, made the following observation:

“I found it ironic that my entire life I had been healthy, and I had always had health insurance – now I was sick, and no one would insure me. For the first time, I understood how a person could “fall through the cracks” of our health care system. I understood that health insurance was for the healthy, and those who could afford it.” (Goranson 2000, 57)

Goranson had received the diagnosis she needed to validate her illness, and yet was now denied the health support due to her illness. But as she observed, health insurance companies do not actually want to support the chronically ill. The ideal beneficiary of a health insurance policy is a healthy beneficiary, continuing to pay into the program without ever needing financial support for a health condition. Though recent developments in insurance reform have attempted to address some of these issues, allowing coverage for preexisting conditions, this is still an experience all too familiar to CFS sufferers diagnosed before the (still imperfect) reforms.

As Peggy Munson notes, CFS sufferers “live in a state of limbo” (P. Munson, *On Life* 2000). Too healthy looking to be sick, too sick to go about their daily lives, too healthy for Social Security but too sick for insurance benefits, they must constantly fight to define their illness, even as they fade into invisibility. In these

cases, the diagnosis at least partially validates a patients symptoms, but cannot relieve the symptom burden itself, or the doubts of those who do not understand or accept the diagnosis.

If CFS is an unseen illness, in the following section I now turn to a condition that is in many cases both unseen, unfelt, and untreated: hypertension.

## Hypertension

Hypertension, or high blood pressure, is “a common condition in which the long-term force of the blood against your artery walls is high enough that it may eventually cause health problems, such as heart disease” (Mayo Clinic Staff 2015). A patient may experience high blood pressure for many years, even without symptoms, though the damage and severity will increase over time. Hypertension develops over time, and will affect nearly everyone by a certain age. About 70 million American adults have hypertension, or 29% of the population, with even more experiencing pre-hypertension, where blood pressure is elevated but not yet high enough to be diagnosed as hypertension (CDC 2015). A normal blood pressure is considered to be 120/80 mmHG or below. Pre-hypertension ranges from 120-139/80-89 mmHg, with full-blown hypertension at 140/90 mmHG or above. High blood pressure can be managed through medication, reduced sodium intake, exercise, or a combination of these therapies.

### Unhealthy Living: Chronic Lifestyle Illnesses

Hypertension can be considered a part of “chronic diseases of lifestyle”, or lifestyle illnesses, which are “are a group of diseases that share similar risk factors because of exposure, over many decades, to unhealthy diets, smoking, lack of exercise, and possibly stress” (Steyn, Fourie and Temple 2006). Urbanization, globalization, and aging populations have contributed to an increase in the prevalence of lifestyle illnesses, particularly in western countries. As populations

live longer, more sedentary lifestyles and consume mass marketed food and “unhealthy” products, they face a greater burden from conditions such as hypertension, diabetes, and obesity. These conditions often develop into further medical issues, such as heart, liver, and kidney diseases.

Many individuals living this modern lifestyle may be considered “unhealthy” due to their food and exercise choices (or lack thereof). But when does “unhealthy” become “ill”? For most, this may simply be normal, with no superior norm to compare it to. For those individuals with hypertension, as previously noted, many may not show symptoms for years, even after a high blood pressure has been observed by a doctor. These patients, still living within their own accepted norm in spite of their blood pressure reading, may not see themselves as “sick”. If the hypertension presents no symptom burden in the moment, despite diagnosis, these patients might not include the future possibility of further illness in their current assessment of health, placing them once again into a murky gray area between health and illness.

### **“Just another thing”**

One patient explained his own experience with hypertension to me. Diagnosed at an early age, he did not feel that his diagnosis profoundly impacted his view of his own health. “At 24 you feel invulnerable, you don’t feel like any disease or illness can actually hurt you.” He also remarked that, having dealt with other illnesses prior to diagnosis, hypertension became just another fact of life. “It was just another thing. By that point I already had other chronic diseases that I already knew about... so I was kind of used to the idea of other diseases. And I wasn’t super



concerned about it, because it didn't make me feel bad the way asthma did." In some cases, the medications prescribed to manage his blood pressure actually made him feel worse than the illness itself, until he was put on a regimen that worked for him.

