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Defining Illness

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BIOGRAPHY

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ABSTRACT

Illness and health are deceptively strange, and peculiar concepts. On the surface, they seem straightforward and simple. They seem like opposites, squarely housed in neat little boxes. However, when it comes time to define these concepts, it becomes difficult to articulate exactly what it means to be "sick" or to be "healthy." Some people that seem to be "healthy" may indeed be "sick."

KEYWORDS

Health, Illness, Disease, Bioethics, Katskee vs Blue Cross/Blue Shield of Nebraska, Social Health, Philosophy of Health, Concepts of Disease and Health

THE STORY OF SINDIE KATSKEE

The stagnate air is thick with tension and worry as a set of needles sting Sindie Katskee's arm. Each of the little points slice through her skin, and steal a little blood. Days later, in an off-site lab, a series of fancy machines spin and churn. Once finished, strings of numbers are printed out, compiled and handed back to Sindie's doctor. Within seconds the doctor works through the strange numbers, translating them into words packed with deep and horrifying meaning. The test results suggest his patient is at risk for cancer. Once he factors in her family history, he decides there is definitely a risk that cancer will develop somewhere within her reproductive system. With the tests completed and the data analyzed, the doctor records the official diagnosis, which is "a genetic condition known as breast-ovarian carcinoma syndrome" (Menikoff 378).

Like a cruel addition of fate, two weeks before Sindie is scheduled for an "abdominal hysterectomy and bilateral salpingo-oophorectomy" (Menikoff 378), a notice from Blue Cross arrives in the mail. As she reads over the letter from her health insurance company, fear that's remained coiled in her bones, lashes out whipping her body in violent waves. Blue Cross has declared they will not pay for her surgery, even though her doctor claims it the most "medically appropriate treatment available" (Menikoff 378). Blue Cross claimed she was free of cancer, and therefore not sick. They stated Sindie's condition was only a "predisposition to an illness" (Menikoff 380), not an illness.

After the surgeons have washed away the blood from their tools, and Sindie is no longer at risk for cancer, she finds herself locked in another battle. This time, she is fighting Blue Cross in the courtroom. After tracing their way up, the court system, Sindie's legal team argued before the Supreme Court of Nebraska, who ultimately ruled in her favor. The court declared that her condition was a "deviation from what is considered a normal, healthy physical state" (Menikoff 381). This meant that she was indeed sick.

BINARY HEALTH?

Cases like Sindie Katskee's represent the dramatic scrimmage between several forces swirling around the healthcare field. In Katskee's case, this battle was played out between a pair of medical professionals, an insurance company and the judicial system. Throughout Katskee's story, each group offers their definition of the term "illness." However, this cluster of definitions does not help illuminate

the murky corners of "illness." These definitions muddy the waters, rather than raking them free of irritants and purifying them. Of these three groups, I feel that the medical professionals are best qualified to offer a meaningful definition of "illness." However, their definition is not immune to risks and potential problems. With these problems in mind, I crafted a definition of "health" and "illness" in an attempt to describe the enigmatic and vibrant relationship between these two concepts. My definitions will insulate medical professionals from the number crunching, money focused mindset of insurance companies so they might provide quality care to their patients. Moreover, my definitions are an attempt to change how we think about health and illness.

Medical professionals have a binary system of health and illness. Patients are either in the "healthy" category or they are in the "sick, ill and diseased" category, there is no in between. The difference between each category is crisp and defined. Patients may pass into the "ill" category if a doctor diagnoses them as such, otherwise they are locked firmly in the default "healthy" category. The insurance company also uses a binary system to determine who is healthy and who is not. However, their requirements to be placed in the "ill" category are more stringent. This is because the more treatments they pay for, the less money they retain. Lastly, the judicial system, in this case, followed suit and employed a binary system. However, they included "genetic predispositions" to the category of "ill." This falls in line with the medical professionals, as they too include genetic abnormalities in the "ill" category.