### **Adaptation and catastrophe**

Under the strictest definition of health, a diagnosis of hypertension would label a patient as definitively ill. However, for many patients with well-controlled hypertension as previously described, it's simply a footnote on their otherwise normal life, resulting in nothing more than a set of pills to take every morning and encouragement to maintain healthy habits. When hypertension really pushes patients into the territory of illness, however, is when it is uncontrolled or compounded with other serious illnesses. Canguilhem explains this type of situation in terms of *preferential behaviors* and *catastrophic reactions*. When hypertension is controlled, the patient uses preferential behaviors to operate successfully within their environment, narrowed perhaps by the need to take medication or adopt different habits. Because they can adapt to their changing circumstances, they are by some definitions "healthy". However, when the patient loses control of their environment, due to unmanaged symptoms or progressing disease, the result is a catastrophic reaction, a failure to adapt to the environment. This catastrophic reaction, under adaptation-based definitions of health, may very well be the defining feature of illness.

The previously mentioned patient gave an example of these behaviors and reactions when he discussed his own father's experience with hypertension.

“His was harder to control, even with the drugs sometimes it would get out of control and get really really high. And he had some weird things – and if he sat down in a certain way his blood pressure would go way up, and then he’d lie down and it would go back to normal. And then there was a certain way of sitting that he’d avoid from then on.”

While not an extreme case, this example illustrates the way that patients rely on preferential behaviors to avoid catastrophic reactions. In this instance, a certain seated position resulted in an extreme spike in blood pressure, what could be considered a *catastrophic reaction*. In order to avoid this occurrence, he changed his habits to avoid that position, adopting another *preferential behavior* in addition to the medications he was taking.

In other cases, the catastrophic reactions can be much greater. Uncontrolled hypertension is widely understood to increase the risk for cardiovascular events, such as coronary heart disease and strokes, which can be fatal or at least result in greatly increased symptom burden. Sharon Bahrych, a Physician’s Assistant, sadly shared the results of one such reaction. An elderly patient insisted “that she didn’t take medications, she didn’t need them” (Bahrych, *Elderly Patients* 2011) Despite coaxing by Bahrych and a cardiologist, the patient refused to be treated for her high blood pressure until she finally underwent open heart surgery for an aortic dissection – something that could have been avoided or at least delayed had she taken her medication. Though she survived the procedure and began taking her meds, Bahrych later shared an update on the patient’s condition, naming all of the following ailments as direct results of her initially uncontrolled hypertension:

“congestive heart failure; sick sinus syndrome with a need to eventually have a pacemaker put in; open heart surgery to repair an aortic aneurysm, which ruptured on the OR table; aortic valve insufficiency; atrial fibrillation; vascular dementia; worsening of her variant angina.” (Bahrych, What Happens Next 2015) This decline demonstrates a slow but certainly catastrophic reaction.

### **Mismatched: Doctors and Definitions**

Much like in the tuberculosis cases previously examined, a mismatch between the physician’s understanding of hypertension and a patient’s experience of their health can once again result in catastrophic consequences, though in this case the patient is not putting others at risk, but themselves. Though many patients may take their doctor’s word as gospel and follow the advice given, many do not, as seen in Bahrych’s case, either because they do not feel the same urgency, or simply are unwilling to put the effort into the necessary lifestyle changes to manage the illness. Only about half of people with high blood pressure have their condition under control (CDC 2015). The other half, though perhaps perceiving themselves as healthy in the short term, may be setting themselves up for a future catastrophic reaction once the hypertension pulls the environment out of their control. This is why, once again, it is important that physicians make an effort to reach a common ground with their patient. A physician’s perception is much more likely to account for future risks when determining a patient’s state of health. No matter what label is applied in the moment, healthy or ill, a failure to control conditions such as hypertension can lead to a future, definitive label of illness.