The definition of "illness" that arises out of the court's decision worked great for Katskee. Their ruling may even benefit other patients that are fighting their insurance provider so they can receive much needed treatment. However, the court did not create a new definition for illness, they merely agreed with the one the medical professionals issued. While their decision did add Katskee's "genetic-predisposition-to-cancer" to the "illness" side of the spectrum, it did not craft anything new. Some might think the court systems are the most appropriate entity to construct the definition for "illness" since they are the least biased group. They have nothing to gain from expanding the definition of "illness" to include one's genetic inclination, for example. The Courts would be the least biased of the three groups, however, I do not think they should be writing definitions for "health" and "illness." The Judges consulted *Webster's Dictionary* for a more common definition of "illness." Then, they flipped through *Dorland's Illustrated*

Medical Dictionary in search of a more technical definition. They did not attempt to manufacture a definition. They simply *picked* a version which they agreed with most. Doctors, on the other hand, must examine the body and determine what is normal and abnormal. I believe this investigative process, and the knowledge that results from it, is vital to creating a meaningful definition of illness.

As I said, the Court's decision added genetic predispositions to the already complex definition of illness. This addition does not improve the clarity of this term, in fact, I believe it increases the murkiness of the concept of "illness." While this does "expand" illness, it does not help map out the borders. The edge of illness remains foggy and unclear, even by including genetic problems in the realm of illness. Seemingly in response to this complaint, medical professionals invented a binary system, as there are just two categories; illness and health. On the surface this binary system is clear and understandable. However, this is not the case. The fact Blue Cross and Katskee's doctors arrived at two different interpretations of illness suggest that even with a binary system in place, illness and health are difficult to define.

Sonia Suter, a lawyer that focuses on bioethics, discussed problems associated with this system in an article for the *Journal of Law and the Biosciences*. "Working within the binary structure of health and disease, the common theme has been that individuals with genetic pre-dispositions lie on the side of health, as opposed to disease" (Suter). Such a definition could lead to discrimination with employers, perspective employers and insurance companies, according to Suter.

In addition to these sources of discrimination, a binary system makes it easier for medical professionals to abuse their patients. Depending on a patient's genetics, doctors may urge them to receive treatments that are ultimately unnecessary. A rather vain doctor might even *delay* treatment to benefit their research. Imagine a patient similar to Katskee, who is gripped with worry as they seek out an oncologist. After the doctor preforms a few tests the patient is diagnosed with a similar condition. Their genetic make-up and family history suggest they are pre-cancerous. This particular doctor, being rather selfish, yet forward thinking, does not tell the patient about their condition. The doctor *clears* them of any abnormal risk of cancer. Years later, after the cancer has bloomed and begun ravaging their body, the patient returns to the doctor in need of treatment. Now, the oncologist gladly begins treating the patient, gently guiding them toward a new experimental treatment they have been researching.

This is a terrible and extreme example, but I feel it is within the realm of possibility. Doctors are not infallible. They are human, and while they may have their mind set on what most people would consider the proper end goal, they can unfortunately suffer from lapses in judgement at times.

DOCTORS AND LAWYERS

The Katskee case does more than just offer a new definition for the concept of illness. It highlights a disturbing aspect of how the healthcare system operates in the United States. Insurance companies are allowed to label patients as either sick or healthy. Of course, when an insurance company “diagnoses” someone “healthy”, they liberate themselves from their obligation to pay for treatments. This in turn saves them money, which is the goal of any business. This task is simple for the insurance company, as they only need to create a definition for illness, and include it in their policy.

An insurance company may never confess the motives behind their decision to not pay for someone’s treatment. However, it is entirely possible they do not pay for treatment because it is expensive. After all, as I mentioned, the goal of every business is to make money, not continually spend it. If this is the motive behind an insurance company’s decision, this shows they are placing a higher value on money and their bottom line, rather than on human life. Such actions are intolerable. Even when this is done in the company’s best interest, that is, denying treatment is done because it is a smart business move, the overall action is still disgusting.

I feel it is problematic to allow an insurance company, or any entity that is primarily trying to better itself, to control what happens to our sick and dying. There are sneaky ways these companies could maneuver along legal avenues to get out of paying for treatment, as Blue Cross attempted to do with Katskee. I feel the burden of defining illness should be left to the medical professionals and scientists that have dedicated their lives to understanding the human body. These individuals have a deep wealth of knowledge detailing the human body. They know how it should function. They know how to determine if a symptom is merely a quirk for an individual patient, or if it is a warning for an impending illness.