However, there are cases in which the doctors themselves, not simply the patients, make limited or no attempts to reduce the blood pressure of patients who meet the threshold for hypertension. Are these doctors negligent? In some cases, possibly, but another explanation for this is that these doctors are in fact making that necessary effort to reach common ground. Often, when doctors fail to initiate or intensify a treatment plan for uncontrolled hypertension, they are taking into account other factors relevant to the patient's health and symptom burden. One study found that most common explanations could be grouped in the following ways: "The need for long-term negotiation with a patient whose overall status is taken into account; the lack of confidence in BP measurements; a somewhat distant attitude to accepted guidelines." (Nicodème, et al. 2009)

The first explanation included a significant portion of patients "with a disease affecting their lifestyle or threatening their life expectancy." For these patients, hypertension is "just another thing" with a negligible affect on their symptom burden, whether controlled or uncontrolled. These patients are already likely to see themselves as definitively "ill", so a bit of high blood pressure is unlikely to affect their self perception of health, while treating the hypertension will do little to restore them to "health."

The second and third explanations, on the other hand, indicate a negotiated outcome that results in a label of "healthy". A lack of confidence in BP measurements may be attributed to "white coat syndrome" or simply a physician's determination that previous BP readings present a more accurate picture of the patient's health. A "distant attitude to accepted guidelines" indicates a physician's disagreement with

the definition of hypertension itself. The physician may consider the blood pressure reading acceptable within the greater context of the patient's health and habits, or may feel that the prescribed diagnostics are too strict. Much like in the case of tuberculosis testing, the physician may feel that the threshold for diagnosing hypertension should vary based on risk and lifestyle factors. As such, not all patients would require treatment even with the same blood pressure reading. In these cases, a doctor may choose not to treat a patient they deem to be suitably healthy, who on paper would be defined as ill.

*“Any attempt to define what health means lays the definer open to attack by critics armed with heavy reference books” – Charles M. Wylie*

## Conclusion

In beginning this work, I first presented several competing definitions of health. I then examined the complicating factors of several illnesses, focusing predominantly on the impacts of symptom burden and official diagnosis by a physician. Each disease posed a different challenge to any attempt at defining health. All told, it begs the question: How do I, the author, define health?

To put it simply: I don't. Throughout the process of researching and writing this work, I have come to realize that one's perception of their own health is an intensely personal thing, often at odds with the perceptions of physicians and peers. My own understanding of health is certainly elastic, perhaps following most closely to the adaptive model. I believe that labels of health can be negotiated to some extent, but that it is important for physicians to realize that the patient will ultimately decide for themselves what that label means and how it will lead them to act. Most importantly, I believe that the most valuable definition of health is the one that allows an individual to best come to terms with their own body and environment, while accessing the resources and spaces that allow them to strive towards whatever their ideal of health may be.

However, attempting to understand how we label someone as “sick” or “healthy” is more than just an academic exercise in semantics. As evidenced by several of the situations examined, a disconnect between doctor and patient in their

understanding of a patient's state of health can result in real consequences – forced quarantine, unwanted (or wanted, but not given) treatment, social stigmatization, future illness, and more. In order for a doctor-patient relationship to be truly successful, it is important for each individual to recognize that their understanding of health may differ from others, and to work together to reach a place of understanding. Particularly for physicians, it is important to realize that the application of a diagnosis is not the end of the line. A diagnosis merely begins an ongoing conversation, which must take into account a patient's symptom burden and experience of their own health. This same disconnect in understanding can occur not just between doctor and patient, but patient and friend, family, or general public. This is where the stigmatization of illness comes from, particularly in the case of invisible illnesses such as CFS.

Ultimately, health is not a black and white matter. It cannot be neatly divided into quadrants, or covered by a blanket definition for every person. Health is an amalgamation of different factors, perceptions, and norms that must be uniquely examined for each patient and condition. A label of health or illness need not be permanent, and may or may not have a significant impact on a patient's life. What is most important is the recognition of those grey areas inherent in defining health and illness create conflicts that can have real impact on the lives and bodies of patients afflicted with conditions such as tuberculosis, chronic fatigue syndrome, hypertension, or any of the myriad of other conditions that affect the human race.

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