From my understanding, the Medical Community has the least to gain by forming a definition of illness. They are not seeking to improve their profits, nor are they supposed to be seeking fame, as the purpose of the medical profession

is to treat and prevent illness. The expressed purpose of the entire collection of medical professionals, no matter their title or level of education, is to heal their patients. Doctors are to provide their patients with treatments that relieve them of their plight, not ravage their bodies, drain their bank accounts or earn the hospital a few extra dollars.

Despite the ever-helpful persona put forth by the Medical Community, medical professionals and scientists are not immune from abusing a patient or their circumstance. Sometimes a physician may harm their patient, even though they are attempting to heal them. The nature of medicine and healing is treacherous, and spiked with unknown hazards that cast the best and most dedicated individuals away. Despite these faults and perilous conditions, medical professionals, and their allies are an absolutely necessary part of our society.

Medical professionals can easily find themselves in a snarled mess. There is a grand financial temptation threatening to overpower their better judgement. Such issues may crop up if a doctor is told they will receive financial incentives from a pharmaceutical company if they place patients on an experimental drug. Perhaps the new drug will help their patient, and cure them of their ailment; however, it may also worsen their situation. There will be limited data on an experimental drug, especially if it has only just begun human trials. Other doctors may need more patients for research purposes. This might cause a doctor to expand their definition of illness so more people qualify for their research project.

The possibility for abuse is extensive and should not be taken lightly. When medical professionals make mistakes, and perform unwarranted treatments, they are pulverizing the line between "healing" and "harming." However, at their core, medical professionals are supposed to operate with the intent of healing their patients. This constructive notion should propel these negative possibilities far from reach, and purify the actions of the Medical Community.

Courts interpret the laws and cases lawyers argue before them. They are not supposed to create something brand new in their ruling. I believe this lack of creativity disqualifies them being able to define illness. Similarly, insurance companies exist to make as much money as they possibly can. Their goal is not to heal or help a patient. This lack of genuine interest in the patient's wellbeing removes them from being able to define illness. Medical professionals, on the other hand, actively try to help the sick and the dying. At their core, medical professionals wish to dissolve injuries and promote their patient's health. While

trying to mend their patients, medical professionals gain immense knowledge of the human body, which not only aids them in the healing process, it ensures their ability to properly diagnose. These qualities make them uniquely qualified to define illness.

A NEW DEFINITION OF ILLNESS AND HEALTH

I reject the notion of being *either* sick or healthy. I propose that we are always ill, to some degree. Some people may be sicker than others, which may guide some to believe they are not ill, however in fact this is impossible, due to the complex relationship between "health", "illness", and the ever-changing landscape they produce.

One extreme interpretation of my proposal would include disavowing the term "health", and decommissioning it from our lexicon. Given that "health" and "illness" are, broadly speaking, opposite concepts, I do not feel this interpretation is bizarre or unwarranted. We would not have to change much either. For example, instead of "health care" we could simply receive "care." Simply employing this term is appealing because it evokes a more holistic vision of care, one where our bodies, minds and world are cleansed and repaired. However, I do not think we have to revise our vocabulary this much. Rather, I think we should accept that illness is much more pervasive than we currently believe. Illness is routine, and should not be marked with an evil, or gloomy stigma. This does not mean we should be cheerful when someone is diagnosed with cancer, however, we should not look down upon those who are sick either, because we are all sick.

In order to visualize my understanding of health and illness, and their dynamic relationship, imagine a spectrum where each end is a fixed point. The spectrum itself represents health. Somewhere along the spectrum rests a highly mobile, and ever moving slider. This piece represents the individual. The slider's unending movement is governed by numerous variables. For example, exercise habits and cancer, over eating, and genetic health conditions all help push and shove the slider along in a given direction. Some of these variables, such as cancer and eating greasy food would be tossed into the illness pile. On the other hand, exercise and chemotherapy would be reserved for the treatment pile, as both of these endeavor to counter act some ailment.

Illness falls upon a person for any number of reasons. Someone may not manage their diet properly, while someone else may injury part of their body while

climbing a mountain. Still another may inherit some illness from their parents. In all of these cases the individual stricken with the illness receives some damage to their health. This damage may be permanent or temporary depending on the specific illness. Perhaps even someone may be born with an affliction that not only permanently damages their health, but causes other damages, if it remains unopposed.

Picturing the spectrum, one end is painted with the label "Death" or "Dead", and the opposite end embraces the title "Maximum Health." The end entitled "Dead" is universally accessible by all. This end specifically denotes the physical death of the body, and therefore the death of all types of health for the individual. Everyone will one day reach this end of the line, and never return from its murky surface. As an individual "approached" this end of the spectrum, they would ideally receive medical treatment designed to combat their illness and push their health upward.

The opposite end is quite different, since it is impossible to reach "Maximum Health." This end represents the fictional, normative vision of health. There are several components of health, all of which are difficult to maintain at once. These components mesh together, and melt over the heat and friction of the continual movement of the slider. As these components slosh around, they manufacture what could be considered an individual's level of health or health status.

"Health" consists of four components: Biological, Mental, Social and Environmental. Already, just by listing the types of health, it is easy to see how it would be difficult to keep all four of these categories "maxed out" at the normative end of the spectrum. For example, it would be very difficult to boost one's environmental health since the factors that impact it are not all under the control of the individual. Some entities that damage this aspect of health, such as pollutants in the air or water, were placed there by other people. These toxins may even have been released into the world by previous generations that are now long dead.

Biological health (or physical health as some call it) refers to the type most often brought up when "health" is discussed. This component deals with the material body; the heart, finger nails, teeth and bones. One's genetic makeup is included in this section. This is one of the most straight forward, and familiar parts of health. As I argued above, this area needs to be governed by medical

professionals. Medical Doctors, for example, are the best equipped individuals to diagnose and address issues that arise within the body.

Mental health is closely related to Biological health. These two influence one another and alter one another regularly. For example, depression and stress can have a physical impact on a person. Depression may lead to suicide or self-harm, while stress can damage the heart. This is another commonly understood element of health, however I feel it is often forgotten about, even though it directly impacts biological health. Medical professionals are again, well trained in this field, and should be the only individuals defining and treating a patient's illness.

Social health deals with social relationships. These relationships could be as simple as the interactions between an individual and their best friend or they could be as complex as the relationships between citizens of a large nation. Again, this layer of health has impacts on other areas. Prima facie, Social health is largely connected to Mental health. If someone fights with their spouse, and they feel upset about it, their Mental and Social health will take a small hit. This hit is not necessarily calculable; however, it is absolutely noticeable to the individual.

Environmental health, as I touched on above, involves the connection an individual's environment has on them. This part can have nasty effects on the Biological health, if, for example, an individual drank lead infused water for decades. Crime, pollution and having limited access to nutritious food are other negative factors that drag one's Environmental health down, along with their Biological health.

Biological and Mental health explicitly deal with the body and the negative effects a given illness may have on the body. Social and Environmental health primarily deal with factors external to the body, though they account for the damage inflicted on the body. For example, there is not an internal structure or organ in the human body that is connected to Social health. Having an argument with someone will not spur a disease to infect the body. However, stress from a bad or failing relationship may damage the body. Likewise, an angry individual armed with a firearm may annihilate their spouse or friend.

It is a mistake to place too much thought on this spectrum and the slider. They are only a tool designed to increase the understanding of the intensely complex relationship between "illness" and "health." Moreover, they simply help one's visualization of my definitions of "illness" and "health."

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We should not think certain illnesses will drag someone's slider closer to death than other illnesses. Thinking in such terms would mean we missed the point. While the preverbal common cold is less dangerous than overdosing on heroine, both would "drop the slider"; however, we should not be concerned with quantifying the exact position of the slider. Doctors, for example, would not whip out a chart and start crunching numbers to determine where they land on my scale. They would focus on treating the physiological problems afflicting their patient. This does not mean doctors would treat people waiting in the Emergency Room in a linear, first come first serve, fashion. The rules of triage would still apply, as priority cases would still be taken back first. Victims with gunshot wounds would be treated before individuals with a tummy ache.

With this system of "health" and "illness" all of the practices associated with healing the sick and injured, would remain firmly within the realm of medicine, as I mentioned above. Insurance companies and actuaries would no longer taint the Health Care system. Providing care to a patient would not be determined by the cost of the procedure, but rather, it would have been determined by necessity, availability of medical resources, and the will of the patient. This freedom would allow medical professionals room to craft more effective treatment plans that actually promote a holistic view of health, rather than focusing purely on Biological health.

The negative stigma swirling around illness would drain from our communities because illness would no longer be unsuspected or thought of as something tragic. This does not mean people should rejoice when a patient is considered terminal. Death should evoke sadness, but ultimately, death and illness should be expected. Disrespectful banter, as well as frivolous and offensive thoughts, that surround patients should dissipate once we accept the abundance of illness. Given the plethora of illness, people will feel less despicable about a given illness, and cast less judgment toward those suffering. Negative, and critical, attitudes directed toward individuals with mental illnesses, for example, would fade away. Casting shame upon someone because they are autistic would be like shaming someone because they have two legs. It may take a while for the negative connotation to fade from highly stigmatized illnesses, like HIV, however overtime such stains would dissolve.

CRITIQUES

Undoubtedly, there are drawbacks to my view. The biggest being that it will be very easy for the Medical Community to levy great influence over the lives of their patients. Doctors may wish to treat their patients around the clock for their various symptoms and known illnesses. Over treatment could become a big problem. However, this problem already has a remedy that is currently employed in the medical world. Patients would not have to undergo any procedure or treatment they did not want. For example, patients would have to give their consent to a surgeon, before they are sliced open. Thus, patients would have the final say, and have full ability to not receive care.

Even with the solid barrier of informed consent, doctors may still be able to convince their patients they should receive treatment. As with almost every issue in the arena of Medical Ethics, this is a double-edged sword. The patient may need a treatment in order to stay alive, however, for some reason, they do not want it. It would be ridiculous for a doctor not to pursue this patient and try to convince them otherwise. After all, a doctor is supposed to focus on improving the health of their patient, and not providing them with a treatment that will save their life is counterproductive. However, the patient's wishes must always be honored, even if that includes not treating their illness.

Of course, as I mentioned above, doctors may act with a selfish vigor, when trying to convince a patient to undergo a treatment. Doctors could misuse their position as an authority figure to coerce patients into doing whatever they want. Physicians may guide their patient toward a lifesaving treatment, and insist they undergo the procedure, even after the patient continually resists. Other doctors may push a patient toward a treatment plan, so they can further practice their craft. For example, a surgeon may try to convince a patient they need a complex and dangerous surgery simply, so they can be involved with the procedure.

Dismantling the ideology of a malicious doctor would not be easy, nor is cancelling out abusive situations like the ones described above. However, at the core of medicine is the concept of healing. Doctors should not wash their patients with waves of unnecessary agony. Doctors are supposed to slice away the diseased and putrid parts, allowing their patients to go on with their lives. Doctors are supposed to rebuild bones once they've been obliterated, and retrain their patient's arms, legs and hands so they can function again. There is a genuine concern about corrupt doctors mistreating their position, however, once a doctor

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snaps the barrier between restoring-a-patient and exploiting-their-condition, they are no longer healing. They are acting in a brutal manner and unleashing mayhem upon their patient. Doctors need to adhere to the notion of “healing” their patient. Straying from this idea can foster situations where the bodies of patients are damaged, and sometimes destroyed.

TO CONCLUDE

Illness and health are very peculiar concepts, even though they seem straight forward and simple. In some ways, they are even considered opposites. However, they are thoroughly connected by every fiber and strand. One positive swing of one’s “health” pivots “illness” in an appropriate direction. Carrying a malicious pathogen will taint one’s health and promote the growth of illness.

I agree with the decision reached by the Supreme Court of Nebraska in the case of *Sindie Katskee*; I believe that doctors should craft definitions of illness, and by extension health. Insurance companies should have no place in creating these definitions, as they are swayed by other motives. Like any business, they want to make money. While doctors are not immune to problems and corruption, at their core, doctors are supposed to focus on healing their patients and advancing their health. I believe this fundamental notion will help restrain them, and whatever greed they harbor.

I have pieced together my own definition of health and illness. My definition for illness is inclusive, like the one pitched by *Katskee’s* doctors. It includes some maladies, such as genetic pre-dispositions, that are often left outside of the “illness” category. However, according to my view, health and illness are not static. Our health fluctuates, as it is constantly under siege by a variety of illnesses. Our actions and decisions all impact our health, as it evolves second by second. Eating greasy food and not working out will have an adverse effect on an individual’s health, while exercising will promote more desirable results. Furthermore, we are not sick or healthy, rather, we are always sick.

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